

Attachment 4a

NPCR CSS Submission Specifications



2009 NPCR-CSS

Submission

Specifications



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2009 NPCR-CSS Submission Specifications

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2009 NPCR-CSS Submission Specifications

This document and its attachments outline the reporting requirements for the 2009 data submission to the National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS).

Registries that opt to submit data in **Tier I** will submit data in two phases: 1) All cases beginning with your NPCR reference year through December 31, 2006 are to be submitted in Phase I (November – December 1, 2008); 2) All cases diagnosed January 2007 through December 2007 are to be submitted in Phase II (January 2009).

NOTE: For the Tier I registries, retain all instructions and attachments for the second phase of your data submission.

Registries that opt to submit data in **Tier II** will submit all cases beginning with your NPCR reference year through December 31, 2007 in January 2009.

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.**

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:** Include cases diagnosed in all residents of your catchment area beginning with your NPCR reference year (e.g., 1995) through **December 31, 2007**. For guidance on residency, refer to Chapter III of *NAACCR Standards for Cancer Registries*, Volume II.¹ See item #10 for further instructions on submission due dates.
3. **Reportable Diagnoses:** All histologies with a behavior code of /2 or /3 (or in some cases behavior code of /0 [see 3h] or behavior code of /1 [see 3g]) in the *International Classification of Diseases for Oncology*, Third Edition (ICD–O–3) are reportable with the following exceptions or restrictions:^{2,3,4,5}
 - 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 (C21.1, 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 over-ride codes.
- f. Include all pilocytic astrocytomas. If necessary, convert behavior code to /3 before submitting cases.
- g. Include all cases as reportable in the year they were diagnosed. For example, those cases reportable in ICD–O–2 but not ICD–O–3 would be included for diagnosis years 1995-2000 only. However, as noted above, all ICD–O–2 codes should be converted to the corresponding ICD–O–3 codes prior to submission.

The following histologies should be reported for all cases diagnosed prior to January 1, 2001. These histologies are generally coded to ovary (C56.9), but are not limited to this primary site.

Descriptive terms and topography codes	ICD–O–3	ICD–O–2
Serous cystadenoma, borderline malignancy (C56.9)	8442/1	8442/3
Serous tumor, NOS, of low malignant potential (C56.9)	8442/1	8442/3
Papillary cystadenoma, borderline malignancy (C56.9)	8451/1	8451/3
Serous papillary cystic tumor of borderline malignancy (C56.9)	8462/1	8462/3
Papillary serous cystadenoma, borderline malignancy (C56.9)	8462/1	8462/3
Papillary serous tumor of low malignant potential (C56.9)	8462/1	8462/3
Atypical proliferative papillary serous tumor (C56.9)	8462/1	8462/3
Mucinous cystic tumor of borderline malignancy (C56.9)	8472/1	8472/3
Mucinous cystadenoma, borderline malignancy (C56.9)	8472/1	8472/3
Pseudomucinous cystadenoma, borderline malignancy (C56.9)	8472/1	8472/3
Mucinous tumor, NOS, of low malignant potential (C56.9)	8472/1	8472/3
Papillary mucinous cystadenoma, borderline malignancy (C56.9)	8473/1	8473/3
Papillary pseudomucinous cystadenoma, borderline malignancy (C56.9)	8473/1	8473/3
Papillary mucinous tumor of low malignant potential (C56.9)	8473/1	8473/3

- h. Beginning January 1, 2004, all nonmalignant primary intracranial and central nervous system tumors (see following table) with a benign (/0) or borderline (/1) behavior code are reportable, and are to be included in the data submission.^{1, 2, 5} However, exclude benign and borderline tumors of the cranial bones (C41.0). For further guidance, please refer to the following table.

Required Sites for Benign and Borderline Primary Intracranial and Central Nervous System Tumors		
General Term	Specific Sites	ICD-O-3 Topography Code
Meninges	Cerebral meninges	C70.0
	Spinal meninges	C70.1
	Meninges, NOS	C70.9
Brain	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
	Spinal cord, cranial nerves, and other parts of the central nervous system	Spinal cord
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
Pituitary, craniopharyngeal duct, and pineal gland	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*.¹
- a. Data items new to this submission or moved to “coordinated core” from “advanced” surveillance activities are noted in **bold**.
 - b. Unless otherwise noted, leave missing or uncollected data items blank.
 - c. If state law prohibits the release of all or some county codes, please recode the county code to “000” for relevant case records and convert county codes to the derived Rural Urban Continuum variables, Rural-Urban Continuum/Beale Code 1993 [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 NAACCR Web site under the link “Data Analysis Tools”:
http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=463.
- The NPCR County at Dx edit 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. For the Great Circle Distance Calculation program, please visit the NAACCR Web site under the link “Data Analysis Tools”:
http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=463. Please note that this variable is considered “advanced” and optional.
 - e. For cases diagnosed beginning January 1, 2006 and after, please include Follow-Up Source Central [NAACCR data item # 1791]. For cases diagnosed prior to 2006, this data item may be blank.
 - f. Treatment data items are to be submitted by year of diagnosis according to the following table.

Treatment First Course	Coordinated Call for Data Treatment Data Item - Required Status			
	1995-2000	2001-2002	2003-2005	2006-2007
Date of Initial Rx—SEER [1260]	As available	As available	As available	Submit either SEER or COC field; At least one of these items must be completed
Date of 1st Crs Rx—COC [1270]	As available	As available	As available	
Rx Summ—Surg Prim Site [1290]	As available	Required, as available	Required	Required
Rx Summ—Scope Reg LN Sur [1292]	As available	Required, as available	Required	Required
Rx Summ—Surg Oth Reg/Dis [1294]	As available	Required, as available	Required	Required
Reason for No Surgery [1340]	As available	As available	As available	Required
RX Summ—Radiation [1360]	As available	As available	As available	As available
RX Summ—Surg/Rad Seq [1380]	As available	As available	As available	Required
Rx Summ—Chemo [1390]	As available	As available	As available	Required
Rx Summ—Hormone [1400]	As available	As available	As available	Required
Rx Summ—BRM [1410]	As available	As available	As available	Required
Rx Summ—Other [1420]	As available	As available	As available	Required
First Course Calc Method [1500]	As available*	As available*	As available*	Required
Rad—Regional Rx Modality [1570]	As available	As available	As available	Required
Rx Summ—Transplnt/Endocr [3250]	As available	As available	As available	Required

As available—blanks allowed

Required, as available—blanks allowed

Required—blanks not allowed

As available*—edit associated with this data item does not allow the field to be blank if either Date of Initial Rx—SEER or Date of 1st Crs Rx—COC is not blank

5. For cases diagnosed beginning January 1, 2004, report the Derived Summary Stage 2000 [NAACCR data item #3020] using the Collaborative Staging (CS) Algorithm version 01.04.00 or later.
6. **Edits: Attachment 3, 2009 Data Edits**, contains a list of edits; single field, inter-field, and inter-record; that will be used to evaluate your data submission.
 - a. Edits new to this submission or moved from “advanced” to “coordinated core” surveillance activities are noted in **bold**.

- b. Coordinated Core Edits will be used to assess program standards (i.e., percentage of records passing edits; see item #15).
 - c. “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. “Advanced” data edits are not used to assess program standards.
 - d. Both “coordinated core” and “advanced” inter-record edits will be run at the same time through the Inter-Record Edits standalone utility program 2009, downloadable from the utilities Web site (<https://www.npcrcss.org/docserver/>).
7. **Report Linkage and Algorithm Results:**
- i. Prior to performing the Indian Health Service (IHS) Linkage and running the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA), review your data carefully to make sure that variables used in the linkages (i.e., SSN, birth date, names, etc.) are complete and valid.
 - ii. If you have performed the IHS Linkage, report the results in IHSLink [NAACCR #192]. See **Attachment 13**, *NPCR and IHS Record Linkage Procedures*, for detailed information.
 - iii. Next, run the NHAPIIA algorithm and place the output for NHIA in column 231 and the output for NAPIIA in column 236-237.
 - iv. To download a copy of the combined SAS program for NHAPIIA algorithm and its associated files, please visit the NAACCR Web site under the link “Data Analysis Tools”:
http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=463
Please contact Joe Rogers at (770) 488-4701 for assistance in obtaining a SAS license to run the SAS algorithm.
8. **Identification of Duplicate Records Form:** Please assess duplicate records in your database using the *NAACCR Protocol for Assessing Duplicate Cases* and copy the results to **Attachment 9**, *Duplicate Protocol Results*.
9. **Record Format:** Create a file in a **NAACCR Record Layout Version 11 (including versions 11.1, 11.2 and 11.3)** that includes only the data items listed in **Attachment 2**, *Data Items by Diagnosis Year*. Do not include data from the Patient-Confidential Section portion of the record. A file extraction program is available on the NPCR-CSS utilities Web site (<https://www.npcrcss.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. For those registries that have data files in a NAACCR version lower than Version 11 format, you may use a free-standing Windows program that will convert files into other NAACCR versions. Input files may contain NAACCR version 6, 7, 8, 9, 10 or their derivatives. Converted output files can be version 7, 8, 9, 10.2, or 11. You can download a copy of this conversion program from the following Web site:

10. **Submission Due Dates:** Data for the first phase of the **Tier I** submission can be submitted during the month of **November 2008 (through December 1)**, holidays excluded. Data for the second phase of the **Tier I** submission can be submitted during the month of **January 2009 (through January 30)**. Data for the **Tier II** submission can be submitted during the month of **January 2009 (through January 30)**. Submission hours are from 8 a.m. EST to 6 p.m. EST, Monday through Friday. If you need extended hours, contact the NPCR-CSS Help Line at (301-572-0502), and Macro International 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 12-month data**) and all required data items are included. **Attachment 4, NPCR-CSS Checklist**, 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 (SSL) strong encryption, the same level of protection used by e-commerce sites to protect financial transactions.

12. **File Transfer Instructions:** Refer to **Attachment 5, File Transfer Instructions**. Macro International 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, Macro International has developed and implemented the NPCR-CSS Security Plan. **Attachment 6, Overview of the Security Plan**, is provided.

14. **Transmitting Forms:** The following forms are in electronic format at the NPCR-CSS document server (<https://www.npcrcss.org/>) log-in page. Choose the “Submit Forms” option before you log in:

Attachment 7	2009 NPCR-CSS Data Submission Form
Attachment 8	2009 Data Items Not Transmitted Form
Attachment 9	2009 Duplicate Protocol Results
Attachment 10	2009 NPCR-CSS Dataset Participation Agreement
Attachment 11	2009 Registry Follow-Up Sources

These forms are available through a secure Web interface, may be completed, and submitted on-line. Alternatively, the forms may be printed, completed and submitted:

- 1) to your state folder on the NPCR-CSS document server, or
- 2) via fax [(301) 961-8537] with attention to Dr. Kevin Zhang, or
- 3) via postal mail to:

Dr. Kevin Zhang, Cancer Surveillance Project Director
Macro International
7315 Wisconsin Avenue, Suite 400W
Bethesda, MD 20814

15. **Questions about Your Submission:** Refer to **Attachment 12, *Frequently Asked Questions about the NPCR-CSS Data Submission***, or call the **NPCR Help Line (301) 572-0502**.

Topic	Point of Contact
Technical questions related to data submission (including user ID, password, or accessing the NPCR-CSS Web site)	NPCR Help Line (301) 572-0502
Completion of Attachments 7–11 (see #13 above)	Cheryll C. Thomas: (770) 488-3254 Reda Wilson: (770) 488-3245
SAS license to run NHAPIIA algorithm	Joe Rogers (770) 488-4701

15. **Data Evaluation:** Data will be evaluated according to the following NPCR standards, and results will be reported in the NPCR-CSS Data Evaluation Reports, which will be made available in May 2009.

Criteria		NPCR 12-Month Standard	NPCR 24-Month Standard	USCS ^a Publication Criteria	U.S. County Public-Use File Criteria ^b	Measurement Error
Percentage Completeness of Case Ascertainment ^c		>=90%	>=95%	>=90%	>=90%	-1.0%
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) ^d		NA	<=3%	<=5%	<=5%	-0.4%
Unresolved Duplicates (per 1,000) ^e		NA	<=1	NA	NA	-0.4
Percentage Passing Coordinated Core Edits ^f		>=97%	>=99%	>=97%	>=97%	NA

Notes

- a United States Cancer Statistics
 - b See NPCR-CSS Data Release Policy, on the utilities Web site (<https://www.npcrcss.org/docserver/>).
 - c 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.
 - d The registry must perform death clearance.
 - e Based on the results of NAACCR duplicate protocol.
 - f Only coordinated core edits will be used to evaluate data.
- NA Not applicable

References

1. Hultstrom D, editor. *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*. Springfield, IL: North American Association of Central Cancer Registries (Version 11, Tenth Edition, November 2004; Version 11.1 Eleventh Edition, April 2006; Version 11.2, Twelfth Edition, April 2007; Version 11.3, Thirteenth Edition, April 2008).
2. Funding Opportunity Announcement #DP07-703, National Cancer Prevention and Control Program, CDC, 2007.
3. Program Announcement #2060, National Cancer Prevention and Control Program, CDC, 1992.
4. Public Law 102-515. NPCR Home Page: <http://www.cdc.gov/cancer/npcr/npcrpdfs/publaw.pdf>.
5. Johnson CH, Adamo M (eds.), *SEER Program Coding and Staging Manual 2007*. National Cancer Institute, NIH Publication number 07-5581, Bethesda, MD 2007, pages 1–4.



Attachment 1 Programs on the NPCR-CSS Utilities Web Site

The following programs have been or will be posted to the NPCR-CSS utilities Web site (<https://www.npcrcss.org/docserver/>). Please use your state-specific login to access these programs. For assistance with these utility programs, please call Macro International 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 2.1 (NHIA v2.1) and the NAACCR Asian Pacific Islander Identification Algorithm, version 1.1 (NAPIIA v1.1). All NPCR registries are required to run this combined SAS program or equivalent in the 2009 Coordinated Call for Data submission. The output for NHIA should be placed in column 231 and the output for NAPIIA should be put in columns 236-237; the columns refer to the NAACCR Record Layout version 11 (including versions 11.1, 11.2 and 11.3). To download a copy of the combined SAS program and its associated files, please visit the NAACCR Web site under the link “Data Analysis Tools”:

http://www.naacrr.org/index.asp?Col_SectionKey=11&Col_ContentID=463

Please contact Joseph Rogers at (770) 488-4701 for assistance in obtaining a SAS license to run the SAS program.

3. **GenEDITS Plus with the 2009 Combined Edits Metafile**—This is an edits program that contains the edits metafile to run the 2009 **Combined** edits on NAACCR record layout version 11.2. The program produces summary and detailed reports of core and advanced edit errors.
4. **2009 Combined Edits Metafile**—For those registries that prefer to use another edits program, this download contains the runtime metafile for the 2009 Combined edits.
5. **2009 Coordinated Call for Data Edits Online Help**—This program installs Windows help files containing information that may be useful to registries when preparing their 2009 Coordinated Call for Data submission.
6. **Inter-Record Edits Standalone Program 2009**—This program runs SEER and NPCR inter-record edits on NAACCR Record Layout version 11 (including versions 11.1, 11.2 and 11.3), 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 2009 combined edits have been run and errors have been corrected.**

- 7. Data Extraction Utility 2009**—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 2009 Coordinated Call for Data. **By clicking the tab labeled “CSS” the user will be prompted to the application to extract data for 2009 Coordinated Call for Data submission.** This application will read NAACCR record layout version 11 (including versions 11.1, 11.2 and 11.3) and write a new ASCII text file in NAACCR record layout Version 11 that contains only those data items requested for the 2009 submission. Once you execute the program and click the “CSS” tab, a help file that describes how to use the program is available by clicking “Help” near the bottom of the application interface.
- 8. Northcon11 Record Conversion Program**—For those registries that have data file in NAACCR version lower than v11 format, you may use a free-standing Windows program that will convert files of cancer registry records in NAACCR data formats. Input files may contain NAACCR version 6, 7, 8, 9, 10, or their derivatives. Converted output files can be version 7, 8, 9, 10.2, or 11. You can download a copy of this conversion program from the following web site:
http://www.cdc.gov/cancer/npcr/tools/registryplus/up_download.htm
- 9. NPCR and IHS Record Linkage Procedures** – This document contains a detailed description of the background, objectives and methods/processes involved in linking state incidence data to the Indian Health Service (IHS) records for more complete cancer case reporting on American Indians/Alaska Natives.



Attachment 2

Data Items by Diagnosis Year

Record ID and Demographic Section—(Name and [Number])	Required Status 1995–2007
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] ¹	Y ¹
Rural-Urban Continuum/Beale Code 1993 [3300]¹	As needed¹
Rural-Urban Continuum/Beale Code 2003 [3310]¹	As needed¹
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] ²	Y ²
Census Tr Cert 1970/80/90 [364]	Y
Census Tr Certainty 2000 [365] ²	Y ²
Great Circle Distance Calculation [use columns 1399-1428]	Optional
Race 1 [160]	Y
Race 2 [161]	Y
Race 3 [162]	Y
Race 4 [163]	Y
Race 5 [164]	Y
Spanish/Hispanic Origin [190]	Y
NHIA Derived Hisp Origin [191] ³	Y ³
IHS Link [192] ⁴	Y ⁴
NAPIIA [use columns 236-237] ³	Y ³
Sex [220]	Y
Age at Diagnosis [230]	Y
Birth Date [240]	Y
Birthplace [250]	Y

Cancer Identification Section—(Name and [Number])		Required Status 1995–2007
	Sequence Number—Central [380]	Y
	Date of Diagnosis [390]	Y
	Primary Site [400]	Y
	Laterality [410]	Y
	Grade [440]	Y
	Site Coding Sys—Current [450]	Y
	Morph Coding Sys—Current [470]	Y
	Diagnostic Confirmation [490]	Y
	Type of Reporting Source [500]	Y
	Histologic Type ICD-O-3 [522] ⁵	Y ⁵
	Behavior Code ICD-O-3 [523] ⁵	Y ⁵
	ICD-O-3 Conversion Flag [2116] ⁵	Y ⁵
Treatment First Course Section—(Name and [Number])		Required Status 1995–2007
	Date of Initial Rx—SEER [1260]⁶	Y⁶
	Date of 1st Crs Rx—COC [1270]⁶	Y⁶
	Rx Summ—Surg Prim Site [1290]⁷	Y⁷
	Rx Summ—Scope Reg LN Sur [1292]⁷	Y⁷
	Rx Summ—Surg Oth Reg/Dis [1294]⁷	Y⁷
	Reason for No Surgery [1340]⁷	Y⁷
	RX Summ—Radiation [1360]⁷	Y⁷
	RX Summ—Surg/Rad Seq [1380]⁷	Y⁷
	Rx Summ—Chemo [1390]⁷	Y⁷
	Rx Summ—Hormone [1400]⁷	Y⁷
	Rx Summ—BRM [1410]⁷	Y⁷
	Rx Summ—Other [1420]⁷	Y⁷
	First Course Calc Method [1500]	Y⁷
	Rad—Regional Rx Modality [1570]⁷	Y⁷
	Rx Summ—Transplnt/Endocr [3250]⁷	Y⁷

Stage/Prognostic Factors Section—(Name and [Number])		Required Status 1995–2007
	SEER Summary Stage 2000 [759] ⁸	Y ⁸
	SEER Summary Stage 1977 [760] ⁸	Y ⁸
	CS Tumor Size [2800] ⁹	As available ⁹
	CS Extension [2810] ⁹	Y ⁹
	CS Lymph Nodes [2830] ⁹	Y ⁹
	CS Mets at DX [2850] ⁹	Y ⁹
	CS Site-Specific Factor 1 for C38.4 (pleura) [2880] ⁹	Y ⁹
	CS Site-Specific Factor 3 for C61.9 (prostate) [2900] ⁹	Y ⁹
	CS Version 1st [2935] ⁹	Y ⁹
	CS Version Latest [2936] ⁹	Y ⁹
	Derived SS2000 [3020] ⁹	Y ⁹
	Derived SS2000—Flag [3050] ¹⁰	Y ¹⁰
Follow-Up/Recurrence/Death Section—(Name and [Number])		Required Status 1995–2007
	Date of Last Contact [1750]	Y
	Vital Status [1760]	Y
	Follow-Up Source [1790]	As available ¹¹
	Follow-Up Source Central [1791]	Y ¹¹
	Cause of Death [1910]	Y
	ICD Revision Number [1920]	Y
Over-Rides/Conversion/System Admin. Section—(Name and [Number])		Required Status 1995–2007
	Over-Ride Age/Site/Morph [1990]	Y
	Over-Ride SeqNo/DxConf [2000]	Y
	Over-Ride Site/Lat/SeqNo [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

NOTES:

Shaded items denote variables that are considered **advanced** surveillance data. Non-shaded variables denote **coordinated 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 11.

Status key: Y = Yes

¹ 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.

² Use of this field is recommended for reportable cases diagnosed in 1998 and later and required for reportable cases diagnosed in 2003 and later.

³ Report the results from the 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 NHIA data item.

⁴ Report the results of cases submitted for IHS linkage. See the Submission Specifications document and/or Attachment 13 for further details.

⁵ For reportable cases diagnosed in 2001 or later, data should be coded using the ICD–O–3 manual, and data should be 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 and use the ICD–O–3 Conversion Flag [2116] to document the conversion.

⁶ Submit either the SEER or COC field; for reportable cases diagnosed prior to 2006, as available. For cases diagnosed 2006 and later, at least one of these data items must be completed.

⁷ For reportable cases diagnosed prior to 2001, as available. For all other years, please refer to the Submission Specifications, Section 4.f. for details.

⁸ For reportable cases diagnosed prior to 2001, code using *SEER Summary Staging Guide 1977*. For reportable cases diagnosed in 2001–2003, code using *SEER Summary Staging Manual 2000*.

⁹ For reportable cases diagnosed in 2004 and later, this is used to derive, or is the derived, “Summary Stage 2000” from the CS algorithm.

¹⁰ For reportable cases diagnosed 2004 and later, this item is the flag to indicate whether the “Summary Stage 2000” was derived from the CS algorithm.

¹¹ For reportable cases diagnosed 2006 and later, Follow-Up Source Central [1791] is required. For cases diagnosed prior to 2006, Follow-Up Source [1790] should be submitted as available.

COORDINATED CORE EDITS		
Single Field Edits		
Addr at Dx—State		(NAACCR)
Age at Diagnosis		(SEER AGEDX)
Behavior ICD-O-3 Conversion		(NAACCR)
Birth Date		(NAACCR DATEEDIT)
Birthplace		(COC)
County at DX ¹		(NPCR)
CS Extension		(CS)
CS Lymph Nodes		(CS)
CS Mets at DX		(CS)
CS Site-Specific Factor 1		(CS)
CS Site-Specific Factor 3		(CS)
CS Tumor Size		(CS)
CS Version 1st		(CS)
CS Version Latest		(CS)
Date of Diagnosis		(NAACCR DATEEDIT)
Date of 1st Crs Rx—COC²		(NPCR)
Date of Initial Rx—SEER²		(NPCR)
Derived SS2000		(CS)
Derived SS2000-Flag		(CS)
Diagnostic Confirmation		(SEER DXCONF)
First Course Calc Method³		(SUBM)
Grade		(COC)
Histologic Type ICDO3 Conversion		(NAACCR)
ICD-O-3 Conversion Flag		(NAACCR)
IHS Link		(NPCR)
Laterality		(SEER LATERAL)
Morph Coding Sys—Current		(NAACCR)
NAACCR Record Version		(NAACCR)
NAPIIA		(SUBM)
NHIA Derived Hisp Origin		(NAACCR)
Patient ID Number		(SEER CASENUM)
Primary Site		(SEER SITE)
Race 1		(SEER RACE)
Race 2		(NAACCR)
Race 3		(NAACCR)
Race 4		(NAACCR)
Race 5		(NAACCR)
Rad—Regional Rx Modality		(NPCR)
Reason for No Surgery		(NPCR)
Record Type		(NAACCR)
Registry ID		(SUBM)

	RuralUrban Continuum 1993	(NAACCR)
	RuralUrban Continuum 2003	(NAACCR)
	RxSumm—BRM	(NPCR)
	RxSumm—Chemo	(NPCR)
	RxSumm—Hormone	(NPCR)
	RxSumm—Other	(NPCR)
	RX Summ—Radiation	(SUBM)
	RxSumm—Scope Reg LN Surg	(SEER SCOPE)
	RxSumm—Surg Oth Reg/Dis	(SEER SURGOTH)
	RxSumm—Surg Prim Site	(SEER SURGPRIM)
	RxSumm—Surg/Rad Seq	(NPCR)
	RxSumm—Transplnt/Endocr	(NPCR)
	Sequence Number—Central	(SEER SEQUENC)
	Sex	(SEER SEX)
	Site Coding Sys—Current	(NAACCR)
	Spanish/Hispanic Origin	(SEER SPANORIG)
	Summary Stage 1977	(NAACCR)
	Summary Stage 2000	(NAACCR)
	Type of Reporting Source	(SEER RPRTSRC)
COORDINATED CORE EDITS		
Inter-Field Edits		
	Age, Birth Date, Date of Diagnosis	(NAACCR IF13)
	Age, Primary Site, Morphology ICDO3—Adult	(SEER)
	Age, Primary Site, Morphology ICDO3—Pediatric	(NPCR)
	Age, Primary Site, Morphology ICDO3	(SEER IF15)
	Behav ICDO3, Date of DX, ICDO3 Conv Flag	(SEER IF87)
	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)
	Birth Date, Date of Diagnosis	(NAACCR IF47)
	County at DX, Addr at DX--State	(SUBM)
	CS Extension, CS Lymph Nodes, CS Mets at DX	(CS)
	CS Extension, CS Tumor Size, Site, Hist ICDO3	(CS)
	CS Extension, Hematopoietic	(CS)
	CS Extension, Primary Site, Behavior ICDO3	(CS)
	CS Extension, Primary Site, Histol ICDO3	(NAACCR)
	CS Extension, Renal Pelvis/Ureter Schema	(CS)
	CS Items, Date of DX	(NPCR)
	CS Items, DX Pre-2004	(SUBM)
	CS Items, Type Reporting Source	(NPCR)
	CS Lymph Nodes, Primary Site, Histol ICDO3	(NAACCR)
	CS Mets at DX, Primary Site, Histol ICDO3	(NAACCR)
	CS SSF 1, Primary Site, Histol ICDO3	(NAACCR)
	CS SSF 3, Primary Site, Histol ICDO3	(NAACCR)
	CS Tumor Size, Primary Site, Histol ICDO3	(NAACCR)
	CS Tumor Size, Site, Histol ICDO3	(CS)
	CS Version 1st, CS Version Latest	(CS)
	Date of 1st Crs RX--COC, Date Init RX--SEER	(SUBM)

Date of 1st Crs Rx—COC, Date of Dx	(COC)
Date of Init Rx—SEER, Date of Dx	(NAACCR IF18)
Derived Items, Date of DX	(NPCR)
Derived Items, DX Pre-2004	(SUBM)
Derived SS2000-Flag, Derived SS2000	(CS)
Diagnostic Confirm, Seq Num—Central	(SEER IF23)
Diagnostic Confirmation, Behavior ICDO3	(SEER IF31)
Diagnostic Confirmation, Histology ICDO3	(SEER IF48)
Edit Over-rides	(SEER REVIEWFL)
First Crs Calc Meth, Date 1st Crs RX	(SUBM)
Hemato ICD-O-3, Summ Stg 1977	(NAACCR)
Hist ICDO3, Date of DX, ICDO3 Conv Flag	(SEER IF86)
Laterality, Primary Site	(NAACCR IF24)
Laterality, Primary Site, Morphology ICDO3	(SEER IF42)
Lymphoma ICD-O-3, Site, Summ Stg 1977	(NAACCR)
Morphology—Type and Behavior ICDO3	(SEER MORPH)
Obsolete Codes - CS Extension	(SEER IF146)
Obsolete Codes - CS Lymph Nodes	(SEER IF147)
Obsolete Codes - CS Mets at DX	(SEER IF148)
Obsolete Codes - CS SSF 3	(SEER IF150)
Primary Site, Behavior Code ICDO3	(SEER IF39)
Primary Site, Histology, Behav ICDO3	(NAACCR)
Primary Site, Laterality	(SEER IF82)
Primary Site, Morphology—Imposs ICDO3	(SEER IF38)
Primary Site, Morphology—Type, Beh ICDO3	(SEERIF25)
Race 1, Race 2, Race 3, Race 4, Race 5	(SEER IF93)
Race 2, Date of Dx	(SEER IF89)
Race 3, Date of Dx	(SEER IF90)
Race 4, Date of Dx	(SEER IF91)
Race 5, Date of Dx	(SEER IF92)
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—Chemo, Date of DX	(NPCR)
RX Summ—Hormone, Date of DX	(NPCR)
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, Primary Site, ICDO3	(SEER IF108)
RX Summ—Surg/Rad Seq, Date of DX	(NPCR)
RX Summ—Transplnt/Endocr, Date of DX	(NPCR)
Seq Num—Central, Prim Site, Morph ICDO3	(SEER IF22)
Sex, Primary Site	(SEER IF17)
Summary Stage 1977, Date of Diagnosis	(NAACCR)
Summary Stage 1977, Summary Stage 2000	(NAACCR)
Summary Stage 1977, Type of Reporting Source	(NAACCR)
Summary Stage 2000, Date of Diagnosis	(NAACCR)

	Summary Stage 2000, Site, Hist ICDO3, Rpt Srce	(NAACCR)
	Surgery, Rad, Surg/Rad Seq	(COC)
	Type of Report Srce (DC/AO), Diag Conf	(SEER IF05)
	Type of Report Srce (DC), Seq Num—Cent, ICDO3	(SEER IF04)
	Unknown Site Hist ICDO3, Summary Stage 1977	(NAACCR)
	Unknown Site, Laterality	(SEER IF138)
COORDINATED CORE EDITS		
Inter-Record Edits⁴		
	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)
	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)
ADVANCED DATA EDITS		
Single Field Edits		
	Addr at Dx—Postal Code	(COC)
	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)
	Census Tract 1970/80/90	(SEER TRACT)
	Census Tract 2000	(SEER)
	Date of Last Contact	(NAACCR DATEEDIT)
	Follow-up Source	(COC)
	Follow-up Source Central	(NAACCR)
	ICD Revision Number	(SEER ICD CODE)
	Vital Status	(COC)
ADVANCED DATA EDITS		
Inter-Field Edits		
	Age, Histologic Type, COD ICDO3	(SEER IF43)
	Census Tract 1970/80/90, Census Tract Coding Sys	(SEER IF45)
	Date of 1st Crs Rx—COC, Date of Last Contact	(COC)

	Date of Init Rx—SEER, Date Last Cont	(NAACCR IF35)
	Date of Last Contact, Date of Diag.	(NAACCR IF19)
	Follow-up Source Central, Date of DX	(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 Srce (DC/AO), COD	(SEER IF09)
	Type of Report Srce (DC/AO), Date of Dx	(SEER IF02)
	Type of Report Srce (DC/AO), Vit Stat	(COC)
ADVANCED DATA EDITS		
Inter-Record Edits		
	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.npcrccs.org/docserver/>) for the edits programs.

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

¹ This edit has been modified to allow “000” as a valid code for recode if state law prohibits the release of county codes.

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

³ Required if either Date of Initial Rx—SEER or Date of 1st Crs Rx—COC is submitted, blanks allowed only if both of these date fields are blank.

⁴ Inter-record edit errors from these IR-edits are required to be resolved and will be used to assess program standards.



Attachment 4 2009 NPCR-CSS Checklist

For registry purposes 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 (1995 or your NPCR reference year–2006 and 2006 alone)</i> and then copy your Duplicate Protocol Assessment results to Attachment 9.
	Run the ICD-O-2 to ICD-O-3 conversion program on cases diagnosed prior to 2001 if you have not completed the conversion for your state data.
	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 NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm to assign the derived Hispanic ethnicity and Asian/Pacific Islander race to incident cases.
	Run the edits program using the 2009 NAACCR/NPCR Combined edits metafiles and resolve single field and inter-field edit errors.
	Run the inter-record edits standalone program 2009 and resolve edit errors.
	Extract the data file; verify that all required diagnosis years are included (i.e., from your NPCR reference year through 2007).
	Follow the steps for creating and transmitting data and send the data file to Macro International by November 30, 2008.
	Complete Attachments 7-11 via the secure web interface from the CSS login page, or submit these forms via CSS document server, or fax, or mail to Macro International.



Attachment 5 File Transfer Instructions

Data transmitted to NPCR-CSS is encrypted during transmission to render it useless to anyone who might attempt to intercept the transmission. The encryption is accomplished via Secure Socket Layer strong encryption—the same level of protection used by e-commerce sites to protect financial transactions.

NPCR-CSS staff at Macro International will call each program in early December to provide the login, user ID, and password and to answer questions.

We will accommodate on-line form completion and submission this year. For data submission, it is recommended that each state use PKZIP or WINZIP to compress its files prior to posting them to the secure web site.

Instructions:

1. Open an Internet browser capable of 128-bit encrypted communication. Some, but not all, versions of Microsoft (MS) Internet Explorer (5.x and higher) and Netscape (4.x and higher) support 128-bit encryption. If your browser is not capable of 128-bit encrypted communication, you will be instructed on how to download the required browser software.
2. In the address or location line of your browser, type <https://www.npcrcss.org/> and press Enter.
3. A Security Warning page will pop up. Accept the security certificate by clicking on the **Yes** button (if using MS Internet Explorer) or the **OK** button (if using Netscape). The login screen will appear. Choose from the options by checking a radio button for either Forms submission or Data upload. Enter your user-specific ID and password and click on the **Login** button.
4. If you choose to submit the forms, you will be directed to a secure area where all of the required forms (i.e., Attachments 7-11) are available so that you can fill them in on-line and submit them through a web application. For each form completed, a PDF version of the completed form will be generated after you click on the “Submit” button. A copy of the PDF file will be automatically delivered to your 2009 folder on the CSS document server for you to download. Download a copy for your own record if you wish.
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 2009 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 the **Browse** button 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 NAACCR layout version. For example, use the name **GA95V11** for 1995 Georgia data in Version 11.1 and **GA9507V11** for 1995–2007 Georgia data in Version 11.1. Once you have selected the file and entered any descriptive text that you want to include with the submission, click on the **Continue** button.

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 6 Overview of Data Security

The NPCR-CSS project data reside on a dedicated server at Macro International. To ensure the security and confidentiality of project data, the following provisions have been incorporated into the Macro International 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 Macro International's Bethesda office with a guard on duty in the lobby 24 hours a day. Elevator and stairwell access is controlled by card key. The server resides on its own local area network (LAN) behind Macro International's firewall.

- Access to the NPCR-CSS server is limited to authorized Macro International project staff (see below). It is password protected on its own security domain. No one, including nonproject staff at Macro International, is allowed access to the NPCR-CSS data.
- All Macro International project staff must sign a confidentiality agreement before passwords and keys are assigned. All staff must 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 Macro International'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 will be destroyed when no longer needed.
- A comprehensive security plan has been developed by Macro International's security team. The security team consists of Donald McMaster, Business Steward; Kevin Zhang, Project Director; Leo Shen, Security Officer; David Radune, Database Administrator; and Gretchen Stanton, LAN and WAN Security Steward. All project staff receive annual security awareness training covering security procedures. The Macro International project security team oversees operations to prevent unauthorized disclosure of the NPCR-CSS data.
- Periodic (currently quarterly, but no less than once a year) review and update of Macro International 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.

**Macro International
Authorized Project Staff**

Staff Member	Position
Donald McMaster, M.B.A., M.S.	Business Steward
Kevin Zhang, Ph.D.	Project Director
Leo Shen, M.B.A.	Deputy Director/Security Officer
David Radune, B.S.	Development Manager/Database Administrator
Gretchen Stanton, M.S.	LAN and WAN Security Steward
Qiming He, Ph.D.	QA Manager/Sr. Programmer Analyst
Yuan Ren, Ph.D.	Data and Statistical Manager/Sr. Statistical Programmer
Suling Huang, M.S.P.H., CTR	QA Specialist/Data Analyst
Jagruti Rana, M.S.	Sr. Developer
Phillips Schaeffer, M.S.	Sr. SAS Programmer
Jonathan Stanger, M.P.A.	SQL Programmer
Shaobin Xu, M.S.	Programmer Analyst



Attachment 7 2009 NPCR-CSS Data Submission Form

Registry name: _____ Date: _____
 Name: _____ Phone number: _____

(Primary contact for data submission)

Please provide the following information. Instructions for completing the form are on page 2.

Diagnosis Year	(1) Death Clearance Conducted (Yes/No)	(2) NHAPIIA Run (S/M/N)	(3) IHS Linkage (Y/N, N/A)	(4) Comments	(5) File Name	(6) NAACCR Version	(7) NAACCR Record Type
1995							
1996							
1997							
1998							
1999							
2000							
2001							
2002							
2003							
2004							
2005							
2006							
2007							

Instructions for Completing the 2009 NPCR-CSS Data Submission Form

NOTE: A Microsoft Word version of this form can be downloaded from the NPCR-CSS utilities Web site (<https://www.npcrcss.org/utilities/>) and submitted upon completion via the document server along with your 2009 data submission.

- (1) **Death Clearance Conducted:** Enter “Yes” if death clearance was performed that year to the extent allowed by state law. Enter “No” if it was not. If follow-up was initiated and information was not received, report the case as DCO.
- (2) **NHAPIIA Run:** Run the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm and record the derived NHIA and NAPIIA variable. For details, refer to 2009 Submission Specification. Enter “S” if the SAS algorithm was run, “M” if done manually, or “N” if not done.
- (3) **IHS Linkage:** Data linkage between your 1995–2006 incidence data and Indian Health Service files and IHS Link variable must be coded and reported accordingly. Enter “Yes” for those years that linkage has been performed and “No” if not. Enter “N/A” if not applicable (e.g., beyond reference year).
- (4) **Comments:** Use this space as needed.
- (5) **File Name:** Begin your filename with the two-character state postal code, a year range, and NAACCR layout version. For example:
 - 1995 Georgia data, Version 11.1 = GA95V111
 - 1995–2007 Georgia data, Version 11.1 = GA9506V111
- (6) **NAACCR Version:** NAACCR Version 11 (including version 11.1, 11.2, 11.3).
- (7) **NAACCR Record Type:** Should be “I,” Incidence (length = 1946) or “A,” Full Case Abstract (length = 6694), with the Patient Confidential Section blanked out.



Attachment 8
2009 NPCR-CSS Data Items Not Transmitted

Registry Name: _____ Person Completing Form: _____

If there are data items listed in the **Attachment 2, Data Items by Diagnosis Year**, that are not transmitted, please check “Yes” below and write the NAACCR data item name, NAACCR data item number, and a brief explanation for not transmitting the data item(s). Otherwise, if all requested data items are transmitted, please check “No” below.

Are there requested data items in Attachment 2, Data Items by Diagnosis Year, not transmitted? No _____ Yes _____

No	Data Item Not Transmitted (Name and [Number])	Reason for Not Transmitting
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		



Attachment 9 2009 Duplicate Protocol Results

Registry name: _____

Date: _____

To complete this form, you must conduct the “NAACCR Protocol for the Identification of Duplicate Cases” (Please refer to the 2009 NPCR-CSS Submission Specifications). The duplicate rates will be used to adjust the completeness of case ascertainment estimates. The 1995–2006 duplicate rate will be used to adjust the 1995–2006 estimates. The 2006 duplicate rate will be used to adjust the 2006 estimate. Please return this form with your data submission.

Diagnosis Year	Criteria	Results
1995–2006	1. Number of duplicates found 2. Number of records examined 3. Duplicate rate per 1,000 records* 4. Number of records in incidence file 5. Duplicates corrected in file	1. _____ 2. _____ 3. _____ 4. _____ 5. Yes No N/A
2006	1. Number of duplicates found 2. Number of records examined 3. Duplicate rate per 1,000 records* 4. Number of records in incidence file 5. Duplicates corrected in file	1. _____ 2. _____ 3. _____ 4. _____ 5. Yes No N/A

* [Number of duplicates found (1.) / Number of records examined (2.)] * 1,000 = Duplicate rate per 1,000 records.

N/A = not applicable

Comments:



Attachment 10 2009 NPCR-CSS Data Set Participation Agreement

2009 Data Submission

(For more information see the NPCR-CSS Data Release Policy.)

Registry name: _____

Please indicate whether data from your registry, from diagnosis years 2006 and earlier, submitted in January 2009 data submissions may be included in the following NPCR-CSS data sets:

- Public-Use Data Sets*
 - USCS expanded data set (WONDER) Yes No
 - USCS county data set with age-adjusted rates only Yes No
 - USCS county data set with age-adjusted and crude rates Yes No
- Restricted-Access Data Sets*
 - State level data set Yes No
 - Regional level data set Yes No
- Data release to state and national partners
 - CBTRUS^t Yes No

* For a description of the data sets, see the 2009 NPCR-CSS Data Release Policy.

t See attached project descriptions and proposals.

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

Person completing form:

Name: _____

Title: _____

Phone: _____

E-mail address: _____

Signature: _____

Date: _____

Central Brain Tumor Registry of the United States (CBTRUS) Data Set

CDC will provide individual, record-level data (see below) for the list of variables to be included in the data set for CBTRUS. CBTRUS will use these data to generate statistics for the print and web versions of the statistical report titled *Primary Brain Tumors in the United States Statistical Report Supplement, 2004-2005*; a previous version of the report is available at:

<http://www.cbtrus.org/reports/reports.html>. Age-adjusted rates and corresponding 95% confidence intervals on brain and other central nervous system tumors will be presented by state, histology, major histology grouping, primary site, behavior, gender, race, ethnicity, and age at diagnosis. Only states that agree to participate and meet the USCS publication criteria will be included in the data set. CBTRUS will sign data use agreements that the data are to be used the statistical report only. For questions, contact CBTRUS staff at cbtrus@aol.com.

Name	NAACCR Data Item	Notes
Demographic Data Items		
Patient ID Number	[20]	
Address at Diagnosis—State	[80]	
NPCR Race Recode	Derived based on [160], [161] and [192]	Same as race for USCS
NHIA Derived Hispanic Origin	[191]	
Sex	[220]	
NPCR Age Recode	Derived based upon [230]	Same as age at diagnosis in SEER*Stat
Cancer Identification Data Items		
Sequence Number—Central	[380]	
NPCR Year of Diagnosis	Derived based upon [390]	
NPCR Month of Diagnosis	Derived based upon [390]	
Primary Site	[400]; limit to C30.0, C70.0–C72.9, C75.1–C75.3	
Laterality	[410]	
Grade	[440]	
Diagnostic Confirmation	[490]	
Type of Reporting Source	[500]	
Histologic Type ICD-O-3	[522]	
Behavior Code ICD-O-3	[523]	



Attachment 11 2009 Registry Follow-Up Sources

Registry name: _____ Person completing form: _____

Instructions for completing the form are on the next page.

Follow-Up Year*	Diagnosis Year														
		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	
1995	Source														
	Sites														
1996	Source														
	Sites														
1997	Source														
	Sites														
1998	Source														
	Sites														
1999	Source														
	Sites														
2000	Source														
	Sites														
2001	Source														
	Sites														
2002	Source														
	Sites														
2003	Source														
	Sites														
2004	Source														
	Sites														
2005	Source														
	Sites														
2006	Source														
	Sites														
2007	Source														
	Sites														
2008	Source														
	Sites														

*Follow-Up Year, source of follow-up, and cancer sites followed up for vital status.

Do not complete shaded areas.

Under the heading of source, by each diagnosis year and follow-up year, enter the following:

P = Pre-NPCR reference year.

A = Conducts active follow up for purpose of determining vital status.

V = Linkage with state vital statistics records for purpose of updating vital status, including date and cause of death.

N = Linkage with National Death Index for purpose of updating vital status, including date of death.

N+ = Linkage with National Death Index for purpose of updating vital status, including date and cause of death.

S = Linkage with Social Security Death Master File.

O = Other linkage sources used for purpose of updating vital status (please specify below).

- = No linkages performed.

Other linkage sources: _____

NOTE: If multiple sources were used, enter all appropriate acronyms in cell (e.g., V, N).

Under the heading of cancer sites:

- = Not applicable; linkages not performed.

AS = All sites.

S = Selected site (please specify: _____)



Attachment 12

Frequently Asked Questions About the NPCR-CSS Data Submission

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

- **Incorrect registry ID number:** The registry ID number is the 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 1947–6694) in the NAACCR Record Layout (v11, including versions 11.1, 11.2 and 11.3) 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?

We made all submission forms available electronically this year so that you can fill them out on-line using your secure login to the CSS document server. However, if for some reason you have to send your forms via other means, you may fax ((301) 961-8537) or mail the forms to Macro International. If you fax the forms, please notify Macro International staff by calling the NPCR-CSS Help Line at (301) 572-0502. If there are problems with the fax transmissions, you will be notified.

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

Make corrections on the form on-line and submit your form again. You will receive a copy of the revised form in PDF in your state folder on the CSS document server. Please make sure you download a copy of the updated form for your own record. You should also notify Macro International of any changes you made by sending an email to: npcr-css@orcmacro.com.

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 file size, so we 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 (in zip).

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

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

8. What version of Microsoft Internet Explorer or Netscape must be used to upload my data?

You will need Microsoft Internet Explorer 5.x or higher or Netscape 4.x or higher that allows 128-bit encryption. The software can be downloaded from the Microsoft Web site (<http://www.microsoft.com/windows/ie/downloads/recommended/128bit/default.asp>).

9. What diagnosis years must be submitted for this submission?

Data from your NPCR reference year (not your registry reference year) through 2007 are required to be submitted.

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

To the extent possible, please clean up all edit errors including inter-record edit errors. Please note that some of the IR-edits are now considered “coordinated 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 2008 Restricted Access Dataset.

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

Please note that “County at Dx” is a coordinated core data element. If certain elements cannot be submitted, please leave the fields blank (unless otherwise noted in **Attachment 2**).

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, please contact your CDC Program Consultant, who will in turn notify Macro International staff.

13. When can we expect to receive the Data Evaluation Reports?

Reports will be available in early May 2009.

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 the **Cancel** button 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, the file is automatically transferred from the document server to a secure Macro International server. The user cannot delete a file once it has been uploaded. If you want to have the file deleted, please notify Macro International by sending an email to npcr-css@ormacro.com or call NPCR-CSS Help Line at: 301-572-0502, with an instruction to Macro International staff to delete the file. Macro International will confirm the deletion of the file by e-mail.



Attachment 13

NPCR and IHS Record Linkage Procedures

Note: The full protocol for the NPCR and Indian Health Services (IHS) record linkages is available at the NPCR-CSS utilities page (<https://www.npcrcss.org/docserver/>) and includes the confidentiality and security measures necessary in conducting the linkages. The following is an abbreviated version of the protocol.

Participating registries with one or more Contract Health Service Delivery Area (CHSDA) counties (Table 1) will be asked to capture a static copy of their master file—**State File 1 (SF1)**—based on the following selection criteria:

- All incident cases diagnosed during the time period 1995-2006,
- Reportable diagnoses (see #3 of 2009 NPCR-CSS submission specifications).

SF1 will contain sufficient patient-identifying information to allow records to be linked with an administrative file from the IHS. 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. SF1 should follow the NAACCR confidential record layout version 11.2; see Table 2 for specific data items.

SF1 PREPARATION PROCEDURES

1. Download the following two programs from the NPCR CSS Utilities page (<https://www.npcrcss.org/docserver/>):
 - a) SAS Linkage Extraction Program (or the standalone IHS Linkage Extraction utility program) and
 - b) GenEdits Plus software.
2. Install both programs.
3. Create an extract using the SAS Linkage Extraction program.
4. Run GenEdits Plus and the IHS linkage edit set against this extract. The GenEdits Plus install will have a meta file/edit set specifically configured to help identify edit errors on those fields used in the IHS linkage process.
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.
8. Place final extract in an encrypted and password-protected format.
9. Deliver in one of the following 2 methods
 - Electronically submit via a secure and encrypted site:
<https://www.ihs.gov/NonMedicalPrograms/IHPES/EPI/CancerRegistry/index.cfm?module=CancerRegistry&option=dataUpload>

- Ship according to a pre-arranged schedule via express courier service to:
IHS Division of Epidemiology
c/o Melissa Jim
5300 Homestead NE
Albuquerque, NM 87110

If the file is shipped, the password for **SF1** will be sent separately to the IHS Division of Epidemiology and Disease Prevention.

If a state is unable to send their data unaccompanied for administrative reasons, please contact Melissa Jim (email: melissa.jim@ihs.gov ; phone: 505-248-4451) to make individual arrangements.

IHS LINKAGE RESULTS

The results will be available in 2 different files:

- **Match File 3** will contain, in a single record, the following information for the record with the highest match score for each patient ID number in the pairs determined to be matches between the **SF1** 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) The matching variables for the two records
 1. First Name
 2. Last Name
 3. Middle Name
 4. Gender
 5. SSN
 6. DOB
 7. Date of Death
 8. Diagnosis Address
 9. Current Address (street, city, state, zip)
- **Match File 4** will contain ALL records that were submitted for linkage in **SF1**. This file will be in the NAACCR record layout version 11.2 shown in Table 2 with the IHSLink field containing the updated value that will be submitted for the 2009 NPCR-CSS Call for Data.

It is recommended that **Match File 4** be used to update IHSLink [NAACCR #192] prior to submitting data to NPCR. All records that were not submitted to IHS for linkage should be assigned a blank.

If **Match File 3** is used to update IHSLink [NAACCR #192], please note that **ALL** sequences for the patients identified in this match should be updated with IHSLink=1; otherwise, the

interrecord edit for the IHS linkage (NPCR IR01) would result an edit error. All records included in **SF1** with a blank IHSLink field prior to the linkage and 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.

Table 1. States with one or more Contract Health Service Delivery Area (CHSDA) counties¹

- Alabama
- Alaska
- Arizona
- California
- Colorado
- Florida
- Idaho
- Indiana
- Kansas
- Louisiana
- Maine
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Montana
- Nebraska
- Nevada
- New York
- North Carolina
- North Dakota
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Texas
- Washington
- Wisconsin
- Wyoming

¹ Required to link registry data with the Indian Health Services (IHS) service data on an annual basis. All states will conduct linkage every five years; the last linkage for all states was conducted in calendar year 2006. If a registry does not have one or more CHSDA counties and finds the IHS linkage beneficial, then we will link their data if the registry is able to send their data to IHS for linkage.

Table 2. Record Layout for State File 1 (SF1)

NAACCR item #	Columns	Name
10	1-1	Record Type
20	2-9	Patient ID Number
40	20-29	Registry ID
50	19-19	NAACCR Record Version
70	52-71	Addr at DX–City
80	72-73	Addr at DX–State
90	83-85	County at DX
100	74-82	Addr at DX–Postal Code
160	103-104	Race 1
161	105-106	Race 2
162	107-108	Race 3
163	109-110	Race 4
164	111-112	Race 5
190	115-115	Spanish/Hispanic Origin
220	118-118	Sex
230	119-121	Age at Diagnosis
240	122-129	Birth Date
192	232-232	IHSLink ¹
380	281-282	Sequence Number–Central
390	283-290	Date of Diagnosis
1750	1294-1301	Date of Last Contact
1760	1302-1302	Vital Status
1810	1307-1326	Addr Current–City
1820	1327-1328	Addr Current–State
1830	1329-1337	Addr Curr–Postal Code
1840	1338-1340	County–Current
2230	1947-1971	Name–Last
2240	1972-1985	Name–First
2250	1986-1999	Name–Middle
2280	2006-2020	Name–Alias ²
2290	2036-2085	Name–Spouse/Parent
2320	2099-2107	Social Security Number
2330	2108-2147	Addr at DX–No & Street
2335	2148-2187	Addr at DX–Supplement
2350	2188-2227	Addr Current–No & Street
2355	2228-2267	Addr Current–Supplement
2390	2021-2035	Name–Maiden ²

¹Results from previous linkage should be included, if available. These previous results will greatly facilitate the current linkage.

²As available