SEER November 2009 Data Submission Requirements and Guidelines

Please direct all submission questions to: SEERSUBM-L@list.nih.gov

- 1. The data submission is due Monday, November 2, 2009. The data submission should include all resident cases through 12/31/2007 diagnoses.
- 2. All submission files should be posted to the SEER Submission Reports Portal. A November 2009 folder has been created under each registry's folder. Please add the submission files to this folder. Note: this is a change from last year.
- 3. The file should be submitted in NAACCR 11.3 format and should be named rr.nov09.txd.gz where rr represents the two character abbreviation for your registry. A list of the variables to be included in the submission can be downloaded from http://www.seer.cancer.gov/tools/seer09.dataitems.pdf.
- 4. The file should be sorted by the following variables: Registry ID (NAACCR Item #40), Patient ID Number (NAACCR Item #20), Sequence Number Central (NAACCR Item #380). For Los Angeles and NCCC, the legacy id should be put in columns 32-39 and the State of California patient ID number (Eureka ID) should be put in columns 2-9.
- 5. The file should be edited prior to submission using the SEER*EDITS program available on the SEER Submission Reports Portal. Use Attachment B in WORD to notify NCI SEER that the file has been submitted and whether or not SEER is to submit your data for the NAACCR Call for Data.
- 6. IHS indicator (NAACCR Item #192) and Record Linkage: Although the IHS variable is a required field, we are not requiring that you submit your current value in that field. It is fine to submit blanks for all patients. We will update your files with the new IHS linkage value prior to submission to NAACCR.
 - a. All SEER registries, with the exceptions of the Alaska Native Tumor Registry and the Cherokee Nation Cancer Registry, need to submit a file of SEER-reportable cases diagnosed between 01/01/88 and 12/31/07 to IHS. The cases in this file should be identical to those that are included in the November 2, 2009 submission file to NCI. Specific instructions for preparing and submitting this file are contained in Attachment C and the file structure is described in Table 1.
 - b. Results from the IHS linkage will be returned to each registry and to the NCI (only case identification number and linkage results will be provided to NCI; patient-identifying information such as name and social security number will be sent only to the IHS for linkage and will not be sent to NCI).
 - c. NCI will be responsible for updating the November submission files from the registries with the new IHS linkage results and will also supply the linkage results to NAACCR for those registries for which NCI has performed this submission in the past.
 - d. Registries that will submit their own data to NAACCR should update their files with the IHS linkage results since the IHS Link variable [NAACCR #192] is included as part of the NAACCR call for data.

- e. Please direct questions regarding the SEER-IHS linkage project to Ms. Melissa Jim at melissa.jim@ihs.gov (telephone: 505/248-4451) or Dr. Chuck Wiggins at cwiggins@salud.unm.edu (telephone: 505/272-3127). Please also cc SEERSUBM-L@list.nih.gov on all questions.
- 7. NHAPIIA: Run NHAPIIA which updates both the API indicator (NAPIIA, NAACCR Item #193) and the Hispanic indicator (NHIA, NAACCR Item #191). Use the NHAPIIA SAS program found on the NAACCR Call for Data website. Every registry must run the algorithm. Please note to set the parameters needed for your registry before running NHAPIIA.
- 8. Summary stage: If you want SEER to submit your data for the NAACCR call for data, the Summary Stage 77 and Summary Stage 2000 data must be submitted. Either field can be directly coded or recoded via the Summary Stage recode programs for Summary Stage 77 and Summary Stage 2000. Summary Stage 1977 must be on your file for all cases through 2000 and Summary Stage 2000 for all cases 2001-2003.
- 9. Beale codes: County rural-urban continuum codes (Beale codes) do not need to be submitted for the NAACCR Call for Data.
- 10. Collaborative Staging: Please see: http://www.cancerstaging.org/cstage/recodingspecs4v010400.pdf
- 11. Please run your 2004-2007 data through the CS algorithm before submission. It needs to be CS version 010400 or higher.
- 12. VA case counts: To address the backlog of Veterans Affairs Hospital (VA) records, specific data are being requested. The VA tumor case counts are needed for all malignant cancers combined (males only), by race, age, and cancer site. Please restrict case counts to SEER coverage areas. These data are needed for diagnosis years 2000-2007 and for the submission years 2002-2009.
- 13. For prior submission years, we are assuming that registries have archived files of their SEER submissions (archived NAACCR submissions could also be used). If this is not the case, please contact us at SEERSUBM-L@list.nih.gov to discuss possible alternatives. A modification of the SEER Edits program will be available in early October to generate summary case counts.
- 14. For each of the eight submission years, repeat the following steps:
 - a. Create a temporary NAACCR-format data file containing a VA indicator flag in NAACCR item 2220, Column 1575. The VA indicator may be created using facility codes to distinguish three categories of tumor records: 1) records from a VA facility only; 2) records from a VA facility & other facilities; and 3) records from non-VA facilities only. The flag values are 1 = records from a VA facility only; 2 = records from a VA facility & other facilities; 3 = records from non-VA facilities only.
 - b. Use the temporary NAACCR-format data file as input to the SEER Edits program and generate a VA report (the report will be automatically saved to the report RPT file). For each file, users must specify the correct Low and High diagnosis date parameters.
 - c. Post the RPT file to the SEER Submission Reports Portal and delete the temporary NAACCR-format data file containing the VA indicator flag.
- 15. The new version of the SEER Edits program will be available in early October. Detailed instructions will be available at that time. We encourage registries to submit the RPT files for

submission years prior to 2009 early (before November 2) if possible.

Attachment A

SEER Patient Follow-up Calculation

for November 2009 submission only

Note 1: The following explanation of the follow-up calculation is based on the SEER contract statement of work.

2007 is the last year of data being submitted. The percent of patients diagnosed during the years prior to 2007 who have current follow-up is defined as

$$P = 100(D + A)/T$$

where D is the number who died prior to January 1, 2008, A is the number with follow-up dates on or after January 1, 2008 (includes both alive and dead patients), and T is equal to A + D + the number of patients who were last known to be alive with follow-up dates prior to January 1, 2008. P can be calculated for individual years of diagnosis up through 2006 and for all years combined prior to 2007.

For all invasive cancers and calendar years specified by NCI, P shall be at least 95 percent, but must not be below 90 percent.

For patients ages 20-64, and under age 20, P shall be at least 90 percent in each case, but must not be below 80 percent.

For all in situ cancers (excluding cervix in situ) and calendar years specified by NCI, P shall be at least 90 percent, but must not be below 80 percent.

Note 2:Although it is not in the statement of work, follow-up is expected on benign and borderline central nervous system tumor cases diagnosed 1/1/2007 and forward.

Attachment B

November 2009 Submission to NCI Please complete for each submission and e-mail to: SEERSUBM-L@list.nih.gov

Registry Name:
Registry ID number:
Date of file transfer to SEER:
Data file name:
Years of diagnosis submitted:
Number of cases submitted:

When running NHAPIIA, were any optional exclusions applied? YES or NO

If YES:

- 1. In counties in which less than 5% of the population is of Hispanic ethnicity, was the surname portion of the algorithm only applied to cases coded as "Spanish surname only" or "Unknown whether Spanish or not" (item 190 codes 7 or 9)? YES or NO
- In counties in which less than 5% of the population is of Hispanic ethnicity, was the surname portion of the algorithm only applied to cases coded as "Spanish surname only" (item 190 code 7)? Were all cases coded to "Unknown whether Spanish or not" (item 190 code 9) converted to non-Hispanic in NHIA?
- 3. YES or NO

Other; please specify

Attachment B (continued)

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NAACCR Call for Data 2010:

Do you want SEER to submit your data to NAACCR? YES or NO

IF YES:

- 1. What diagnosis years do you want submitted?
- 2. SEER Summary Stage 77(SS77): RECODED or DIRECTLY CODED
- 3. SEER Summary Stage 2000: RECODED or DIRECTLY CODED
- 4. Addr at Diagnosis State or Province (Item #80):
 - a. Have you submitted it to SEER? YES or NO
 - b. Do you want it submitted to NAACCR? YES or NO

If it has not been submitted to SEER and you want it submitted to NAACCR, we will generate values for all records based on the registry.

5. NAACCR has recently requested certain items. Please indicate if you would like the following items submitted to NAACCR.

a.	Date of Initial RXSEER (Item 1260)	YES or NO
b.	RX SummSurg Prim Site (Item 1290)	YES or NO
c.	RX SummRadiation (Item 1360)	YES or NO
d.	NAPIIA (Item 193)	YES or NO

- e. Birthplace (Item 250), if currently collected YES or NO
- f. CS Tumor Size (Item 2800), if currently collected YES or NO
- g. Rad-Regional RX Modality (1570), if currently collected YES or NO
- 6. First Course Calc Method (Item 1500) Are you submitting it to SEER? YES or NO
 - a. If No, do you want a code '2' dummied in for all cases and submitted to NAACCR?
 - b. If YES, do you want it submitted to NAACCR?

Attachment B (continued)

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Technical Contact Name:	
Telephone number: e-mail address:	
Registry Manager Contact Name:	
Telephone number: e-mail address:	
Known data problems including reasons:	
Comments:	

Attachment C

IHS linkage Instructions

Record selection criterion:

- 1) SEER-reportable cases;
- 2) Diagnosed between 01/01/1988 and 12/31/2007 (inclusive);
- 3) Cases in this file should be the <u>same</u> as those that will be submitted in the November 2009 (i.e., no more, no less) to the SEER Program. In previous years, we experienced some confusion when records that were submitted to the SEER Program had not been sent for linkage with IHS.

File structure:

- 1) ASCII format;
- 2) File structure as described in Table 1 (below);
- 3) Encrypted/password protected file (password to be sent separately via e-mail or direct telephone contact).

File can be delivered in one of the following 2 methods:

- 1) Electronically submitted via a secure and encrypted site:
 https://www.ihs.gov/NonMedicalPrograms/IHPES/EPI/CancerRegistry/index.cfm?module=CancerRegistry&option=dataUpload
- 2) Shipped 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

Contacts:

Melissa Jim, M.P.H. Epidemiologist, Indian Health Service 505-248-4451 melissa.jim@ihs.gov

Chuck Wiggins, Ph.D.
Director, New Mexico Tumor Registry 505/272-3127
cwiggins@salud.unm.edu

Attachment C (continued) Table 1. Data Layout for IHS Linkage

NAACCR item #	Columns	Name
10	1-1	Record Type
20	2-9	Patient ID Number
50	19-19	NAACCR Record Version
40	20-29	Registry ID
70	52-71	Addr at DX-City
80	72-73	Addr at DX-State
100	74-82	Addr at DX-Postal Code
90	83-85	County at DX
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
200	116-116	Computed Ethnicity
210	117-117	Computed Ethnicity Src
220	118-118	Sex
230	119-121	Age at Diagnosis
240	122-129	Birth Date
192	232-232	Result of previous IHS linkage
380	281-282	Sequence Number-Cntrl
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
2390	2021-2035	Name-Maiden
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 Curr- No & Street
2355	2228-2267	Addr Curr- Supplement