



# **2013 NPCR-CSS**

## **Submission**

## **Specifications**

# **1995–2011 Diagnosis Years**

Form approved

OMB No. 0920-0469

Expiration date: November 30, 2012

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## 2013 NPCR-CSS Submission Specifications (1995–2010 Diagnoses)

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This document and its attachments outline the reporting requirements for the 2013 Data Submission to the National Program of Cancer Registries (NPCR) Cancer Surveillance System (CSS).

Programs and documents relating to the submission of your data are available at the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver/>). For a description of these programs and documents, see **attachment 1**, “Programs on the NPCR-CSS Utilities Web Site.”

The 2013 NPCR-CSS submission dates are as follows:

Submission Due Dates	Required Years of Diagnosis	Optional Years of Diagnosis
November 1–30, 2012	NPCR reference year–December 31, 2010	January 1–December 31, 2011
January 1–30, 2012	January 1–December 31, 2011 (States that submitted their data in November are <b>not</b> to resubmit.)	

- 1. Report data using ICD-O-3 codes:** Convert your pre-2001 ICD-O-2 morphology data to the corresponding ICD-O-3 codes. Conversion programs are available at: <http://seer.cancer.gov/tools/conversion/>.
- 2. Diagnosis Years:** All NPCR-funded central registries are required to submit cancer cases diagnosed in all residents of your catchment area beginning with your NPCR reference year (e.g., 1995) through **December 31, 2010**, during the first part of the NPCR 2013 Data Submission in November 2012 (November 1–30, 2012). Cases diagnosed from January 1 through December 31, 2011, can be submitted during the November 2012 or January 2013 submission period; however, all States are strongly encouraged to submit the entire 2013 NPCR data during the November 2012 submission period. For guidance on residency, refer to page 19 of *NAACCR Standards for Cancer Registries*, Volume II, Version 12.2 (revised June 2011).
- 3. Reportable Diagnoses:** All histologies with a behavior code of /2 or /3 (or in some cases, a behavior code of /0 [see item 3h] or behavior code of /1 [see item 3g]) in the *International Classification of Diseases for Oncology*, Third Edition (ICD-O-3), are reportable in the year that they were diagnosed with the following exceptions or restrictions:<sup>1–6</sup>

- a. Exclude neoplasms of the skin (C44.0–C44.9) with the following histologies, **UNLESS** they occur at the mucoepidermoid sites [vagina (C52.9), clitoris (C51.2), vulva (C51.0–51.9), prepuce (C60.0), penis (C60.9), and scrotum (C63.2)]:

8000–8005	Neoplasms, malignant, NOS
8010–8046	Epithelial carcinomas
8050–8084	Papillary and squamous cell carcinomas
8090–8110	Basal cell carcinomas

- b. Exclude carcinoma in situ of the cervix (C53.0–C53.9, any morphology and /2) after January 1, 1996.
- c. Exclude prostate intraepithelial neoplasia, grade III (PIN III) (C61.9. 8148/2) after January 1, 2001.
- d. Exclude squamous intraepithelial neoplasia, grade III (8077/2) of the following sites: anus (C21.0–C21.1, AIN III), cervix (C53, CIN III), vagina (C52.9, VAIN III), and vulvar (C51, VIN III).
- e. If a pathologist reports a case as invasive (/3) and the histology is usually associated with a benign (/0) or borderline (/1) behavior code, the case is reportable. Include any appropriate override codes.
- f. Include all cases of pilocytic astrocytoma. If necessary, convert behavior code to /3 before submitting cases.
- g. Include all cases diagnosed prior to January 1, 2001 with the following histologies. These histologies are generally coded to ovary (C56.9) but are not limited to this primary site.

<b>Descriptive terms and topography codes</b>	<b>ICD-O-3</b>
Serous cystadenoma, borderline malignancy	8442/1
Serous tumor, NOS, of low malignant potential	8442/1
Papillary cystadenoma, borderline malignancy	8451/1
Serous papillary cystic tumor of borderline malignancy	8462/1
Papillary serous cystadenoma, borderline malignancy	8462/1
Papillary serous tumor of low malignant potential	8462/1
Atypical proliferative papillary serous tumor	8462/1
Mucinous cystic tumor of borderline malignancy	8472/1
Mucinous cystadenoma, borderline malignancy	8472/1
Pseudomucinous cystadenoma, borderline malignancy	8472/1
Mucinous tumor, NOS, of low malignant potential	8472/1
Papillary mucinous cystadenoma, borderline malignancy	8473/1
Papillary pseudomucinous cystadenoma, borderline malignancy	8473/1
Papillary mucinous tumor of low malignant potential	8473/1

- h. Include all nonmalignant primary intracranial and central nervous system tumors (see following table) with a benign (/0) or borderline (/1) behavior code diagnosed January 1,

2004 and later.<sup>1, 4, 5, 6</sup> Benign and borderline tumors of the cranial bones (C41.0) will continue to be excluded.

<b>Required Sites for Benign and Borderline Primary Intracranial and Central Nervous System Tumors</b>		
<b>General Term</b>	<b>Specific Sites</b>	<b>ICD-O-3 Topography Code</b>
<b>Meninges</b>	Cerebral meninges	C70.0
	Spinal meninges	C70.1
	Meninges, NOS	C70.9
<b>Brain</b>	Cerebrum	C71.0
	Frontal lobe	C71.1
	Temporal lobe	C71.2
	Parietal lobe	C71.3
	Occipital lobe	C71.4
	Ventricle, NOS	C71.5
	Cerebellum, NOS	C71.6
	Brain stem	C71.7
	Overlapping lesion of brain	C71.8
	Brain, NOS	C71.9
<b>Spinal cord, cranial nerves, and other parts of the central nervous system</b>	Spinal cord	C72.0
	Cauda equine	C72.1
	Olfactory nerve	C72.2
	Optic nerve	C72.3
	Acoustic nerve	C72.4
	Cranial nerve, NOS	C72.5
	Overlapping lesion of brain and central nervous system	C72.8
	Nervous system, NOS	C72.9
<b>Pituitary, craniopharyngeal duct, and pineal gland</b>	Pituitary gland	C75.1
	Craniopharyngeal duct	C75.2
	Pineal gland	C75.3

4. **Data Items:** Include all data items listed in **attachment 2**, “Data Items by Diagnosis Year.” Use definitions and codes from chapters IX and X of *NAACCR Standards for Cancer Registries*, Volume II, Version 12.2 (revised June 2011).<sup>7,8</sup>
  - a. Bold font is reserved for data items that are new to this submission or have moved to “coordinated core” from “advanced” surveillance activities. So that CDC-NPCR may

calculate survival rates, please note that data items Date of Last Contact [#1750], Date of Last Contact Flag [#1751], and Vital Status [#1760] have moved from “advanced” to “coordinated core” surveillance activities.

- b. If a data item is **not collected by or reported to** the registry, leave the data item blank and note the reason in the submission form section “Data Items not Transmitted” (see item #13).
- c. If the registry **collects the data item and does not include the data item in this transmission for confidentiality reasons**, then the data item should be recoded to the appropriate codes to indicate “unknown”, except when reporting dates as indicated below. The registry should note item(s) not transmitted due to confidentiality reasons in the submission form section “Data Items not Transmitted” (see item #13).
  - i. For dates, other than Date of Diagnosis [#390] and Date of Last Contact [#1750], considered by the registry to be confidential, the information may be reported in either of two methods:
    1. Report the actual month and year, but do not report the day (leaving that field blank); e.g., 01/\_\_/2011. Do **not** convert the day to unknown; e.g., 01/99/2011.
    2. Report the actual year, but do not report the month and day (leaving those fields blank); e.g., \_\_/\_\_/2011. Do **not** convert the month and day to unknown; e.g., 99/99/2011.
  - ii. So that CDC-NPCR may calculate reliable and valid survival rates, the variables Date of Diagnosis [#390] and Date of Last Contact [#1750] **must be submitted in full**.
  - iii. If State **law prohibits** the release of all or some county codes, recode the county code to “000” for relevant case records. The NPCR County at Dx edit will not accept blanks and will accept code “000” as a valid code. Use code “999” for unknown or missing county information. Do not leave this variable blank. Please note that the use of code “998” (out-of-State resident) will generate an edit error as these cases are not reportable to NPCR.
- d. If the county code is not submitted as a result of state law, convert all county codes to Rural-Urban Continuum/Beale Code 1993 [North American Association of Central Cancer Registries (NAACCR) data item #3300] and Rural-Urban Continuum/Beale Code 2003 [NAACCR data item #3310]. To download a copy of the Rural-Urban Continuum Program, please visit the Data Analysis Tools screen on the NAACCR Web site at:  
<http://www.naacr.org/LinkClick.aspx?fileticket=n5arBZ5OIA0%3d&tabid=118&mid=458>.
- e. For cases diagnosed beginning January 1, 2004, report the derived Summary Stage 2000 [NAACCR data item #3020] using the Collaborative Staging (CS) Algorithm version 02.04. Derived Summary Stage 2000 should be recalculated prior to extracting the final submission file, especially if changes are made to the CS variables used to derive Summary Stage 2000.
- f. As noted in FOA DP12-1205, data linkages between the NPCR and NBCCEDP programs may identify potentially missed cancer cases in either database and are to update the state NBCCEDP minimum data elements (MDE) with the most current data. This linkage is to be expanded to capture post-linkage information at the patient and tumor level.

Information on the fact (NBCCEDP MDE Link variable) and date of linkage (NBCCEDP MDE Link date) should be captured for this submission. For reportable breast and cervical cancer cases, use the NBCCEDP MDE Link variable and NBCCEDP MDE Link date to record results from your registry's data linkage with the appropriate NBCCEDP program(s) in your state/territory/jurisdiction. The NBCCEDP MDE Link variable will identify breast or cervical cancer cases in the registry database that matched the same patient and tumor in the NBCCEDP data set (i.e.; patient Jane Doe right breast infiltrating duct carcinoma diagnosed in 2004 in the registry database matched the same Jane Doe right breast infiltrating duct carcinoma diagnosed in 2004 in the NBCCEDP data set).

Programs should be using the "Guidance on Performing Data Linkages" (8/28/2008) as a guideline for conducting these linkages. Linkages should be performed at least annually on cases diagnosed January 2004 forward. For this submission, the NBCCEDP MDE Link variable and NBCCEDP MDE Link date should be completed for cases diagnosed 2008 forward, at a minimum.

For the NBCCEDP MDE Link variable, use codes 0 (record sent for linkage, no match for this cancer with NBCCEDP data) or 1 (record sent for linkage, match for this cancer with NBCCEDP data) to indicate linkage results. If the record was not sent for linkage or the linkage results are pending, this variable is to be left blank. If the registry database record links with a NBCCEDP database record, indicated by code 1 in the NBCCEDP MDE Link variable, the NBCCEDP MDE Link date must be completed to indicate the date the linkage occurred. Otherwise, the NBCCEDP MDE Link date must be blank. Record information for the NBCCEDP MDE Link variable in column 2840 and NBCCEDP MDE Link date in columns 2841-2848.

Variable	Instructions	Record Layout Columns
NBCCEDP MDE Link	<p>0 - Breast or cervical cancer record sent for linkage, no match for this cancer with NBCCEDP data</p> <p>1 - Breast or cervical cancer record sent for linkage, match for this cancer with NBCCEDP data</p> <p>Blank – Breast or cervical cancer record not sent for linkage, or linkage results are pending, or record not a breast or cervical cancer</p>	2840-2840
NBCCEDP MDE Link Date	Record the date, as yyyy/mm/dd, on which the linkage occurred for the matched registry and NBCCEDP case. Once the registry case matches a NBCCEDP case, the case is not included in future linkage activities and the link date does not change. If the registry case does not match a NBCCEDP case or the linkage results are pending, this variable is left blank.	2841-2848

5. **Edits: Attachment 3**, “2013 Data Edits”, contains a list of single field, inter-field, and inter-record edits that will be used to evaluate your data submission.
- Edits that are new to this submission or that have moved from “advanced” to “coordinated core” surveillance activities are noted in **bold**.
  - Coordinated Core Edits will be used to assess program standards (i.e., percentage of records passing edits; see pages 8–9). Registries are strongly encouraged to resolve all “coordinated core” edits.
  - Advanced Data Edits are to assist you in improving the overall quality of NPCR-CSS data and are to be run by all registries. Registries are strongly encouraged to resolve “advanced” edit errors because these edits may become “coordinated core” edits in future submissions.
  - Both “coordinated core” and “advanced” inter-record edits will be run at the same time through the stand-alone Inter-Record Edits utility.
6. **Duplicate Assessment Protocol:** Identify duplicate records in your database using the *NAACCR Protocol for Assessing Duplicate Cases* (1995 or your NPCR reference year–2010, 2010, 2011). This protocol will be used to evaluate the number of duplicate records that reside in your registry database and have not been identified or corrected using regular matching, linkages, or other registry protocols. The percentage of unresolved duplicates is an important factor in the process to estimate completeness of case ascertainment.

So that completeness of case ascertainment can be appropriately estimated for the Advanced National Data, the duplicate report assessment should also be conducted on the 2011 diagnosis year cases. It is important to select a sample of cases that adequately represents the cases in your registry’s database. **The minimum sample size for the 2011 diagnosis year is 4,500 cases.** Any registry with fewer than 4,500 cases should use all available cases to conduct the duplicate report assessment.

## 7. Report Linkage and Algorithm Results:

- Prior to performing the Indian Health Service (IHS) IHS linkage and running the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA), it is advised that you review your data carefully to make sure that variables used in the linkages (e.g., Social Security number, birth date, and names) are complete and valid. For guidance to IHS linkage, please see attachment 4.
- If you have performed the IHS linkage, report the results of your IHS linkage using the NAACCR data item number 192 and column number 421 in *NAACCR Standards for Cancer Registries*, Volume II, version 12.2 The codes are as follows:
  - Code 0—did not match IHS database
  - Code 1—did match IHS database

Leave the variable blank if the case record was not sent for linkage with IHS records.

- Next, run the NHAPIIA algorithm and place the output for NHIA Derived Hispanic Origin [191] in column 418 and the output for Race—NAPIIA [193] in columns



419–420. Instructions for applying this algorithm are available on the NAACCR website. **In running the NHIA algorithm, it is strongly recommended that registries choose option 1, which limits the Spanish surname portion of the algorithm to cases coded as surname only (item 190=7) or unknown whether Hispanic (item 190=9) in counties that are less than 5% Hispanic.**

- d. To download a copy of the combined SAS program for NHAPIIA algorithm and its associated files, please visit the Data Analysis Tools screen on the NAACCR Web site:

<http://www.naacccr.org/LinkClick.aspx?fileticket=GqkcGSdy8s4%3d&tabid=118&mid=458>

Please note that if a SAS license was not requested as part of your budget request for DP12-1205, CDC is not able to provide a SAS license at this point.

8. **Veterans Hospital Administration (VHA) Data Request:** Create a separate file for the VHA data request as outlined in **attachment 5**. This data request will be used to evaluate the underreporting by VHA. NAACCR is also interested in having State-level correction factors so that they can assess any effect on data completeness as part of their certification process. Please see the data release policy on the NPCR-CSS utilities Web site for additional information.
9. **Record Format:** Create a file in NAACCR record layout version 12.2 that includes only the data items listed in **attachment 2**. Do not include data from the Patient-Confidential Section of the record. A file extraction program is available on the NPCR-CSS utilities Web site (<https://www.npcrccs.org/docserver/>). Please use your State-specific login to access this program.
  - a. Submissions that include data in the Patient-Confidential Section will not be accepted, and the registry will be notified.
  - b. Registries that have data files in a NAACCR version lower than version 12.2 may use the following free-standing Windows programs to convert files into the current NAACCR version. Please note that data files in a NAACCR version lower than version 12.1 must first be converted to each subsequent version before converting to version 12.2.

**Northcon12** – This program is written to convert a file of records conforming to NAACCR specifications for any version of the NAACCR 11 record (11, 11.1, 11.2, 11.3) to NAACCR version 12.

**Northcon121** – This program is written to convert a file of records conforming to the NAACCR specifications for NAACCR version 12 to NAACCR version 12.1. The major update in NAACCR version 12.1 from version 12.0 consists largely of the conversion from Collaborative Stage version 02.02 to version 02.03 (CS v0203). Extensive updates were done to enhance consistency and clarity of the schemas. A conversion of existing data is required before implementing CS v0203.

**Northcon122** – This program is written to convert a file of records conforming to the NAACCR specifications for NAACCR version 12.1 to NAACCR version 12.2, and

includes the Cstage.dll needed to convert to the current Collaborative Staging Data Collection System, version 02.04.

A copy of all conversion programs can be downloaded from the following Web site:  
[http://www.cdc.gov/cancer/npcr/tools/registryplus/up\\_download.htm](http://www.cdc.gov/cancer/npcr/tools/registryplus/up_download.htm)

**10. Submission Due Date:** Data from the registry's NPCR reference year through diagnosis year 2010 must be submitted during the month of November 2012 (through November 30), excluding holidays. Data from diagnosis year 2011 can be submitted during the month of November 2012 **or** January 2013 (through January 30), excluding holidays. If you feel you may be unable to meet the submission deadlines, please contact your Program Consultant and Reda Wilson at [dfo8@cdc.gov](mailto:dfo8@cdc.gov) or 770-488-3245. Submission hours are from 8 a.m. EST to 6 p.m. EST, Monday through Friday. If you need extended hours, contact ICF Macro at [support@npcrccs.org](mailto:support@npcrccs.org) or call the NPCR-CSS Help Line at (301) 572-0502, and ICF Macro staff will try to accommodate your needs.

**11. Preparing and Transmitting Data:** Please check the file prior to submission to ensure that all data years (**including 2011 data, if your State opts to submit these data in November**) and required data items are included. A "2013 NPCR-CSS Checklist" (**attachment 6**) is provided to help you prepare your data submission.

Data transmitted to NPCR-CSS are encrypted during transmission. The encryption is accomplished via Secure Sockets Layer strong encryption, the same level of protection used by e-commerce sites to protect financial transactions.

**12. File Transfer Instructions:** Refer to the "File Transfer Instructions" (**attachment 7**). ICF Macro staff will contact you in early October with your user ID and password for accessing your State folder on the NPCR-CSS document server.

**13. Data Security:** In accordance with the requirements of the 308(d) Assurance of Confidentiality, ICF Macro has developed and implemented the NPCR-CSS Security Plan. The "Overview of the Security Plan" is provided (**attachment 8**).

**14. Consolidated 2013 NPCR-CSS Data Submission Form:** Various data submission forms have been consolidated into a single online form. This form captures information on conducting death clearance, running NHAPIIA, performing IHS linkage, as well as data items not transmitted, duplicate record protocol results, followup source(s), and source of VHA data. Space is provided for comments.

All central registries are required to transmit the requested information through the online form, which will be available on the NPCR-CSS document server prior to the start of the submission (<https://www.npcrccs.org/docserver>). Programs submitting 2011 data in January 2013 will need to update the online form prior to the start of that submission.

**15. 2013 NPCR-CSS Dataset Participation Agreement (Attachment 10):** Programs are required to submit both an online version of the dataset participation agreement and a signed

Adobe Portable Document Format (PDF) version of the agreement. The online form is available at the same location as the Consolidated Data Submission Form. Complete the agreement form online, print a copy of the completed form, and have the appropriate program representative sign the form. The signed form is to be scanned as a PDF document and transmitted to your 2013 Submission folder on the NPCR-CSS document server. For more information on the Data Release Policy, visit the NPCR-CSS Submission Information section under utilities page on the NPCR-CSS document server (<https://www.npcrcss.org/docserver>).

- 16. NPCR-CSS USCS Survival Dataset:** In order to improve cancer control in the US, the survival for this population must be determined and changes mapped over time. Survival data is critical for evaluating the progress and impact of early detection/screening programs and/or comprehensive cancer control plans as well as interventions from other sources. Current US survival rates are estimated based on data from the NCI Surveillance, Epidemiology, and End Results (SEER) program covering approximately 26% of the US population or special studies. With the majority of the 48 NPCR-funded central cancer registries meeting established standards for high quality data, NPCR is now poised to calculate and publish survival rates on this population at the national, state, and regional levels. Utilizing NPCR-CSS data, NPCR has the potential to produce survival rates covering 96% of the US population over time. Growth of, and ongoing support for survival estimates will provide a new evaluation tool for screening programs. In addition, survival data can be used to evaluate the effect of health reform over time; whether in-roads are being made in cancer diagnosis and treatment; and where disparities still exist. Focusing on the entire dataset of NPCR registries will: support analyses of survival estimates for rare cancers that cannot be addressed otherwise; provide data for publication on the United States Cancer Statistics web-site as official statistics for the U.S.; and encourage registries, not currently linking, to link with the National Death Index to establish vital status.

CDC currently supports NPCR registry data linkage with the National Death Index to obtain fact and date of death as well as cause of death information through an Intra-Agency Agreement with the National Center for Health Statistics (NCHS). The NCHS has also produced state life tables with procedures in place to update state life tables for the US on an annual basis. Relative survival is dependent on these two sets of variables.

With data submitted in the 2013 NPCR-CSS, NPCR will edit, clean, and analyze the relevant data variables; prepare analysis files; and implement the appropriate analytic procedures for estimating relative survival for major cancer sites. The survival estimates are expected to be produced and included in a dataset for publication on the USCS web site and release of an NPCR-CSS survival dataset for internal NPCR analyses.

- 17. Central Brain Tumor Registry of the United States (CBTRUS) Dataset:** In lieu of separate analytic and statistical datasets, CBTRUS is collaborating with CDC-NPCR to obtain a single dataset to be used for these purposes; e.g., posters, presentations at scientific meetings, manuscripts for peer-reviewed journals, and statistical reports. The CBTRUS dataset will include all malignant cases for diagnosis years 1995–2010 and non-malignant cases for diagnosis years 2004–2010 for the variables outlined in **attachment 11**. Please note

that CBTRUS is no longer requesting the nonmalignant brain-related tumors diagnosed prior to 2004, from a subset of registries.

**18. Questions about Your Submission:** Refer to “Frequently Asked Questions about the NPCR-CSS Data Submission” (**attachment 12**), contact ICF Macro at [support@npcr.org](mailto:support@npcr.org), or call the NPCR Help Line at (301) 572-0502.

Topic	Point of Contact
Technical questions related to data submission (including user ID, password, or accessing the NPCR-CSS Web site)	<a href="mailto:support@npcr.org">support@npcr.org</a> NPCR Help Line (301) 572-0502
Submission Deadlines (see item 9 above) Completion of the Consolidated Submission Form (see item 13 above) Data Use Agreement Form (see item 14 above)	Reda Wilson (770) 488-3245 <a href="mailto:dfo8@cdc.gov">dfo8@cdc.gov</a>

**19. Data Evaluation:** Data will be evaluated according to the following NPCR standards, and results will be reported in the NPCR-CSS Data Evaluation Reports.

Criteria		NPCR Advanced National Data Quality Standard (12-month)	NPCR National Data Quality Standard (24-month)	USCS <sup>a</sup> Publication Criteria	U.S. County Public-Use File Criteria <sup>b</sup>	Measurement Error
Percentage Completeness of Case Ascertainment <sup>c</sup>		>=90%	>=95%	>=90%	>=90%	-1.0% <sup>g</sup>
Percentage Missing or Unknown	Age	NA	<=2%	<=3%	<=3%	-0.4%
	Sex	NA	<=2%	<=3%	<=3%	-0.4%
	Race	NA	<=3%	<=5%	<=5%	-0.4%
	County	NA	<=2%	NA	<=3%	-0.4%
Percentage Death Certificate Only (DCO) <sup>d</sup>		NA	<=3%	<=5%	<=5%	-0.4%
Unresolved Duplicates (per 1,000) <sup>e</sup>		NA	<=1	NA	NA	-0.4
Percentage Passing Coordinated Core Edits <sup>f</sup>		>=97%	>=99%	>=97%	>=97%	NA

Criteria	NPCR Advanced National Data Quality Standard (12-month)	NPCR National Data Quality Standard (24- month)	USCS <sup>a</sup> Publication Criteria	U.S. County Public-Use File Criteria <sup>b</sup>	Measurement Error

## Notes

<sup>a</sup> *United States Cancer Statistics*

<sup>b</sup> See NPCR-CSS Data Release Policy, August 2012.

<sup>c</sup> Case completeness estimates will be calculated using the NAACCR method and adjusted for duplicates if the duplicate rate was derived from a sample of the incidence file. Adjustment will **not** occur if duplicates were identified and corrected on the entire database.

<sup>d</sup> The registry must perform death clearance. Benign central nervous system (CNS) DCO cases are included in the numerator and denominator for cases diagnosed 2004 and later only, not for cases diagnosed 2003 and earlier.

<sup>e</sup> Based on the results of NAACCR duplicate protocol

<sup>f</sup> Only coordinated core edits will be used to evaluate data.

<sup>g</sup> The measurement error may vary in select circumstances, following review by CDC.

NA Not applicable

## References

1. Funding Opportunity Announcements #DP07-703, National Cancer Prevention and Control Program, CDC, 2007, and subsequent amendments, and #DP12-1205, Cancer Prevention and Control Programs for State, Territorial and Tribal Organizations.
2. Public Law 102-515. NPCR Home Page:  
<http://www.cdc.gov/cancer/npcr/amendmentact.htm>
3. Public Health Service Act, (42 USC 280e-280e-4):  
[http://www.law.cornell.edu/uscode/html/uscode42/usc\\_sup\\_01\\_42\\_10\\_6A\\_20\\_II\\_30\\_M.html](http://www.law.cornell.edu/uscode/html/uscode42/usc_sup_01_42_10_6A_20_II_30_M.html)
4. SEER (Surveillance, Epidemiology, and End Results) Program, 2007. *The SEER Program Coding and Staging Manual*. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. NIH Pub. No. 07-5581. Revised September 2008, pages 1–5.
5. Adamo MB, Johnson CH, Ruhl JL, Dickie, LA, (eds.). *2010 SEER Program Coding and Staging Manual*. National Cancer Institute, NIH Publication number 10-5581, Bethesda, MD, pages 1-7.
6. Adamo MB, Johnson CH, Ruhl JL, Dickie, LA, (eds.). *2011 SEER Program Coding and Staging Manual*. National Cancer Institute, NIH Publication number 11-5581, Bethesda, MD, pages 1-7.
7. Thornton M, O'Connor L, editor. *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 12.2, Sixteenth Edition*. Springfield, IL: North American Association of Central Cancer Registries, June 2011, pages 19–24.
8. Thornton M, O'Connor L, editor. *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 12.2, Sixteenth Edition*. Springfield, IL: North American Association of Central Cancer Registries, June 2011, pages 79–440.



## Attachment 1

### Programs on the NPCR-CSS Utilities Web Site

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The following programs have been or will be posted to the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver/>). For assistance with these utility programs, please contact ICF Macro at [support@npcrcss.org](mailto:support@npcrcss.org) or call the NPCR-CSS Help Line at (301) 572-0502.

1. **ICD-O-2 to ICD-O-3 Conversion Program** — (<http://seer.cancer.gov/tools/conversion/>).
2. **NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA)** — This SAS program combines NAACCR Hispanic Identification Algorithm, version 2 (NHIA version 2.2.1) and the NAACCR Asian Pacific Islander Identification Algorithm, version 1 (NAPIIA version 1.2.1). All NPCR registries are required to run this combined SAS program or equivalent in the 2013 NAACCR/NPCR Coordinated Call for Data submission. Please be mindful of the instructions regarding this algorithm as noted in the 2013 NPCR-CSS Call for Data Submission Specifications.

Place the output for NHIA Derived Hispanic Origin [191] in column 418 and the output for Race – NAPIIA [193] in columns 419–420. To download a copy of the combined SAS program and its associated files, please visit the Data Analysis Tools page on the NAACCR Web site at:

<http://www.naaccr.org/DataandPublications/CallforData.aspx>

Please note that if a SAS license was not requested as part of your budget request for DP12-1205, CDC is not able to provide a SAS license at this point.

3. **GenEDITS Plus with the 2013 NAACCR/NPCR Combined Edits Metafile** — This is an edits program that contains the edits metafile to run the 2013 NAACCR/NPCR Combined Edits on NAACCR record layout version 12.2. The program produces summary and detailed reports of core and advanced edit errors.
4. **2013 NAACCR/NPCR Combined Edits Metafile** — For those registries that prefer to use another edits program, this download contains the runtime metafile for the 2013 NAACCR/NPCR Combined Edits.
5. **2013 NAACCR/NPCR Coordinated Call for Data Edits Dictionary** — This PDF file contains information that may be useful to registries when preparing their 2013 NAACCR/NPCR Coordinated Call for Data submission.
6. **Inter-Record Edits Standalone Program 2013** — This program runs SEER and NPCR inter-record edits on NAACCR record layout version 12.2 containing both ICD-O-2 and ICD-O-3 coded cases. The program produces summary and detailed reports of inter-record

errors. **The Inter-Records Edits program should be run after the 2013 NAACCR/NPCR Combined Edits have been run and errors have been corrected.**

7. **Data Extraction Utility 2013** — This is an executable file that integrates three different extraction applications for different data extraction needs: National Death Index (NDI) linkage, Indian Health Service (IHS) linkage, and 2013 NAACCR/NPCR Coordinated Call for Data. **By clicking the tab labeled “CSS,” the user will be prompted to the application to extract data for 2013 NAACCR/NPCR Coordinated Call for Data submission.** This application will read NAACCR record layout version 12.2 and write a new ASCII text file in NAACCR record layout version 12.2 that contains only those data items requested for the 2013 submission. Once the program is executed, click on the “CSS” tab and then click on “Help” near the bottom of the application interface for a help file that describes how to use the program.

#### 8. **Northcon Record Conversion Programs**

**Northcon12** – This program is written to convert a file of records conforming to NAACCR specifications for any version of the NAACCR 11 record (11, 11.1, 11.2, 11.3) to NAACCR version 12.

**Northcon121** – This program is written to convert a file of records conforming to the NAACCR specifications for NAACCR version 12 to NAACCR version 12.1. the major update in NAACCR version 12.1 from version 12.0 consists largely of the conversion from Collaborative Stage version 02.02 to version 02.03 (CS v0203). Extensive updates were done to enhance consistency and clarity of the schemas. A conversion of existing data is required before implementing CS v0203.

**Northcon122** – This program is written to convert a file of records conforming to the NAACCR specifications for NAACCR version 12.1 to NAACCR version 12.2, and includes the Cstage.dll needed to convert to the current Collaborative Staging Data Collection System, version 02.04.

A copy of all conversion programs can downloaded from the following Web site:  
[http://www.cdc.gov/cancer/npcr/tools/registryplus/up\\_download.htm](http://www.cdc.gov/cancer/npcr/tools/registryplus/up_download.htm)



## Attachment 2

### Data Items by Diagnosis Year 1995-2011

Record ID and Demographic Section—(Name and [Number])		Required Status 1995–2011
	Record Type [10]	Y
	Patient ID Number [20] (unique)	Y
	Registry ID [40]	Y
	NAACCR Record Version [50]	Y
	Address at Dx—State [80]	Y
	County at Dx [90] <sup>1</sup>	Y <sup>1</sup>
	Rural-Urban Continuum/Beale Code 1993 [3300] <sup>1</sup>	Y <sup>1</sup>
	Rural-Urban Continuum/Beale Code 2003 [3310] <sup>1</sup>	Y <sup>1</sup>
	Address at Dx—Postal Code [100]	Y
	Census Tract 1970/80/90 [110]	Y
	Census Cod Sys 1970/80/90 [120]	Y
	Census Tract 2000 [130] <sup>2</sup>	Y <sup>2</sup>
	<b>Census Tract 2010 [135]<sup>2</sup></b>	<b>Y<sup>2</sup></b>
	Census Tr Cert 1970/80/90 [364]	Y
	Census Tr Certainty 2000 [365] <sup>2</sup>	Y <sup>2</sup>
	<b>Census Tr Certainty 2010 [367]<sup>2</sup></b>	<b>Y<sup>2</sup></b>
	Race 1 [160]	Y
	Race 2 [161]	Y
	Spanish/Hispanic Origin [190]	Y
	NHIA Derived Hisp Origin [191] <sup>3</sup>	Y <sup>3</sup>
	IHS Link [192] <sup>4</sup>	Y <sup>4</sup>
	Race--NAPIIA [193] <sup>3</sup>	Y <sup>3</sup>
	Sex [220]	Y
	Age at Diagnosis [230]	Y
	Date of Birth [240]	Y
	Date of Birth Flag [241]	Y
	Birthplace [250]	Y
Cancer Identification Section—(Name and [Number])		Required Status 1995–2011
	Sequence Number—Central [380]	Y
	Date of Diagnosis [390]	Y
	Date of Diagnosis Flag [391]	Y
	Primary Site [400]	Y
	Laterality [410]	Y

	Grade [440]	Y
	Diagnostic Confirmation [490]	Y
	Type of Reporting Source [500]	Y
	Histologic Type ICD-O-3 [522] <sup>5</sup>	Y <sup>5</sup>
	Behavior Code ICD-O-3 [523] <sup>5</sup>	Y <sup>5</sup>
	<b>Primary Payer at DX [630]</b>	<b>As available<sup>14</sup></b>
<b>Treatment First Course Section—(Name and [Number])</b>		<b>Required Status 1995–2011</b>
	Date of Initial Rx—SEER [1260] <sup>6</sup>	Y <sup>6</sup>
	Date of Initial Rx Flag [1261] <sup>6</sup>	Y <sup>6</sup>
	Date of 1st Crs Rx—COC [1270] <sup>6</sup>	Y <sup>6</sup>
	Date of 1st Crs Rx Flag [1271] <sup>6</sup>	Y <sup>6</sup>
	Rx Summ—Surg Primary Site [1290] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Scope Reg LN Sur [1292] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Surg Oth Reg/Dis [1294] <sup>7</sup>	Y <sup>7</sup>
	Reason for No Surgery [1340] <sup>7</sup>	Y <sup>7</sup>
	RX Summ—Radiation [1360] <sup>7</sup>	Y <sup>7</sup>
	RX Summ—Surg/Rad Seq [1380] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Chemo [1390] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Horm [1400] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—BRM [1410] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Other [1420] <sup>7</sup>	Y <sup>7</sup>
	Rad—Regional Rx Modality [1570] <sup>7</sup>	Y <sup>7</sup>
	RX Summ—Systemic/Sur Seq [1639] <sup>7</sup>	Y <sup>7</sup>
	Rx Summ—Transplant/Endocr [3250] <sup>7</sup>	Y <sup>7</sup>
<b>Stage/Prognostic Factors Section—(Name and [Number])</b>		<b>Required Status 1995–2011</b>
	SEER Summary Stage 2000 [759] <sup>8</sup>	Y <sup>8</sup>
	SEER Summary Stage 1977 [760] <sup>8</sup>	Y <sup>8</sup>
	CS Tumor Size [2800] <sup>9</sup>	Y <sup>9</sup>
	<b>CS Extension [2810]<sup>10</sup></b>	<b>Y<sup>10</sup></b>
	<b>CS Tumor Size/Ext Eval [2820]<sup>10</sup></b>	<b>Y<sup>10</sup></b>
	<b>CS Lymph Nodes [2830]<sup>10</sup></b>	<b>Y<sup>10</sup></b>
	<b>CS Lymph Nodes Eval [2840]<sup>11</sup></b>	<b>Y<sup>17</sup></b>
	<b>CS Mets at DX [2850]<sup>10</sup></b>	<b>Y<sup>17</sup></b>
	<b>CS Mets Eval [2860]<sup>11</sup></b>	<b>Y<sup>10</sup></b>
	CS Site-Specific Factor 1 [2880] for:	
	C50 (breast) <sup>10</sup>	Y <sup>10</sup>

	C70.0-C70.9, C71.0-C71.9, C72.0-C72.9, C75.1-C75.3 (brain, CNS) <sup>11</sup>	Y <sup>11</sup>
	<b>C34 (lung)<sup>10</sup></b>	Y <sup>10</sup>
	<b>C384 (pleura)<sup>13</sup></b>	Y <sup>13</sup>
	<b>C692 with 9510/3, 9511/3, 9512/3, 9513/3 (retinoblastoma)<sup>10</sup></b>	Y <sup>10</sup>
	CS Site-Specific Factor 2 [2890] for:	
	C50 (breast) <sup>10</sup>	Y <sup>10</sup>
	<b>C54 (corpus uteri)<sup>10</sup></b>	Y <sup>10</sup>
	<b>CS Site-Specific Factor 3 [2900] for C619 (prostate)<sup>13</sup></b>	Y <sup>13</sup>
	CS Site-Specific Factor 15 [2869] for breast (C50) <sup>12</sup>	Y <sup>12</sup>
	<b>CS Site-Specific Factor 25 [2879]<sup>10</sup></b>	Y <sup>10</sup>
	CS Version Input Original [2935]	Y
	CS Version Derived [2936]	Y
	CS Version Input Current [2937]	Y
	Derived SS2000 [3020] <sup>13</sup>	Y <sup>13</sup>
	AJCC TNM Path Stage Group [910] <sup>14</sup>	As available <sup>14</sup>
	AJCC TNM Clin Stage Group [970] <sup>14</sup>	As available <sup>14</sup>
	Derived AJCC 6th Edition Stage Group [3000] <sup>14</sup>	As available <sup>14</sup>
	Derived AJCC 7th Edition Stage Group [3430] <sup>14</sup>	As available <sup>14</sup>
<b>Follow-Up/Recurrence/Death Section—(Name and [Number])</b>		<b>Required Status 1995–2011</b>
	Date of Last Contact [1750]	Y
	Date of Last Contact Flag [1751]	Y
	Vital Status [1760]	Y
	Follow-Up Source [1790]	As available <sup>15</sup>
	Follow-Up Source Central [1791]	Y <sup>15</sup>
	Cause of Death [1910]	Y
	ICD Revision Number [1920]	Y
<b>Over-Rides/Conversion/System Admin. Section—(Name and [Number])</b>		<b>Required Status 1995–2011</b>
	Over-Ride Age/Site/Morph [1990]	Y
	Over-Ride SeqNo/DxConf [2000]	Y
	Over-Ride Site/Lat/Sequence Number [2010]	Y
	Over-Ride Surg/Dxconf [2020]	Y
	Over-Ride Site/Type [2030]	Y
	Over-Ride Histology [2040]	Y
	Over-Ride Report Source [2050]	Y
	Over-Ride Ill-define Site [2060]	Y
	Over-Ride Leuk, Lymphoma [2070]	Y
	Over-Ride Site/Behavior [2071]	Y
	Over-Ride Site/Lat/Morph [2074]	Y

NPCR Site-Specific Factors		Required Status 1995–2011
	BCCEDP MDE Link Variable [Subm]	Y <sup>16</sup>
	BCCEDP MDE Link Date [Subm]	Y <sup>16</sup>

#### NOTES:

Shaded items denote variables that are considered **advanced** surveillance data. Non-shaded variables denote **core** surveillance data.

Data items new to this submission or having a status change are noted in **bold**.

The data item names and numbers are those used in NAACCR Volume II, Version 12.2.

Status key: Y = Yes

<sup>1</sup> Code “999” for unknown and invalid. Do not include cases with code “998” in the submission file. If State law precludes the registry from identifying specific counties on a file of individual records, recode all valid county codes to “000” and convert county codes to the derived Rural Urban Continuum variables. See Submission Specifications document for more details.

<sup>2</sup> Census Tract 2000 [130] is recommended for reportable cases diagnosed in 1998-2002 and required for reportable cases diagnosed in 2003 and later. Census Tract 2010 [135] is recommended for reportable cases diagnosed in 2010 and later.

<sup>3</sup> Report the results from the combined NHIA/NAPIIA (NHAPIIA) SAS Program. See the Submission Specifications document and/or Attachment 1 for more details. Please note that code 9, unknown, is not a valid code for the NHIA data item.

<sup>4</sup> Report the results of cases submitted for IHS linkage using codes 0 or 1. See the Submission Specifications document for further details.

<sup>5</sup> For reportable cases diagnosed in 2001 or later, data should be coded using the ICD-O-3 manual and submitted with these original ICD-O-3 values. For reportable cases diagnosed before 2001, data should be coded using the ICD-O-2 manual. Prior to submission, convert these ICD-O-2 codes to ICD-O-3 codes.

<sup>6</sup> Submit either the SEER or COC field; for reportable cases diagnosed prior to 2006, as available.

<sup>7</sup> For reportable cases diagnosed prior to 2006, submit as available. For Rad—Regional Rx Modality, cases diagnosed from 2003-2006, submit as available.

<sup>8</sup> For reportable cases diagnosed prior to 2001, code using *SEER Summary Staging Guide 1977*. For reportable cases diagnosed in 2001 and later, code using *SEER Summary Staging Manual 2000*. **Report Summary Stage 2000 as available for diagnosis years 2004 and later.**

<sup>9</sup> For reportable cases diagnosed 2008 and later, CS Tumor Size [2800] is required. For cases diagnosed prior to 2008, submit as available.

<sup>10</sup> For reportable cases diagnosed 2010 and later, CS Extension, CS Tumor Size/Ext Eval, CS Lymph Nodes, CS Mets at DX, SSF1 for breast, lung, and retinoblastoma, SSF2 for breast and corpus uteri, and SSF25 are required. For cases diagnosed 2004-2009, submit as available.

<sup>11</sup> For reportable cases diagnosed 2011, CS Lymph Nodes Eval, CS Mets Eval, and SSF1 for brain/CNS is required. For cases diagnosed 2004-2010, submit as available.

<sup>12</sup> For reportable cases diagnosed 2011, SSF15 is required. For cases diagnosed 2010, submit as available.

<sup>13</sup> For reportable cases diagnosed in 2004 and later, SSF1 for pleura, SSF3 for prostate, and Derived Summary Stage 2000 [3020] is required.

<sup>14</sup> For reportable cases diagnosed 1995-2011, submit as available.

<sup>15</sup> For reportable cases diagnosed 2006 and later, Follow-Up Source Central [1791] is required. For cases diagnosed prior to 2006, Follow-Up Source [1790] submit as available.

<sup>16</sup> For linkage results of reportable breast and cervical cancer cases. Report the BCCEDP MDE Link Variable in column 2840 and the BCCEDP MDE Link Date in columns 2841-2848 as instructed in the 2013 NPCR-CSS Submission Specifications.

## Attachment 3 2013 Data Edits

COORDINATED CORE EDITS		
Single Field Edits		
	Addr at DX--State	(NAACCR)
	Age at Diagnosis	(SEER AGEDX)
	Behavior ICDO3 Conversion	(NAACCR)
	Birthplace	(COC)
	County at DX <sup>1</sup>	(NPCR)
	<b>CS Extension</b>	<b>(CS)</b>
	<b>CS Lymph Nodes (CS)</b>	<b>(CS)</b>
	<b>CS Lymph Nodes Eval</b>	<b>(CS)</b>
	<b>CS Mets at DX (CS)</b>	<b>(CS)</b>
	<b>CS Mets Eval</b>	<b>(CS)</b>
	<b>CS Site-Specific Factor 1</b>	<b>(CS)</b>
	<b>CS Site-Specific Factor 2</b>	<b>(CS)</b>
	<b>CS Site-Specific Factor15</b>	<b>(CS)</b>
	<b>CS Site-Specific Factor25</b>	<b>(CS)</b>
	CS Tumor Size	(CS)
	<b>CS Tumor Size/Ext Eval</b>	<b>(CS)</b>
	CS Version Derived	(Subm)
	CS Version Input Current	(Subm)
	CS Version Input Original	(Subm)
	Date of 1st Crs RX Flag	(NAACCR)
	Date of 1st Crs RX--COC <sup>2</sup>	(COC)
	Date of Birth	(NAACCR)
	Date of Birth Flag	(NAACCR)
	Date of Diagnosis	(NAACCR DATEEDIT)
	Date of Diagnosis Flag	(NAACCR)
	Date of Initial RX Flag	(NAACCR)
	Date of Initial RX--SEER <sup>2</sup>	(NAACCR)
	<b>Date of Last Contact</b>	<b>(NAACCR DATEEDIT)</b>
	<b>Date of Last Contact Flag (NAACCR)</b>	<b>(NAACCR)</b>
	Derived SS2000	(CS)
	Diagnostic Confirmation	(SEER DXCONF)
	Grade	(COC)
	Histologic Type ICDO3 Conversion (NAACCR)	(NAACCR)
	IHS Link (NPCR)	(NPCR)
	Laterality	(SEER LATERAL)
	NAACCR Record Version	(NAACCR)
	NHIA Derived Hisp Origin	(NAACCR)
	Patient ID Number	(SEER CASENUM)

Primary Site	(SEER SITE)
Race 1	(SEER RACE)
Race 2	(NAACCR)
Race--NAPIIA(derived API)	(NAACCR)
Rad--Regional RX Modality	(NPCR)
Reason for No Surgery	(NPCR)
Record Type (NAACCR)	(NAACCR)
Registry ID	(Subm)
RuralUrban Continuum 1993	(NAACCR)
RuralUrban Continuum 2003	(NAACCR)
RX Summ--BRM	(NPCR)
RX Summ--Chemo	(NPCR)
RX Summ--Hormone	(NPCR)
RX Summ--Other	(NPCR)
RX Summ--Radiation	(Subm)
RX Summ--Scope Reg LN Sur	(SEER SCOPE)
RX Summ--Surg Oth Reg/Dis	(SEER SURGOTH)
RX Summ--Surg Prim Site	(SEER SURGPRIM)
RX Summ--Surg/Rad Seq	(NPCR)
RX Summ--Systemic/Sur Seq	(COC)
RX Summ--Transplnt/Endocr	(NPCR)
Sequence Number--Central	(SEER SEQUENC)
Sex	(SEER Sex)
Spanish/Hispanic Origin	(SEER SPANORIG)
Summary Stage 1977	(NAACCR)
Summary Stage 2000	(NAACCR)
Type of Reporting Source	(SEER RPRTSRC)
<b>Vital Status</b>	<b>(Subm)</b>

## COORDINATED CORE EDITS

### Inter-Field Edits

Age, Birth Date, Date of Diagnosis	(NAACCR IF13)
Age, Primary Site, Morph ICDO3--Adult	(SEER)
Age, Primary Site, Morph ICDO3--Pediatric	(NPCR)
Age, Primary Site, Morphology ICDO3	(SEER IF15)
Autopsy Only, RX	(NPCR)
Behavior Code ICDO3, Seq Num--Central	(SEER IF114)
Behavior ICDO3, Site, Histology ICDO3	(NAACCR)
Behavior ICDO3, Summary Stage 1977	(NAACCR)
Behavior ICDO3, Summary Stage 2000	(NAACCR)
Bladder, RX Summ--Surg Prim Site, BRM	(COC)
County at DX, Addr at DX--State <sup>1</sup>	(Subm)
<b>CS Eval Items, Type of Reporting Source</b>	<b>(CS)</b>
<b>CS Eval Items, Vital Status</b>	<b>(CS)</b>
<b>CS Ext, Histol ICDO3, Breast Schema</b>	<b>(CS)</b>
<b>CS Ext, LN, Mets at DX, SSF 1, Retinoblastoma</b>	<b>(CS)</b>
<b>CS Ext, LN, Mets at DX, SSF 3, Prostate</b>	<b>(CS)</b>
<b>CS Extension, Brain Schema</b>	<b>(CS)</b>

CS Extension, CS Lymph Nodes, CS Mets at DX	(CS)
CS Extension, CS Tumor Size, Breast Schema	(CS)
CS Extension, CS Tumor Size, Site, Hist ICDO3	(CS)
CS Extension, Hematopoietic	(CS)
CS Extension, Hist, Grade, Esophagus Schema	(CS)
CS Extension, Hist, Grade, EsophagusGEJunction	(CS)
CS Extension, KidneyRenalPelvis Schema	(CS)
CS Extension, Lymphoma Schema	(CS)
CS Extension, Morphology, Bladder ICDO3	(CS)
CS Extension, Mycosis Fungoides Schema	(CS)
CS Extension, MyelomaPlasmaCellDisorder	(CS)
CS Extension, Primary Site, Behavior ICDO3	(CS)
CS Extension, Schema	(CS)
CS Extension, SSF 1, Lung Schema	(CS)
CS Extension, SSF 3, Behavior, Prostate	(CS)
CS Extension, Surgery, Prostate Schema	(CS)
CS Extension, TS/Ext Eval, Prostate Schema	(CS)
CS Items - NPCR Required - Non-SSF	(Subm)
CS Items, DX Pre-2004	(CS)
CS Items - NPCR Required - SSF 1	(Subm)
CS Items - NPCR Required - SSF 2	(Subm)
CS Items - NPCR Required - SSF 3	(Subm)
CS Items - NPCR Required - SSF 15	(Subm)
CS Items, Type Reporting Source-DCO	(CS)
CS Lymph Nodes Eval, Lymph Nodes, Breast Schema(CS	(CS)
CS Lymph Nodes Eval, Schema	(CS)
CS Lymph Nodes, IntracranialGland Schema	(CS)
CS Lymph Nodes, MyelomaPlasmaCellDisorder	(CS)
CS Lymph Nodes, Schema	(CS)
CS Mets at DX, Lung, Laterality	(CS)
CS Mets at DX, Schema	(CS)
CS Mets Eval, Mets at DX, CS Version Inp Orig	(CS)
CS Mets Eval, Schema	(CS)
CS Site-Specific Factor 1, Schema	(Subm)
CS Site-Specific Factor 2, Schema	(Subm)
CS Site-Specific Factor 3, Schema	(Subm)
CS Site-Specific Factor15, Schema	(Subm)
CS Site-Specific Factor25, Schema	(CS)
CS SSF 1, RX Summ--Surg, Retinoblastoma Schema	(CS)
CS SSF 3, RX Summ--Surg, Prostate Schema	(CS)
CS SSF 3, TS/Ext Eval, Prostate Schema	(CS)
CS TS/Ext Eval, Surgery, Bladder Schema	(CS)
CS TS/Ext Eval, Surgery, Prostate Schema	(CS)
CS Tumor Size, Schema	(CS)
CS Tumor Size, Site, Histol ICDO3	(CS)
CS Tumor Size/Ext Eval, Schema	(CS)
CS Validate Schema	(CS)
CS Verify CStage Version 0204xx	(CS)
CS Version Input Current, CS Version Derived	(CS)



CS Version Input Original, CS Version Derived	(CS)
CS Version Input Original, Version Input Curr	(CS)
Date of 1st Crs RX--COC, Date Flag	(NPCR)
Date of 1st Crs RX--COC, Date Init RX--SEER	(Subm)
Date of 1st Crs RX--COC, Date of DX	(COC)
Date of Birth, Date Flag	(NAACCR)
Date of Birth, Date of Diagnosis	(NAACCR IF47)
Date of Diagnosis, Date Flag	(NAACCR)
<b>Date of Init RX--SEER, Date Last Cont</b>	<b>(NAACCR IF35)</b>
Date of Init RX--SEER, Date of DX	(Subm)
Date of Initial RX--SEER, Date Flag	(NPCR)
<b>Date of Last Contact, Date Flag</b>	<b>(NAACCR)</b>
<b>Date of Last Contact, Date of Diag.</b>	<b>(NAACCR IF19)</b>
Death Certificate Only, RX	(NPCR)
Derived Items, Date of DX	(NPCR)
<b>Derived Items, DX Pre-2004</b>	<b>(CS)</b>
<b>Derived SS2000, Behavior ICDO3</b>	<b>(CS)</b>
Diagnostic Confirm, Seq Num--Central	(SEER IF23)
Diagnostic Confirmation, Behavior ICDO3	(SEER IF31)
Diagnostic Confirmation, Histology ICDO3	(SEER IF48)
<b>Edit Over-rides</b>	<b>(SEER REVIEWFL)</b>
Hemato ICDO3, Summ Stg 1977	(NAACCR)
<b>Histology ICDO3, Grade, Date of DX (SEER)</b>	<b>(SEER)</b>
Laterality, Primary Site	(COC)
Laterality, Primary Site, Morph ICDO3	(SEER IF42)
Lymphoma ICDO3, Site, Summ Stg 1977	(NAACCR)
Morphology--Type/Behavior ICDO3	(SEER MORPH)
NBCCEDP MDELink, MDEDate	(Subm)
<b>Non-Reportable Skin ICDO3</b>	<b>(SEER IF117)</b>
<b>Obsolete Codes - CS Extension</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Lymph Nodes</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Lymph Nodes Eval</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Mets at DX</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Mets Eval</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Site-Specific Factor 1</b>	<b>(Subm)</b>
<b>Obsolete Codes - CS Site-Specific Factor 2</b>	<b>(Subm)</b>
<b>Obsolete Codes - CS Site-Specific Factor 3</b>	<b>(Subm)</b>
<b>Obsolete Codes - CS Site-Specific Factor15</b>	<b>(Subm)</b>
<b>Obsolete Codes - CS Site-Specific Factor25</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Tumor Size</b>	<b>(CS)</b>
<b>Obsolete Codes - CS Tumor Size/Ext Eval</b>	<b>(CS)</b>
PIN III ICDO3, Date of Diagnosis	(SEER IF110)
Primary Site, Behavior Code ICDO3	(SEER IF39)
<b>Primary Site, CS Extension</b>	<b>(SEER IF176)</b>
Primary Site, Laterality	(SEER IF82)
<b>Primary Site, Laterality, CS Extension</b>	<b>SEER IF177)</b>
Primary Site, Morphology-Imposs ICDO3	(SEER IF38)
Primary Site, Morphology-Type,Beh ICDO3	(SEER IF25)

Attachment 3-4

August 2012

*NPCR-CSS 2013 Data Submission  
1995–2011 Diagnosis Years*

Race 1, Race 2	(Subm)
Race 2, Date of DX	(SEER IF89)
Rad--Regional RX Modality, Date of Diagnosis	(NPCR)
Reason for No Surgery, Date of DX	(NPCR)
RX Summ--BRM, Date of DX	(NPCR)
RX Summ--BRM, Vital Status	(COC)
RX Summ--Chemo, Date of DX	(NPCR)
RX Summ--Chemo, Vital Status	(COC)
RX Summ--Hormone, Date of DX	(NPCR)
RX Summ--Hormone, Vital Status	(COC)
RX Summ--Other, Date of DX	(NPCR)
RX Summ--Scope Reg LN Sur, Date of DX	(NPCR)
RX Summ--Scope Reg LN Sur, Site, ICDO3	(SEER IF109)
RX Summ--Surg Oth Reg/Dis, Date of DX	(NPCR)
RX Summ--Surg Prim Site, Date of DX	(NPCR)
RX Summ--Surg Prim Site, Diag Conf	(SEER IF76)
RX Summ--Surg Prim Site, Site, ICDO3	(SEER IF108)
RX Summ--Surg/Rad Seq, Date of DX	(NPCR)
RX Summ--Systemic/Sur Seq, Date of DX	(COC)
RX Summ--Transplnt/Endocr, Date of DX	(NPCR)
RX Summ--Transplnt/Endocr, Primary Site	(SEER IF28)
RX Summ--Transplnt/Endocr, Vital Status	(COC)
Seq Num--Central, Prim Site, Morph ICDO3	(SEER IF22)
Sex, Primary Site	(SEER IF17)
Spanish/Hispanic Origin, NHIA Derived	(NAACCR)
Summ Stg 2000, Site, Hist ICDO3, Rpt Srce	(NAACCR)
Summary Stage 1977, Date of Diagnosis	(NAACCR)
Summary Stage 1977, Summary Stage 2000	(NAACCR)
Summary Stage 1977, Type of Report Source	(NAACCR)
Summary Stage 2000, Date of Diagnosis	(NAACCR)
Surgery, Rad, Surg/Rad Seq	(COC)
Type of Rep Srce(DC),Seq Num--Cent,ICDO3	(SEER IF04)
<b>Type of Report Srce (AO), Date of Dx</b>	<b>(SEER IF02)</b>
Type of Report Srce(DC/AO), Diag Conf	(SEER IF05)
<b>Type of Report Srce(DC/AO), Vital Stat</b>	<b>(SEER IF08)</b>
Unknown Site, Hist ICDO3, Summ Stg 1977	(NAACCR)
Unknown Site, Laterality	(SEER IF138)

## COORDINATED CORE EDITS

### Inter-Record Edits<sup>3</sup>

Verify Place of Birth Same on All Records for a Patient	(SEER IR01)
Verify Date of Birth Same on All Records for a Patient	(SEER IR02)
Verify Sequence Number-Central of 00-59 using Age at Diagnosis	(SEER IR03A)
Verify Sequence Number-Central of 60-87 Using Age at Diagnosis	(SEER IR03B)
Verify Race Same on All Records for a Patient	(SEER IR04)
Verify Sex Same on All Records for a Patient	(SEER IR05)
Verify Sequence Number-Central of 00-59 Using Dates of Diagnosis	(SEER IR06A)
Verify Sequence Number-Central of 60-87 Using Dates of Diagnosis	(SEER IR06B)

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	Verify Sequence Number-Central not in Conflict with Number of Primaries in Sequence Range of 00-59, and 99	(SEER IR07A)
	Verify Sequence Number-Central Not in Conflict with Number of Primaries in Sequence Range of 60-88	(SEER IR07B)
	Verify Same Primary Not Reported Twice for a Person	(SEER IR09)
	Verify No Multiple Bladder Primaries Reported for a Person	(SEER IR13A)
	Verify No Multiple Prostate Primaries Reported for a Person	(SEER IR13B)
	Verify No Multiple Kaposi Sarcoma Primaries Reported for a Person	(SEER IR13C)
	Verify Spanish Surname or Origin Same on all Records for a Person	(SEER IR14)
	Verify NHIA Derived Hisp Origin Same on all Records for a Person	(SEER IR15)
	Verify IHS Linkage Same on all Records for a Person	(NPCR IR01)
<b>ADVANCED DATA EDITS</b>		
<b>Single Field Edits</b>		
	Addr at DX--Postal Code	(NAACCR)
	Cause of Death	(SEER COD)
	Census Cod Sys 1970/80/90	(SEER RESSYST)
	Census Tr Cert 1970/80/90	(SEER CENS CERT)
	Census Tr Certainty 2000	(SEER)
	<b>Census Tr Certainty 2010</b>	<b>(SEER)</b>
	Census Tract 1970/80/90	(SEER TRACT)
	Census Tract 2000	(SEER)
	<b>Census Tract 2010</b>	<b>(SEER)</b>
	<b>Derived AJCC-6 Stage Group</b>	<b>(CS)</b>
	<b>Derived AJCC-7 Stage Group</b>	<b>(CS)</b>

	Follow-up Source	(COC)
	Follow-up Source Central	(NAACCR)
	ICD Revision Number	(NPCR)
	<b>TNM Clin Stage Group</b>	<b>(COC)</b>
	<b>TNM Path Stage Group</b>	<b>(COC)</b>
<b>ADVANCED DATA EDITS</b>		
<b>Inter-Field Edits</b>		
	Age, Histologic Type, COD, ICDO3	(SEER IF43)
	Census Tract 1970/80/90, Census Tract Coding Sys	(SEER IF45)
	Follow-up Source Central, Date of DX	(NPCR)
	Follow-Up Source Central, Vital Status	(NPCR)
	Follow-up Source, Vital Status	(COC)
	ICD Revision Number, Cause of Death	(SEER IF37)
	ICD Revision, Vital Stat, Date Last Contact	(NPCR)
	Type of Report Sree (DC/AO), COD	(SEER IF09)
	Vital Status, Cause of Death	(Subm)
<b>ADVANCED DATA EDITS</b>		
<b>Inter-Record Edits</b>		
	Verify Date of Follow-up Same on All Records for a Patient	(SEER IR08)
	Verify Vital Status Same on All Records for a Patient	(SEER IR10)
	Verify Cause of Death Same on All Records for a Patient	(SEER IR11)
	Verify Type of Reporting Source and Sequence Number—Central 00-59	(SEER IR16A)
	Verify Type of Reporting Source and Sequence Number—Central 60-87	(SEER IR16B)

#### NOTES:

Edits new or having a status change to this submission are noted in **bold**.

See the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver/>) for the edits programs.

Edits labeled "Subm" are specifically for the NPCR-CSS submission and should be run only on the submission file.

<sup>1</sup> This edit has been modified to allow "000" as a valid code for recode if state law prohibits the release of county codes.

<sup>2</sup> Central registries may code either the SEER or COC data item; the appropriate edit will be run on the completed field.

<sup>3</sup> Inter-record edit errors from these IR-edits are required to be resolved and will be used to assess program standards.



## Attachment 4

### NPCR and Indian Health Services (IHS) Record Linkage Procedures

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#### I. BACKGROUND

Previous studies have documented misclassification of American Indians/Alaska Natives (AI/ANs) as non-AI/AN in some central cancer registries and geographic areas (Frost, 1992; Kwong, 1998; Sugarman 1996; Partin, 1999; Burhansstipanov, 1999). Further, cancer surveillance data for AI/ANs may be suppressed in some reports due to small numbers. Therefore, the ability to correctly classify AI/ANs in NPCR-supported and other cancer registries would not only improve the overall quality of data, but would likely increase the number of AI/AN cancer cases available for inclusion in future reports. Projects to improve the quality of cancer surveillance data for AI/ANs in NPCR registries are consistent with the CDC's goal to eliminate racial and ethnic health disparities. AI/AN populations are diverse groups of individuals from distinct cultural backgrounds (Joseph, 1998). Numerous studies have documented that cancer-related incidence rates, mortality rates, and survival rates differ among the various AI/AN tribal groups, and that their cancer patterns often differ from those of the other populations in the United States (Espey, 2007; MAS, 1999; DHHS, 1998; Cobb, 1998).

Misclassification of AI/ANs as any non-AI/AN race has been found to be as high as 40 percent in the Cancer Surveillance System in northwestern Washington State (Frost, 1992). Similarly high rates of misclassification were also documented in statewide cancer registries in California (Kwong, 1998) and Minnesota (Partin, 1999). Unpublished results from a recent investigation indicate that such misclassification in the central registry often reflects inadequate or inaccurate information on American Indian ancestry in the medical record (Wiggins, personal communication). It should be noted, however, that high levels of racial misclassification have not been documented in all central cancer registries. Misclassification of AI/ANs in the New Mexico Tumor Registry, for example, appears to be negligible (Kolonel, 1992). Nonetheless, such misclassification in some registries could have profound effects on cancer surveillance statistics for AI/AN populations. This, in turn, could lead to faulty program planning for cancer prevention activities in AI/AN populations since they would be based on underestimates of cancer burden.

Indian Health Service (IHS) patient registration data have been and are used on a routine basis for quality control and quality improvement in several projects. One of the reasons that the New Mexico Tumor Registry has so little misclassification of cancer cases in AI/ANs is that they routinely link their data

with the IHS patient registration database and update those AI/AN individuals who have been misclassified as non-AI/AN. IHS data are routinely shared with the Census Bureau where they are used to validate race. The IHS also conducts routine data linkages with the Center for Medicare and Medicaid Services (CMS) to provide more accurate information for assessing outreach to AI/AN Medicare beneficiaries. Another benefit of collaborating with CMS is that matched records may be used to help analyze patterns of Medicare utilization among AI/ANs. In addition, IHS uses the data linkage in claims processing to help reduce the number of IHS Medicare claims rejected by CMS fiscal intermediaries for errors in the health insurance claim number, social security number, race, and name variations.

In a similar fashion, we propose a routine linkage of NPCR registry data with IHS data for data quality improvement to more accurately describe the burden of cancer in the AI/AN populations. The NPCR-IHS linkage data were used in the “Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives” (Espey, 2007) in a supplement to *Cancer* (Espey, 2008).

**II. OBJECTIVES:** Records from registries that participate in NPCR will be linked with patient registration records from IHS in order to:

- A. Identify cancer cases among AI/ANs who were misclassified as non-AI/AN, using data reported by selected NPCR-supported registries.
- B. Address such errors in the databases of the participating registries to improve the quality of cancer surveillance data on AI/ANs in both the individual NPCR registries and in the NPCR as a whole by recording results of the linkage in IHS Link [North American Association of Central Cancer Registries (NAACCR) data item #192].
- C. Provide improved AI/AN race and date of death information to improve estimates of cancer incidence and survival among AI/ANs, based on the combined experience of NPCR-supported registries before and after successfully completing the record linkage.
- D. Include cancer incidence data for AI/ANs in *United States Cancer Statistics* annually
- E. Include cancer survival data for AI/ANs in a peer-reviewed journal article

**III. METHODS OR PROCESS:**

- A. Participating registries (see table 1) will be asked to capture a static copy of their master file based on the following selection criteria:

1. All incident cases diagnosed during the time period 1995-2010 (inclusive of cases diagnosed in calendar years 1995 and 2010);
2. Reportable cases (see item 3 of the 2013 NPCR-CSS Submission Specifications); only include in situ cases of urinary bladder and breast
3. This file should contain one record per primary cancer site/type per individual, with one unique identifying number per individual and a sequence number to uniquely identify each primary cancer.

The registries that have one or more IHS Contract Health Service Delivery Area (CHSDA) counties are required to link registry data with IHS annually. All States will conduct the linkage every 5 years; the last linkage for all States was conducted in calendar year 2011. If a registry does not have one or more CHSDA counties and finds the IHS linkage beneficial, we will link its data if the registry is able to send its data to IHS for linkage.

- B. One file from the state registry will be generated in the course of this project:

**State File 1 (SF1):** This file will contain sufficient patient-identifying information to allow records to be linked with an administrative file from the IHS. We respectfully request that State File 1 follow the NAACCR confidential record layout Version 12.2. This file should contain one record per primary cancer site/type per individual, with one unique identifying number per individual and a sequence number to uniquely identify each primary cancer. This record layout accommodates maiden name and alias, as available. We also request that the variable, IHSLink, be included. IHSLink captured the results from the previous linkage and its inclusion will greatly facilitate the linkage by eliminating from consideration records that previously linked to the IHS database.

Table 2 displays the specific data items to be included in State File 1. (Item number and columns from the NAACCR record layout version 12.2 are shown).

### **Preparation Procedures for the IHS Linkage**

1. Go to the NPCR CSS Utilities page (<https://www.npcrcss.org/utilities/>) and download two programs:
  - a. SAS Linkage Extraction Program (or standalone extraction utility program by choosing the IHS linkage option after executing the utility program)
  - b. GenEdits Plus software customized for IHS linkage
2. Install both programs. The GenEdits Plus install will have a meta file/edit set specifically configured to clean fields used in the IHS linkage process.

3. Using the SAS Linkage Extraction program, create an extract file containing the data items shown in table 2 for reportable cases diagnosed during 1995-2010(or the standalone extraction utility program).
4. Run GenEdits Plus and the IHS linkage edit set against this extract.
5. Resolve any errors found in the edit report. All errors should only be resolved in the Central Cancer Registry database.
6. Repeat steps 3-5 until all errors have been resolved
7. Create a final extract to be used in the IHS Linkage

**Note:** These steps should be 2 weeks before the linkage takes place.

- C. At each participating registry, State File 1 (see item III.B) will be placed in an encrypted and password protected format and transmitted to IHS in one of the following two methods:

1. Details regarding the secure data transfer method will follow shortly. Please contact Melissa Jim ([melissa.jim@ihs.gov](mailto:melissa.jim@ihs.gov) or [ere0@cdc.gov](mailto:ere0@cdc.gov)).
2. Encrypted, password-protected, and shipped according to a pre-arranged schedule via express courier service to:

IHS Division of Epidemiology and Disease Prevention  
c/o Melissa Jim  
5300 Homestead Road NE  
Albuquerque, NM 87110

The password for State File 1 will be sent separately to the IHS Division of Epidemiology and Disease Prevention.

At a mutually agreeable time, the project team composed of CDC/Division of Cancer Prevention and Control (DCPC) staff (Dr. David Espey, Melissa Jim, Donald Haverkamp, Diana Roberts) and IHS staff (Roberta Paisano), will meet at the IHS Division of Epidemiology and Disease Prevention in Albuquerque to conduct computer-assisted record linkages between files from participating NPCR registries (**SF1**) and the administrative file from IHS (**IHS File**). If a State is unable to send its data unaccompanied for administrative reasons, please contact Melissa Jim to make individual arrangements.

- D. State File 1 will be stored at the IHS Division of Epidemiology and Disease Prevention and placed in a locked filing cabinet maintained specifically for data security. Access to the files will be restricted. Dr. David Espey will be the custodian of the data at IHS Division of Epidemiology and Disease Prevention in Albuquerque, NM.
- E. Computer-assisted record linkages will be conducted under the supervision of the project team. All linkages will be conducted on the premises of the IHS



Division of Epidemiology and Disease Prevention, with the assistance of project team members and (at a registry's request) registry staff members. All persons who participate in the record linkage process will sign appropriate confidentiality pledges.

- F. Computer-assisted record linkages will be conducted only on a standalone computer (i.e., data will not be placed on a network or on a device that is accessible by a network). At the conclusion of the record linkage process, the hard drive that was utilized will be erased in accordance with government security standards. Appropriate project staff will witness and verify that these procedures were followed. At the conclusion of the record-linkage process, State File 1 records will either be destroyed or returned to their respective registries (in their original, encrypted formats), in accordance with the requests of respective registries.
- G. We will perform probabilistic record linkages between State File 1 and the IHS File using Link Plus, a software package developed by DCPC in support of NPCR.
- H. Two files will be generated as a result of the record linkage process.
  - 1. The first file (**Match File 1**) will contain all records that were determined to have been perfect or near perfect matches between the two data sources. The file will contain patient-identifying information from both the contributing NPCR registry and IHS.
  - 2. The second file (**Match File 2**) will contain records that most probably represent matches based on an intermediate matching score (clerical reviews). The project team will resolve the clerical reviews using the following protocol:
    - a) For each registry, the clerical review file will be given to two reviewers from the project team.
    - b) Each person will review the clerical review file and make an independent determination as to whether or not each clerical review pair is a match.
    - c) They will compare their results. Disagreements regarding the results will be adjudicated by a third reviewer, who will be selected by the project team.
    - d) To the extent possible, a common protocol will be applied to determine whether a clerical review is a match.
- I. From the two files from Step H, above, linkage results will be available in two different files:

1. A file will be generated (**Match File 3**) that contains, in a single record, the following information for the record with the highest match score for each patient identification (ID) number in the pairs determined to be matches between the State File 1 and IHS File:

- a) IHS record ID (for this project only)
- b) Patient ID number
- c) Patient sequence number
- d) Overall match score according to Link Plus
- e) AI/AN race
- f) IHSLink
- g) Vital Status
- h) Date of Last Contact
- i) The matching variables for the two records
  1. First Name
  2. Last Name
  3. Middle Name
  4. Gender
  5. SSN
  6. Date of Birth
  7. Date of Death
  8. Diagnosis Address
  9. Current Address (street, city, State, ZIP code)

Match File 3 will be sent to the State registry as the results of the final match.

2. A file will be generated (**Match File 4**) that will contain all records that were submitted for linkage in State File 1. This file will be in the NAACCR record layout version 12.2 (according to the state's needs) shown in table 1, and the IHSLink, Vital Status and Date of Last Contact fields will contain the updated values that will be submitted for the 2013 NPCR-CSS Call for Data.
- J. It is preferable that participating registries use **Match File 4** to update the IHSLink, Vital Status and Date of Last Contact fields for records that linked with an IHS record this year that will capture the results of the linkage. The updated values for IHSLink, Vital Status and Date of Last Contact will be submitted to NPCR in the Call for Data. All records that were not submitted to IHS for linkage should be assigned a blank for IHSLink.
1. If participating registries use **Match File 3** to update the IHSLink, Vital Status and Date of Last Contact fields, please note that: ALL sequences for the patients identified in this match should be updated with IHSlink=1. All records included in State File 1 with a blank IHSLink field prior to the linkage and that were not identified as matches should

be updated in the State registry with IHSLink=0. All records that were not submitted to IHS for linkage should be assigned a blank for IHSLink.

#### K. Summary of Project Files

1. **State File 1:** This file will contain all NPCR-reportable cancer cases. It will contain sufficient patient-identifying information to allow records to be linked with an administrative file from the IHS and will include the NPCR variable, IHSLink.
2. **IHS File:** This file will contain IHS patient registration data from 1985 to the present. It will be linked with State File 1 to identify individuals misclassified as non-AI/AN in the State registry. A determination of whether a person in the IHS database is AI/AN is made by examining three fields:
  - a) Beneficiary code ("01" = AI/AN)
  - b) Valid tribe code
  - c) Quantum (degree of Native ancestry)
3. **Match File 1:** This file will contain match pairs resulting from the probabilistic linkage between the State File 1 and IHS File that are considered perfect or near-perfect matches as a result of high match scores.
4. **Match File 2:** This file will contain match pairs resulting from the probabilistic linkage between the State File 1 and IHS File that are considered possible matches as a result of intermediate match scores. These are called "clerical matches" since they will require a clerical review to determine whether they represent true matches.
5. **Match File 3:** This file will contain clerical matches from Match File 2 that are judged to be true matches combined with the perfect and near-perfect matches from Match File 1. It will contain the record with the highest matching score for each patient ID number, which are matches from State File 1 and IHS File. It will also contain the updated values for the IHSLink, Vital Status and Date of Last Contact variables that will be submitted to 2013 NPCR-CSS Call for Data. Because all the records are considered to be matches on this file, all values of IHSLink on Match File 3 will be '1'.
6. **Match File 4:** This file will contain all records that were submitted for linkage in State File 1. This file will be in the NAACCR record layout version 12.2, (according to the state's needs) shown in table 1 with the IHSLink, Vital Status and Date of Last Contact fields containing the

updated values that will be submitted to 2013 NPCR-CSS Call for Data.

#### IV. PRODUCTS OR RESULTS

These linkage results will be used for analyses by States and CDC staff and included in State and Federal reports and publications (i.e. *United States Cancer Statistics*). In addition to improving cancer incidence rates presented in USCS, an analytic database will be maintained by Melissa Jim for DCPC AI/AN activities, which include data requests for AI/AN cancer incidence rates from tribal epidemiology centers and tribal organizations contingent upon permission from the state registries that comprise the IHS Areas of interest.

#### V. STEWARDSHIP OR RESPONSIBLE PARTY:

- A. **Participating NPCR registries** prepare and submit data file for linkage, report results from linkage and incidence rate analyses, submit data/results for joint project publication, and maintain data security.
- B. **IHS Division of Epidemiology and Disease Prevention** receives and links data, return data files to participating registries; and safeguards all data, data analysis, and report writing.
- C. **CDC** participates in and monitors data linkage, data analysis, and report writing.

#### VI. TIME FRAME:

<u>Month</u>	<u>Activity</u>
Aug	Prepare data files from registries and IHS
Sept-Oct	Data linkage at central data processing location Adjudication of clerical reviews at central data processing location Development of registry file with updated AI/AN population data
Nov	Central cancer registries update IHSLink in their registry database Central cancer registries submit data to CDC and NAACCR with updated IHSLink
Jan-Feb	Project team generates analysis files from data submitted to CDC with case data for AI/ANs

#### VII. REFERENCES

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**Table 1. IHS Linkage Schedule**

<b>NPCR Registry</b>	<b>Every year*</b>	<b>Every 5 years</b>
Alabama	X	X
Alaska	X	X
Arizona	X	X
Arkansas		X
California	X	X
Colorado	X	X
Delaware		X
District of Columbia		X
Florida	X	X
Georgia		X
Idaho	X	X
Illinois		X
Indiana	X	X
Kansas	X	X
Kentucky		X
Louisiana	X	X
Maine	X	X
Maryland		X
Massachusetts	X	X
Michigan	X	X
Minnesota	X	X
Mississippi	X	X
Missouri		X
Montana	X	X
Nebraska	X	X
Nevada	X	X
New Hampshire		X
New Jersey		X
New York	X	X
North Carolina	X	X
North Dakota	X	X
Ohio		X
Oklahoma	X	X
Oregon	X	X
Pennsylvania	X	X
Rhode Island	X	X
South Carolina	X	X
South Dakota	X	X
Tennessee		X
Texas	X	X
Vermont		X
Virginia		X
Washington	X	X
West Virginia		X
Wisconsin	X	X
Wyoming	X	X

\* Registries with Contract Health Service Delivery Area (CHSDA) counties

**Table 2. NAACCR Record Layout for State File 1**

Version 12.2		Name
Item #	Column #	
10	1-1	Record Type
20	42-49	Patient ID Number
50	17-19	NAACCR Record Version
40	30-39	Registry ID
70	95-144	Addr at DX--City
80	145-146	Addr at DX--State
100	147-155	Addr at DX--Postal Code
90	156-158	County at DX
160	177-178	Race 1
161	179-180	Race 2
162	181-182	Race 3
163	183-184	Race 4
164	185-186	Race 5
190	189-189	Spanish/Hispanic Origin
220	192-192	Sex
230	193-195	Age at Diagnosis
240	196-203	Date of Birth
241	204-205	Date of Birth Flag
192	421-421	Result of previous IHS linkage
380	528-529	Sequence Number--Cntrl
390	530-537	Date of Diagnosis
391	538-539	Date of Diagnosis Flag
1750	2116-2123	Date of Last Contact
1751	2124-2125	Date of Last Contact Flag
1760	2126-2126	Vital Status
1810	2131-2180	Addr Current--City
1820	2181-2182	Addr Current--State
1830	2183-2191	Addr Curr--Postal Code
1840	2192-2194	County--Current
2230	3340-3379	Name--Last
2240	3380-3419	Name--First
2250	3420-3459	Name--Middle
2280	3466-3505	Name--Alias
2390	3506-3545	Name--Maiden
2290	3546-3605	Name--Spouse/Parent
2320	3619-3627	Social Security Number
2330	3628-3687	Addr at DX--No & Street
2335	3688-3747	Addr at DX--Supplement
2350	3748-3807	Addr Curr--No & Street
2355	3808-3867	Addr Curr--Supplement



## Attachment 5 2013 VHA Data Request 2000–2010 Diagnosis Years Based on 2013 NPCR-CSS Data Submission

This data request is needed so that the National Program of Cancer Registries (NPCR) can evaluate the ongoing effect of under-reporting by the Veterans Hospitals Administration (VHA). These data will be used to estimate the percent and number of cancer cases that were not reported to the central cancer registry due to delays or other issues created by the new VHA requirements. In addition to providing estimates for NPCR overall, correction factors at a State level will be estimated and provided to central cancer registries that submit data for this request.

Ideally, NPCR would like to know which cases were reported to you only by the VHA hospitals and requests these cases, if possible. This will enable NPCR to better estimate how many cases are likely to be missing from the central registry if the VHA hospitals do not report. However, since it may not be known which cases were received only through VHA reporting, there is the option of submitting information about VHA cases regardless of whether additional information is received from another source. Using the consolidated online submission form, indicate whether the data are VHA-only cases or all cases reported by VHA hospitals. Please provide comments on the form related to the VHA cases in your program, including a statement that no cases were received in the time period requested (if that is the case). If providing comments, please be as thorough as possible.

If either of the two situations listed below applies to you, you may not submit VHA data. But please provide the comment to indicate which situation applies.

1. VHA never reports to your registry and you don't have any VHA cases in your 2013 NPCR-CSS data submission.
2. VHA never stops reporting to your registry and all VHA cases are included in your 2013 NPCR-CSS submission.

Data should be provided to CDC in a SAS format through use of the secure document server (<https://www.npcrcss.org/docserver>) maintained by ICF Macro. This will provide the same security to the data that are in place for your annual data submission. Please complete this data request by **November 30, 2012**.

The data variables and data definitions for the SAS file are included with these instructions. The SAS programs to create the file are available for download on the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver>), under "Utilities Page."

Please follow the instructions exactly as stated below to create the requested file:



1. When preparing for the 2013 data submission, cut/extract a separate flat file in the NAACCR version 12.2 format that includes only the VHA data to be summarized for CDC. This file will include otherwise NPCR-reportable cases but with the VHA as the sole reporting source (and are thus useful for estimating the extent of unreported VA tumors for time periods when VA data were withheld from the central registry). If you cannot identify cases where the VHA is the sole source, please include all cases submitted by a VHA to your registry. The same edits for the 2013 NPCR-CSS submission should be run, and all errors should be corrected.

The raw file should contain the following key variables:

Address at Dx—State [80]
Race 1 [160]
Sex [220]
Age at Diagnosis [230]
Date of Diagnosis [390]
Primary Site [400]
Histologic Type ICD-O-3 [522]
Behavior Code ICD-O-3 [523]

2. Use the SAS programs provided by ICF Macro to generate the aggregate count file.
  - a. Two programs are provided for generating a SAS dataset containing case counts from the VHA reporting source: the main program [VHA\_Count\_by\_site\_age\_sex\_race.sas] and a site recode program [SiteRecode\_ICDO3.sas]. The user needs to run only the main program since the site recode program is called from the main program.
  - b. To use the main program, we assume that all VHA-only cases are NPCR reportable cases and that the input file is created in a NAACCR record layout version 12.
  - c. Only the locations and names of input and output files and the location of the site recode program need to be changed by the user in the main program. See the comment lines of the SAS program for detailed instructions.
3. The resulting count file will contain the following information:

Special notes		
Overall request	Sum of cancer cases reported to the registry <i>only</i> by VHA hospitals by gender; age group; year of diagnosis; and race recode categories.	If you cannot identify cases that were reported only by the VHA and no other sources, please include all cases reported by a VHA hospital and indicate this on the form submitted with the data.
Dataset	Should be based upon the 2013 data submission that	

Special notes		
	has passed edits.	
Diagnosis years requested	2000, 2001, 2002, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010	
Cancers included	26 cancers reported in USCS and “All Cancers Combined”	<p>“All Cancers Combined” includes all cancers not limited to the 26 specifically requested. Please see specific list of cancers requested below:</p> <ul style="list-style-type: none"> <li>(1) All Cancer Sites Combined</li> <li>(2) Brain and Other Nervous System</li> <li>(3) Breast</li> <li>(4) Breast, In Situ</li> <li>(5) Cervix Uteri</li> <li>(6) Colon and Rectum</li> <li>(7) Corpus and Uterus, NOS</li> <li>(8) Esophagus</li> <li>(9) Hodgkin Lymphoma</li> <li>(10) Kaposi Sarcoma</li> <li>(11) Kidney and Renal Pelvis</li> <li>(12) Larynx</li> <li>(13) Leukemias</li> <li>(14) Liver and Intrahepatic Bile Duct</li> <li>(15) Lung and Bronchus</li> <li>(16) Melanomas of the Skin</li> <li>(17) Mesothelioma</li> <li>(18) Myeloma</li> <li>(19) Non-Hodgkin Lymphoma</li> <li>(20) Oral Cavity and Pharynx</li> <li>(21) Ovary</li> <li>(22) Pancreas</li> <li>(23) Prostate</li> <li>(24) Stomach</li> <li>(25) Testis</li> <li>(26) Thyroid</li> <li>(27) Urinary Bladder</li> </ul>
Age groups	19 age groups (0, 1–4, 5–9.... to age 85 plus).	
NPCR Race recode	Race recode using Race1 variable	SAS program will create Race recode

4. Use the following naming convention to name your final count file before submitting to your 2013 submission folder on the NPCR-CSS document server: ST\_Countfile (“ST” is your state’s postal abbreviation (e.g., AL\_Countfile for Alabama)).

For additional help, States should contact ICF Macro at the NPCR Help Line at (301) 572-0502 or via e-mail at [support@npcrcss.org](mailto:support@npcrcss.org).



## Attachment 6 2013 NPCR-CSS Checklist

For registry use only. Do not submit.  
Place a checkmark (✓) next to the tasks completed.

*Please note that the order of tasks may vary.*

✓	Task
	Identify duplicate records in your database using the <i>NAACCR Protocol for Assessing Duplicate Cases</i> (1995 or your NPCR reference year–2010, 2010, 2011), and then enter your Duplicate Protocol Assessment results in the Consolidated Submission Form available at: <a href="https://www.npcrcss.org/docserver">https://www.npcrcss.org/docserver</a> by selecting the “Submission Form” option on the login page.
	If you have not already done so, run the ICD-O-2 to ICD-O-3 conversion program on cases diagnosed prior to 2001.
	If applicable, have the Indian Health Service (IHS) perform the IHS linkage on your State data and update your database with the linkage information.
	Run the North American Association of Central Cancer Registries (NAACCR) Hispanic and Asian/Pacific Islander Identification Algorithm to assign the derived Hispanic and Asian/Pacific Islander ethnicity to incident cases. Please be mindful of the instructions regarding this algorithm as noted in the 2013 NPCR-CSS Submission Specifications, (7.c).
	Run the edits program using the 2013 NAACCR/NPCR combined edits metafiles, and resolve single field and inter-field edit errors, if any.
	Run the inter-record edits standalone program 2013, and resolve edit errors, if any.
	Extract the data file; verify that all required diagnosis years are included (i.e., from your NPCR reference year through 2010 for your November 2012 submission, and from January 1 through December 31, 2011, for your January 2013 submission).
	Run the SAS program provided to extract the aggregated Veterans Health Administration (VHA) case count for selected sites for the specified diagnosis years (2000–2010).
	Follow the steps for creating and transmitting data, and send the data files (NPCR-CSS Call for Data submission and VHA data request) to ICF Macro before the submission deadline on November 30, 2012.
	Complete the Consolidated Submission Form online via the secure Web interface from the CSS login page, complete and sign the NPCR-CSS Data Set Participation Agreement (see attachment 10), scan the signed form into an Adobe Portable Document Format (PDF) file, and then upload the PDF file to your registry’s “2013 Submission” folder on the document server.



## Attachment 7 File Transfer Instructions

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Data transmitted to NPCR-CSS are encrypted during transmission. The encryption is accomplished via Secure Sockets Layer strong encryption—the same level of protection used by e-commerce sites to protect financial transactions.

NPCR-CSS staff at ICF Macro will call each program in early October to provide the login, user identification (ID), and password and to answer questions.

We are requiring online form completion and submission this year. For data submission, it is recommended that each State use data compression software such as PKZIP or WINZIP to compress its files prior to posting them to the secure Web site.

### Instructions:

1. Open an Internet Web browser capable of 128-bit encrypted communication. Some but not all versions of Microsoft (MS) Internet Explorer (5.x and higher) support 128-bit encryption. If your browser cannot support 128-bit encryption, you will be instructed on how to download the required browser software.
2. In the address or location line of your browser, enter the following link, <https://www.npcrcss.org/>, and press the Enter key.
3. A Security Warning page may pop up. Accept the security certificate by clicking on **Yes** (if using MS Internet Explorer). The login screen will appear. Choose from the options by clicking on the radio button for either Forms submission or Data upload. Enter your user-specific ID and password, and click on **Login**.
4. You will be directed to a secure area for the Consolidated Submission Form so that you can complete it online and submit it through a Web application. For each form completed, an Adobe Portable Document Format (PDF) version of the completed form will be generated after you click on **Submit**. A copy of the PDF file will be automatically delivered to your 2013 submission folder on the NPCR-CSS document server for you to download. You can download a copy for your own records, if you wish. (If you submit the same form multiple times, you will see multiple PDF copies of the form saved under your 2013 submission folder, one for each form submission. To find the most recent form submission, note the time stamp for each form.

5. When you choose to upload your dataset, you will see a folder that appears on the left-hand side of the screen labeled with your State's name. In order to upload your data file, open this folder and click on the 2013 submission folder that appears under your State's folder. Next, click on the yellow arrow labeled **Upload a File** on the right-hand side of the screen.

A new page will appear with the title, Document Upload. You will need to enter a title for the document and then click on **Browse** to locate the data file on your local hard drive or network drive. For naming your document, begin the file name with the two-character State postal abbreviation, then use the year range of the file and the North American Association of Central Cancer Registries layout version. For example, use the name MS11V122 for 2011 Mississippi data in version 12.2 and MS9510V122 for 1995–2010 Mississippi data in version 12.2. Once you have selected the file and entered any descriptive text that you want to include with the submission, click on **Continue**.

6. Depending on the size of the file and the speed of your Internet connection, the file uploading may take a few seconds to 30 minutes or more. You will receive a confirmation message after the file has been successfully uploaded.
7. Click on **Logout** in the upper right-hand corner, and you will return to the login screen.



## Attachment 8 Overview of Data Security

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The NPCR-CSS project data reside on a dedicated server maintained by ICF Macro at secure facility at Terremark. To ensure the security and confidentiality of project data, the following provisions have been incorporated into the ICF Macro's NPCR-CSS Security Plan in accordance with the requirements of the Assurance of Confidentiality.

The NPCR-CSS server is housed in a secure facility at Terremark, Culpeper, VA with a guard on duty 24 hours a day. Only authorized staff is allowed access to the server location. Support people are escorted by an authorized staff member if needed. The server resides on its own local area network (LAN) behind ICF Macro's firewall. ICF project staff access the server via VPN from their Rockville, MD location. Elevator and stairwell access to Rockville office is controlled by card key 24 hours. During business hours an attendant is always present at the reception desk.

- Access to the NPCR-CSS server is limited to authorized ICF Macro project staff (see below). The server is password-protected on its own security domain. No one, including non-project staff at ICF Macro, is allowed access to the NPCR-CSS data.
- All ICF Macro project staff must sign a confidentiality agreement before passwords and keys are assigned. All staff must also pass background checks appropriate to their responsibilities for a public trust position.
- NPCR-CSS data that are submitted electronically are encrypted during transmission from the States. They arrive on a document server behind ICF Macro's firewall. Each State has its own directory location so that no State has access to another State's data. The data are moved automatically from the document server to the NPCR-CSS server.
- Receipt and processing logs are maintained to document data receipt, file processing, and report production. All reports and electronic storage media containing NPCR-CSS data are stored under lock and key when not in use, and they will be destroyed once they are no longer needed.
- A comprehensive security plan has been developed and maintained by ICF Macro's security team. The security team consists of Donald McMaster, Business Steward; Kevin Zhang, Project Director; Jagruti Rana, Development Manager and Security Officer; Gretchen Stanton, LAN and WAN Security Steward and Kristopher Hall, System Administrator. All project staff receives annual security awareness training covering security procedures. The ICF Macro project security team oversees operations to prevent unauthorized disclosure of the NPCR-CSS data.
- Periodic (currently quarterly, but no less than once per year) reviews and updates of ICF Macro's security processes will be conducted to adjust for rapid changes in computer technology and to incorporate advances in security approaches. The security plan will be amended as needed to maintain the continued security and confidentiality of NPCR-CSS

data.

**ICF Macro  
Authorized Project Staff**

<b>Staff Member</b>	<b>Position</b>
Donald McMaster, M.B.A., M.S.	Business Steward
Kevin Zhang, Ph.D.	Project Director
Jagruti Rana, M.S.	Development Manager/Security Officer
Gretchen Stanton, M.A.	LAN/WAN Security Steward
Kristopher Hall, MCSA	System Administrator
Qiming He, Ph.D.	QA Manager/Sr. Programmer Analyst
Yuan Ren, Ph.D.	Data and Statistical Manager/Sr. Statistical Programmer
Olga Galin, M.S.	Sr. SAS Programmer/QA Specialist
Shailendra Bhavsar, B.S.	Sr. Programmer Analyst
Xing Dong, M.S.	Sr. Statistical Programmer
Phillip Schaeffer, M.S.	Sr. SAS data Consultant
David Radune, B.A.	Technical Consultant
Jonathan Stanger, M.P.A.	Database Developer
Shaobin Xu, M.S.	Programmer Analyst
Jing Guo, B.S.	Programmer Analyst





**Attachment 9**  
**Consolidated 2013 NPCR-CSS Data**  
**Submission Form**  
**1995–2011 Diagnosis Years**

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All central registries are to transmit requested information through a consolidated online submission form, which will be available at the NPCR-CSS document server (<https://www.npcrcss.org/docserver>) prior to the start of the submission period. All requested information relating to your 2013 NPCR data submission, including the Dataset Participation Agreement (see attachment 10), must be filled out online and submitted through the document server.

The new online consolidated form will capture information on:

- Death clearance
- NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA)
- Indian Health Service (IHS) linkage (if conducted)
- Data items not transmitted
- Duplicate record protocol results
- Follow-up source(s)
- Sources of Veterans Health Administration (VHA) data



## Attachment 10

### 2013 NPCR-CSS Dataset Participation Agreement

Registry name: \_\_\_\_\_

For diagnosis years 2010 and earlier, please indicate whether data from your registry that were submitted in the 2013 data submission may be included in the following NPCR-CSS datasets or data releases. For more information, see the NPCR-CSS Data Release Policy, available on the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver/>).

(Roman Numerals represent the location of the dataset description in the 2013 NPCR-CSS Data Release Policy)

#### IV. Data Requests and Notification of States

IV.B. USCS survival dataset

☐ Yes ☐ No

#### V. Public-Use Datasets

V.B. USCS expanded dataset (WONDER)

☐ Yes ☐ No

V.C. USCS county dataset

☐ Yes ☐ No

Age-adjusted rates only\*

Age-adjusted and crude rates<sup>†</sup>

☐ Yes ☐ No

V.D. Environmental Public Health Tracking<sup>‡</sup>

Unsmoothed rates (similar to State Cancer Profiles)

☐ Yes ☐ No

Smoothed rates

Data release from EPHT national portal to state portal

☐ Yes ☐ No

#### VI. Restricted-Access Dataset (RADs)

All variables and County at Dx§

All variables except County at Dx

☐ Yes ☐ No

Data release to State, national, and international partners

☐ Yes ☐ No

#### VII. Data Release to Collaborating Partners

VII.A. CBTRUS

☐ Yes ☐ No

VII.B. NAACCR (VHA State-specific correction factors)

☐ Yes ☐ No

VII.C. IHS

☐ Yes ☐ No

\* Currently used for State Cancer Profiles.

<sup>†</sup> Currently used for the U.S. Department of Health and Human Services Office of Women's Health Quick Data Online application.

‡ If unable to sign for the Environmental Public Health Tracking Public-Use Dataset, please mark the checkbox for “Defer to different official,” print a copy for the official to sign, and upload a separate signed form with this form.

§ County data will only be used in approved analyses and in the following ways: a) used as a linkage variable (linkage to census data, for example) only by National Center for Health Statistics Research Data Center (RDC) staff. The county variable will not be available to the researcher, but the RDC analyst would use it to create a linked dataset and then remove the county variable; b) included as a confounder or other control variable, but no data are presented by county. Again, it will be possible for the RDC data analyst to mask the actual county name and create dummy variables for this purpose; c) used in geographically aggregated form such as large metropolitan statistical areas (e.g., those with a population of 1 million or larger), multi-county regions, or geographical areas (e.g., Appalachia or IHS Contract Health Services Delivery Areas (CHSDA) counties). It will be possible for RDC analysts to create these areas for the researcher. If unable to sign for the RADS, please mark the checkbox for “Defer to different official,” print a copy for the official to sign, and upload a separate signed form with this form.

#### Data Presentation Suppression:

Please indicate if data are to be suppressed for Hispanic, American Indian/Alaskan Native (AIAN), and/or Asians/Pacific Islanders (API) populations for USCS, State Cancer Profiles, Office of Women’s Health, and/or WONDER data products **above** and **beyond the standard small cell size suppression rules**, as addressed in the link provided below. In addition to these suppression rules, the suppression rules for AIAN and API will also apply. The data for API and AIAN will be presented only for the nation and states with at least 50,000 population because of concerns regarding possible misclassification of race data and the relatively small sizes of these populations in the United States.

[http://www.cdc.gov/cancer/npcr/uses/2006/technical\\_notes/stat\\_methods/suppression.htm](http://www.cdc.gov/cancer/npcr/uses/2006/technical_notes/stat_methods/suppression.htm).

**Check if data for Hispanic, AIAN, and API are to be suppressed even if the counts/population are above the stated threshold. Do not check to suppress if the NPCR-CSS standard small cell size suppression rules, as described in the 2013 NPCR-CSS Data Release Policy, are acceptable because those rules will be automatically applied.**

	USCS	State Cancer Profiles	Office of Women’s Health	CDC WONDER
Hispanic				
AIAN				
API				

This agreement will remain in place until a new agreement is signed. CDC will send a new agreement form with each submission.

Person completing form:

Signature: \_\_\_\_\_ Name: \_\_\_\_\_

Date: \_\_\_\_\_ Title: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail address: \_\_\_\_\_

Attachment 10-2  
August 2012

***NPCR-CSS 2013 Data Submission  
1995–2011 Diagnosis Years***



# Attachment 11

## Central Brain Tumor Registry of the United States Analytic Dataset Variables 1995–2010 Diagnosis Years\*

*\*Diagnosis Years 2004-2010 invasive, benign, and borderline cases*

Item Name	NAACCR Data Item Number	Comments
Patient ID (unique)	20	
NAACCR Record Version	50	
State of Residence at Diagnosis	80	
Rural/Urban Continuum/Beale Code 1993	3300	
Rural/Urban Continuum/Beale Code 2003	3310	
NPCR Race Recode	Derived based on [160], [161], and [192]	<i>Same as race for USCS</i>
NHIAv2 Derived Hispanic Origin (Results of NAACCR Hispanic/Latino Identification Algorithm)	191	
NAPIIA	193	
Sex	220	
Age at Diagnosis	230	<i>Single year up to age 84; 85+ grouped into one category</i>
Sequence Number—Central	380	
Date of Diagnosis ( <i>YEAR portion only</i> )	390	<i>Day and month of diagnosis not requested</i>
Primary Site	400	
Laterality	410	
Grade	440	
Diagnostic Confirmation	490	
Type of Reporting Source	500	
Histologic Type (ICD-O-3)	522	
Behavior (ICD-O-3)	523	
SEER Summary Stage 1977	760	
SEER Summary Stage 2000	759	

Item Name	NAACCR Data Item Number	Comments
Derived Summary Stage 2000	3020	
EDITS overrides	1990–2074	
CS Site-Specific Factor 1	2880	WHO Grade



## Attachment 12

### Frequently Asked Questions About the NPCR-CSS Data Submission

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#### 1. What are the most frequent errors made when preparing data for submission?

- **Incorrect registry identification (ID) number:** The registry ID number is the North American Association of Central Cancer Registries (NAACCR) registry ID number (see NAACCR Vol. II).
- **Non-unique patient ID number:** In order to run inter-record edits, patients must have unique patient ID numbers assigned. Only patients with multiple primaries should have the same patient ID, and the sequence number for each primary should be different. If different patients have the same patient ID, the inter-record edits program will group them together as the same patient, and multiple edit errors will be triggered.
- **Confidential data:** NPCR-CSS will not accept any confidential data. Submitting data (columns 3340–22824) in the NAACCR record layout (version 12.2) will comply with NPCR requirements, but make sure that all confidential data elements are excluded. In addition, there is a stand-alone program available on the NPCR-CSS Web site that will extract only NPCR-CSS required data elements from the NAACCR record layout (see attachment 1 for details).

#### 2. Can data submission forms be faxed?

No. Submission forms sent via fax will no longer be accepted. All submission forms are available electronically so that you can fill them out online using your secure login to the CSS document server. The NPCR-CSS Data Set Participation Agreement (see attachment 10) should be completed, signed, and scanned into an Adobe Portable Document (PDF) file before it can be uploaded to your registry's 2013 Submission folder on NPCR's secure document server.

#### 3. How can I make corrections to my submission form?

Make corrections to the form online, and submit your form again. You will receive a copy of the revised form as a PDF file in your State folder on the CSS document server. Please make sure that you download a copy of the updated form for your own records. You should also notify ICF Macro of any changes made by sending an e-mail message to [support@npcrcss.org](mailto:support@npcrcss.org).

**4. Will I be notified when my transmission is received?**

As soon as your data are successfully uploaded to the NPCR-CSS Web site, you will receive an automatic e-mail notification.

**5. Is the NPCR-CSS user ID/password case-sensitive?**

No.

**6. Should files be zipped prior to data submission, and should each year be in a separate file?**

Zipped files can be transmitted in a significantly shorter period of time due to the compression of the files, so we strongly recommend that you zip your files prior to transmission. Zipping files should allow you to send data from all years together; extremely large files may need to be submitted by individual year as individual zip files.

**7. Can I password-protect my zipped data submission file?**

You do not need to password-protect your data files because they are transmitted through a secure Web server and are encrypted during transmission. If you password-protect your files, please notify ICF Macro staff by calling the NPCR-CSS Help Line at (301) 572-0502.

**8. What version of Microsoft (MS) Internet Explorer must be used to upload my data?**

You will need MS Internet Explorer 5.x (or higher), which can support 128-bit encryption. The latest version of MS Internet Explorer (currently version 8) can be downloaded from the MS Web site at: <http://www.microsoft.com/windows/internet-explorer/default.aspx>.

**9. Which diagnosis years must be submitted for this submission?**

Data from your NPCR reference year (not your registry reference year) through 2011 must be submitted.

**10. Should inter-record edits be run prior to submission?**

Yes. To the extent possible, please clean up all edit errors including inter-record edit errors. Please note that some of the inter-record edits are now considered “core” edits and will be assessed for standards. This is especially important if you want your registry’s data to be considered for inclusion in the 2013 Public Use Datasets and NCHS Restricted Access Dataset.

**11. What should we do if we cannot submit a required field (e.g., Census tract and county)?  
Should these fields be left blank?**

If certain elements cannot be submitted but are collected by the registry, please recode to indicate “unknown” (unless otherwise noted in the submission specifications), and then note it in the consolidated submission form available online. For county at diagnosis, please see item 4c of the submission specifications.

**12. What if we cannot meet the submission deadline?**

Every effort should be made to meet the submission deadline. If you know that you cannot meet the deadline, please contact your CDC program consultant, who will notify ICF Macro staff.

**13. When can we expect to receive the data evaluation reports?**

The reports are expected to be available Spring 2013.

**14. What if the wrong file is uploaded?**

If you choose not to upload a file or want to stop an upload in progress, click on **Cancel** at the bottom of the Document Upload screen. You will be returned to the File Management screen, where you can begin a new upload.

**15. Can I delete a file after it has been uploaded?**

When you upload a file, it is automatically transferred from the document server to another secure server within ICF Macro. The user cannot delete a file once it has been uploaded. If you want to have the file deleted, please notify ICF Macro by sending an e-mail message to [support@npcrcss.org](mailto:support@npcrcss.org) or call the NPCR-CSS Help Line at (301) 572-0502 with an instruction to ICF Macro staff to delete the file. ICF Macro will confirm the deletion of the file via e-mail.