Attachment 1

Public Law 102-515 Cancer Registries Amendment Act

Public Law 102-515
102d Congress

An Act

Oct. 24, 1992
[S. 3312]

Entitled the "Cancer Registries Amendment Act".

Cancer Registries Amendment Act.
Diseases.
Health and health care.
42 USC 201 note.
42 USC 280e note.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Cancer Registries Amendment Act".

SEC. 2. FINDINGS AND PURPOSE.

(a) FINDINGS.—Congress finds that—

(1) cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs;

(2) cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity;

(3) statewide cancer incidence and cancer mortality data, can be used to identify cancer trends, patterns, and variation for directing cancer control intervention;

(4) the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and

(5) AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.

(b) PURPOSE.—It is the purpose of this Act to establish a national program of cancer registries.

SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following new part:

"PART M—NATIONAL PROGRAM OF CANCER REGISTRIES

42 USC 280e.

"SEC. 399H. NATIONAL PROGRAM OF CANCER REGISTRIES.

"(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning—

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69-139 O - 92 (515)

"(1) demographic information about each case of cancer;

"(2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;

"(3) administrative information, including date of diagnosis and source of information;

"(4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and

"(5) other elements determined appropriate by the Secretary.

"(b) MATCHING FUNDS.—

"(1) IN GENERAL.—The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or $1 for every $3 of Federal funds provided in the grant.

"(2) DETERMINATION OF AMOUNT OF NON-FEDERAL CONTRIBUTION; MAINTENANCE OF EFFORT.—

"(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

"(B) With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.

"(c) ELIGIBILITY FOR GRANTS.—

"(1) IN GENERAL.—No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this

section, and that the applicant will comply with the peer review requirements under sections 491 and 492.

"(2) ASSURANCES.—Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will—

"(A) provide for the establishment of a registry in accordance with subsection (a);

"(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;

"(C) provide for the annual publication of reports of cancer data under subsection (a); and

"(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing—

"(i) a means to assure complete reporting of cancer cases (as described in subsection (a)) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;

"(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;

"(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;

"(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;

"(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;

"(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

"(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data,

including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

"(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

"(d) RELATIONSHIP TO CERTAIN PROGRAMS.—

"(1) IN GENERAL.—This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).

"(2) SUPPLANTING OF ACTIVITIES.—In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.

"(3) TRANSFER OF RESPONSIBILITY.—The Secretary may not transfer administration responsibility for such SEER program from such Director.

"(4) COORDINATION.—To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.

"(e) REQUIREMENT REGARDING CERTAIN STUDY ON BREAST CANCER.—In the case of a grant under subsection (a) to any State specified in section 399K(b), the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

"SEC. 399I. PLANNING GRANTS REGARDING REGISTRIES. 42 USC 280e-1.

"(a) IN GENERAL.—

"(1) STATES.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2).

"(2) OTHER ENTITIES.—For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.

"(b) APPLICATION.—The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification required in subsection (a)(2) (if the application is for a grant under such subsec-

tion), and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

42 USC 280e–2.

"SEC. 399J. TECHNICAL ASSISTANCE IN OPERATIONS OF STATEWIDE CANCER REGISTRIES.

"The Secretary, acting through the Director of the Centers for Disease Control, may, directly or through grants and contracts, or both, provide technical assistance to the States in the establishment and operation of statewide registries, including assistance in the development of model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system.

42 USC 280e–3.

"SEC. 399K. STUDY IN CERTAIN STATES TO DETERMINE THE FAC TORS CONTRIBUTING TO THE ELEVATED BREAST CANCER MORTALITY RATES.

"(a) IN GENERAL.—Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that breast cancer mortality rates in the States specified in subsection (b) are elevated compared to rates in other States.

"(b) RELEVANT STATES.—The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.

"(c) COOPERATION OF STATE.—The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a).

"(d) PLANNING, COMMENCEMENT, AND DURATION.—The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.

"(e) REPORT.—Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

42 USC 280e–4.

"SEC. 399L. AUTHORIZATION OF APPROPRIATIONS.

"(a) REGISTRIES.—For the purpose of carrying out this part, the Secretary may use $30,000,000 for each of the fiscal years 1993 through 1997. Out of any amounts used for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399I, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under subsection 399J.

"(b) BREAST CANCER STUDY.—Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV for any fiscal year in which the study required in section 399K is being carried out, the Secretary shall expend not less than $1,000,000 for the study.".

Approved October 24, 1992.

Authorization extended through 1998.

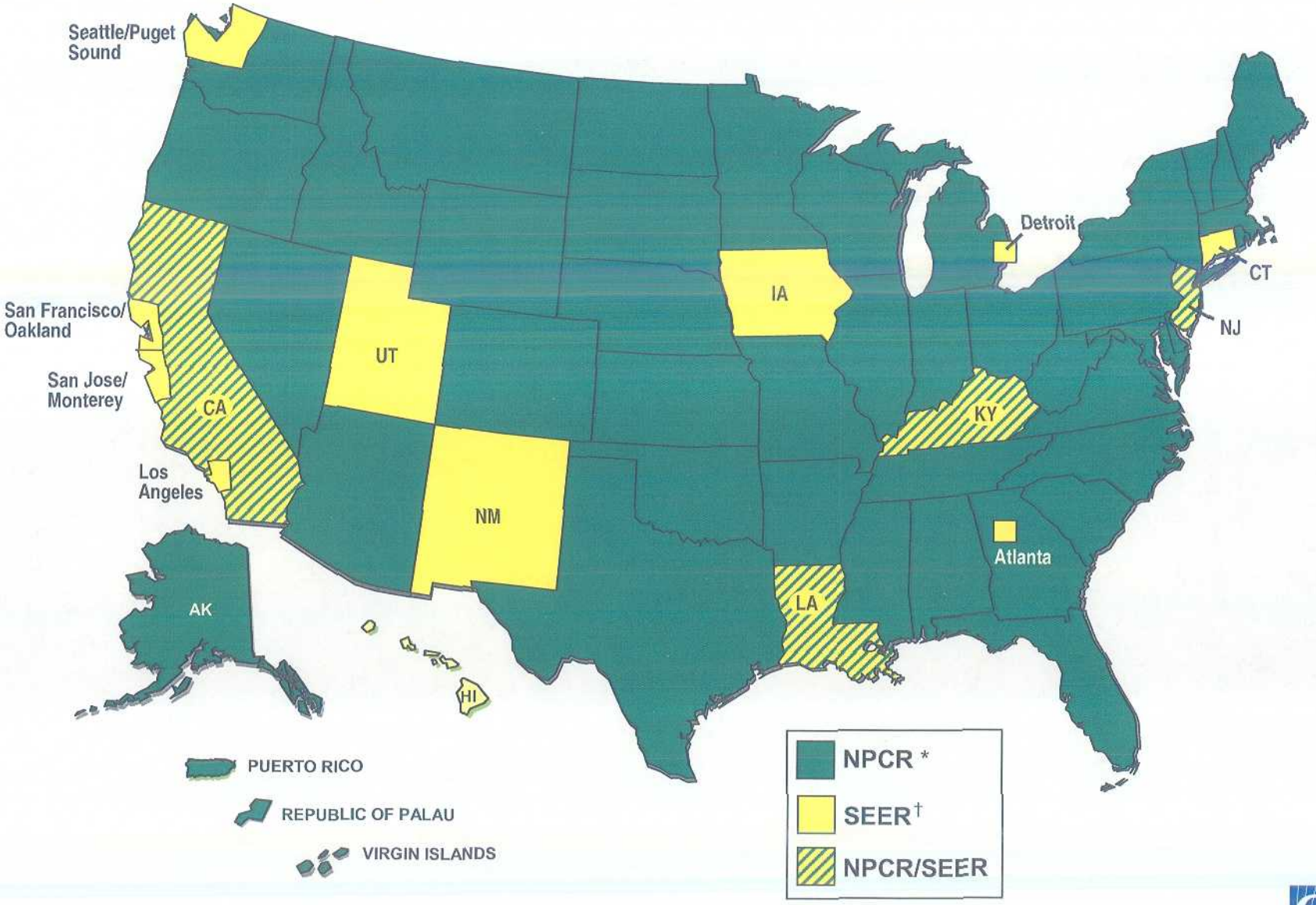
LEGISLATIVE HISTORY–S. 3312:

CONGRESSIONAL RECORD, Vol. 138 (1992):
Oct. 2, considered and passed Senate.
Oct. 5, considered and passed House, amended.
Oct. 7, Senate concurred in House amendment.

Attachment 2

Map of National Program of Cancer Registries grantees

Federally Funded Cancer Registries, 2005



*National Program of Cancer Registries (CDC)
†Surveillance, Epidemiology, and End Results Program (NCI)

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Attachment 3

Public Health Service Act

ATTACHMENT A

Public Health Service Act
Section 306(a) & (b)

NATIONAL CENTER FOR HEALTH STATISTICS

Section 306. [242k](a) There is established in the Department of Health and Human Services the National Center for Health Statistics (hereinafter in this section referred to as the "Center") which shall be under the direction of a Director who shall be appointed by the Secretary and supervised by the Assistant Secretary for Health (or such officer of the Department as may be designated by the Secretary as the principal adviser to him for health programs).

(b) In carrying out section 304(a), the Secretary, acting through the Center-

(1) shall collect statistics on-

(A) the extent and nature of illness and disability of the population of the United States (or any groupings of people included in the population), including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality,

(B) the impact of illness and disability of the population on the economy of the United States and on other aspects of the well-being of its population (or of such groupings),

(C) environmental, social, and other health hazards,

(D) determinants of health,

(E) health resources, including physicians, dentists, nurses, and other health professionals by specialty and type of practice and supply of services by hospitals, extended care facilities, home health agencies, and other health institutions,

(F) utilization of health care, including utilization of (i) ambulatory health services by specialties and type of practice of health professionals providing such service, and (ii) services of hospitals, extended care facilities, home health agencies, and other institutions,

(G) health care costs and financing, including the trends in health care prices and costs, the sources of payments for health care services, and Federal, State, and local governmental expenditures for health care services, and

(H) family formation, growth, and dissolution;

(2) shall undertake and support (by grant or contract) research, demonstrations, and evaluations respecting new or improved methods for obtaining current data on the matters referred to in a paragraph (1);

(3) may undertake and support (by grant or contract) epidemiologic research, demonstrations, and evaluations on the matters referred to in paragraph (1); and ...."

(4) may collect, furnish, tabulate, and analyze statistics, and prepare studies, on matters referred to in paragraph (1) upon request of public and nonprofit entities under arrangements under which the entities will pay the cost of the service provided.

Amounts appropriated to the Secretary from payments made under arrangements made under paragraph (4) shall be available to the Secretary for obligation until expended.

Attachment 4

NPCR-CSS Submission Specification document

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

2006 NPCR-CSS Submission Specifications

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

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NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

2006 NPCR-CSS Submission Specifications

The purpose of this document and attachments is to outline reporting requirements for the January 2006 data submission to the National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS).

For your convenience, a number of programs and documents relating to the submission of your data have been placed on the NPCR-CSS utilities Web site (https://www.npcrcss.org/utilities/). For a description of these programs and documents, see Attachment 1, Files on the NPCR-CSS Utilities Web Site.

Diagnosis Years: Include cases diagnosed in all residents of your catchment area beginning with your NPCR reference year (e.g., 1995) through December 31, 2004. For guidance on residency, refer to page 15 of *NAACCR Standards for Cancer Registries*, Volume II, Version 10.2 (March 2004).

Reportable Diagnoses: Please note that the definition for reportable diagnoses has changed over time.

- **Cases diagnosed before 2001:** All histologies with a behavior code of "2" or "3" in the *International Classification of Diseases for Oncology,* Second Edition (ICD-O-2) are reportable diagnoses. The following are exclusions:[1, 2, 3, 4]

8000-8004	Neoplasms, malignant, NOS of the skin (C44.0-C44.9)
8010-8045	Epithelial carcinomas of the skin (C44.0-C44.9)
8050-8082	Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
8090-8110	Basal cell carcinomas of the skin (C44.0-C44.9)
	For the cervix, carcinoma in situ (any /2) (C53.0-C53.9)
8077	CINIII, VINIII, VAINIII (C51.0-0.53.9)

NOTE 1 **The above lesions are reportable for skin of the genital sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C51.0-C51.9, C60.0, C60.9, C63.2). For cancer cases diagnosed before 2001, collection of these lesions may vary because of the lack of detail in Program Announcement 426 and Public Law 102-515. Registries that have not been collecting these lesions and cannot report them will not be penalized.**

NOTE 2 **If a "0" or "1" behavior code term in ICD-O-2 is verified as in situ: "2," or malignant: "3," by a pathologist, the case is reportable.**

- **Cases diagnosed beginning January 1, 2001:** All histologies with a behavior code of "2" or "3" in the *International Classification of Diseases for Oncology,* Third Edition (ICD-O-3) are reportable diagnoses. The following are exclusions:[1, 2, 3, 4]

8000-8005	Neoplasms, malignant, NOS of the skin (C44.0-C44.9)
8010-8046	Epithelial carcinomas of the skin (C44.0-C44.9)
8050-8084	Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
8090-8110	Basal cell carcinomas of the skin (C44.0-C44.9)
	For the cervix, carcinoma in situ (any/2) (C53.0-C53.9)
8148	PIN III (C61.9)
8077	AINIII (C21.1), CINIII, VINIII, VAINIII (C51.0-C53.9)

NOTE 1 **The above histology codes are reportable for the following mucoepidermoid sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C51.0-C51.9, C60.0, C60.9, C63.2).**

NOTE 2 **If a "0" or "1" behavior code term in ICD-O-3 is verified as in situ: "2," or malignant: "3," by a pathologist, the case is reportable.**

NOTE 3 **Histology/behavior code 9421/1 (Pilocytic astrocytoma) should be reported as 9421/3.**

- **Cases diagnosed beginning January 1, 2004:** The same as for cases diagnosed January 1, 2001, and later **and** including nonmalignant primary intracranial and central nervous system tumors with a behavior code of "0" or "1."[1, 2, 3, 4] However, benign and borderline tumors of the cranial bones (C410) are not reportable. For further guidance, please refer to the following table from the *SEER Program Coding and Staging Manual 2004* (http://seer.cancer.gov/tools/codingmanuals/).

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	C700
	Spinal meninges	C701
	Meninges, NOS	C709
Brain	Cerebrum	C710
	Frontal lobe	C711
	Temporal lobe	C712
	Parietal lobe	C713
	Occipital lobe	C714
	Ventricle, NOS	C715
	Cerebellum, NOS	C716
	Brain stem	C717
	Overlapping lesion of brain	C718
	Brain, NOS	C719
Spinal cord, cranial nerves, and other parts of the central nervous system	Spinal cord	C720
	Cauda equine	C721
	Olfactory nerve	C722
	Optic nerve	C723
	Acoustic nerve	C724
	Cranial nerve, NOS	C725
	Overlapping lesion of brain and central nervous system	C728
	Nervous system, NOS	C729
Pituitary, craniopharyngeal duct, and pineal gland	Pituitary gland	C751
	Craniopharyngeal duct	C752
	Pineal gland	C753

Data Items: Attachment 2, Data Items by Diagnosis Year, is a list of data items to be submitted. Data items new to this submission are noted in **bold.**

- Use definitions and codes from Chapters X and XI of *NAACCR Standards for Cancer Registries,* Volume II for NAACCR record layout Version 10.2 (March 2004).[5]

NOTE: Except for County at Dx [90], leave missing or uncollected data items blank.

- Depending on the date of diagnosis, the primary site and morphology must be coded according to the ICD-O-2 or ICD-O-3 coding system. The primary site codes did not change from ICD-O-2 to ICD-O-3.

NOTE: New this year: 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/).

- If state law prohibits the release of all or some county codes, please recode the county code to "000" for relevant case records. 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" will generate an edit error because out-of-state residents are not reportable to NPCR.**

- Run the NHIA algorithm (NHIA V2 SAS Program 10.2) on the file to be submitted and populate the data item "NHIA Derived Hisp Origin" (NAACCR item number 191). The computerized algorithm developed in SAS can be found at http://www.naaccr.org/ under "NAACCR Call for Data 2006." Please contact Joe Rogers at (770) 488-4701 for assistance in obtaining and/or running the SAS algorithm.

- This year, only selected NPCR registries are required to perform the Indian Health Service (IHS) linkage for 1995–2003 incidence data. Regardless, all registries are required to report the results of cases submitted for linkage either from this year's linkage or from last year's linkage. The codes are as follows: code 0—did not match IHS database; code 1—did match IHS database. IHS Link is not included in *NAACCR Standards for Cancer Registries,* Volume II (V10.2) but has been assigned the NAACCR data item number 192 and column number 232 that became official in Volume II (V11). Leave the variable blank if the case record was not sent for linkage with IHS records.

- For Vital Status [1760] use 0 (CoC) for "dead."

Edits: Attachment 3, 2006 Data Edits, contains a list of single field, inter-field, and inter-record edits that will be used to evaluate your data submission.

- **Core** edits are nearly identical to the 2006 NAACCR Call for Data. Core edits will be used to assess program standards (i.e., percentage of records passing edits).

- **Advanced** edits are for informational purposes only. However, registries are encouraged to run these edits and attempt to resolve errors because these edits may become core edits in future submissions.

- Inter-record edits are now listed as both **core** and **advanced** edits but are to be run separately using the Inter-Record Edits Standalone Program (see attachment 1-1).

NOTE: New this year: Core inter-record edits will be used to assess program data standards.

Identification of Duplicate Records Form: Please assess duplicate records in your database using the *NAACCR Protocol for Assessing Duplicate Cases* (NAACCR Call for Data 2006, http://www.naaccr.org/index.asp?Col_SectionKey=12&Col_ContentID=377).

NOTE: If you have completed this protocol for your NAACCR Call for Data 2006 submission, it is not necessary to rerun the protocol.

Record Format: Create a file in **NAACCR Record Layout Version 10.2** that includes only the data items listed in attachment 2. 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/utilities/).

NOTE: Submissions that include non-blank data in the Patient-Confidential Section will not be accepted, and the registry will be notified.

Submission Due Date: Data can be submitted during the month of January 2006 (through January 31), holidays excluded. Submission hours are from 8 a.m. EST to 6 p.m. EST, Monday through Friday. If you are on the West coast or need extended hours, contact the NPCR-CSS Help Line at (301-572-0502, and ORC Macro staff will try to accommodate your needs.

Preparing and Transmitting Data: Please check the file prior to submission to ensure that all data years (**including 2004, 12-month data**) and all required data items are included. An NPCR-CSS checklist (see attachment 4) 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.

NOTE 1 Do not submit the 2006 NAACCR Call for Data file. The case definitions and diagnosis years are not the same for the NPCR-CSS and NAACCR submissions.

NOTE 2 If the NPCR-CSS data extraction utility is not used to extract the data for submission, it is recommended that you use PKZIP or WINZIP to compress your files prior to submission.

File Transfer Instructions: Refer to the file transfer instructions (see attachment 5). ORC Macro staff will contact you in early December with your user ID and password for accessing your State folder on the NPCR-CSS document server.

Data Security: In accordance with the requirements of the 308(d) Assurance of Confidentiality, ORC Macro has developed and implemented the NPCR-CSS Security Plan. An overview of the security plan is provided (see attachment 6) .

Transmitting Forms: Please complete the following forms and send them with your data submissions:

- **Attachment 7** 2006 NPCR-CSS Data Submission Form
- **Attachment 8** 2006 Data Items Transmitted Form
- **Attachment 9** 2006 Duplicate Protocol Results
- **Attachment 10** 2006 NPCR-CSS Dataset Participation Agreement
- **Attachment 11** 2006 Registry Follow-Up Sources

These attachments are available on the NPCR-CSS utilities Web site (https://www.npcrcss.org/utilities/). You are encouraged to complete and submit these forms to your State folder on the NPCR-CSS document server or you can fax or mail the forms to ORC Macro:

ORC Macro
Attn: Cancer Surveillance Project
7315 Wisconsin Avenue, Suite 400W
Bethesda, MD 20814
Fax: (301) 961-8537

Questions About Your Submission: Refer to the frequently asked questions about the NPCR-CSS Data submission (see attachment 12) or call:

Hannah Weir (770) 488-3006 or Karen Ledford (770) 488-4869	For assistance completing forms (attachments 7–10)
Joe Rogers (770) 488-4701	For assistance obtaining and/or running the NHIA SAS algorithm
NPCR Help Line (301) 572-0502)	For assistance with technical issues related to data submission, including obtaining a user ID and password and accessing the NPCR-CSS Web site (npcrcss.org)

For issues unrelated to data submission, contact your CDC Program Consultant.

Data Evaluation: Data will be evaluated according to the following NPCR standards, and results will be reported in the NPCR-CSS Data Evaluation Reports sent to participating programs in May 2006.

Criteria		NPCR 12-Month Standard	NPCR 24-Month Standard	USCS[a] Publication Standard	U.S. County Public-Use File Standard[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 Core Edits[f]		>=97%	>=99%	>=97%	>=97%	NA

Notes

a United States Cancer Statistics

b See NPCR-CSS Data Release Policy, September 2004

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 edits designated as "core" will be used to evaluate data, including core inter-record edits

NA Not applicable

References

1. Program Announcement #426, National Program of Cancer Registries, CDC, March 1994.
2. Public Law 102-515. NPCR Home Page: http://www.cdc.gov/cancer/npcr/npcrpdfs/publaw.pdf.
3. SEER (Surveillance, Epidemiology, and End Results) Program, 2004. The SEER Program Coding Manual, 2004 Fourth Edition. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. NIH Pub. No. 04-5561. January 2004, pages 1–5.
4. Hultstrom D, editor. Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 10.2, Ninth Edition. Springfield, IL: North American Association of Central Cancer Registries, March 2004, pages 15–19.
5. Hultstrom D, editor. Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 10.2, Ninth Edition. Springfield, IL: North American Association of Central Cancer Registries, March 2004, pages 67–354.

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

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/utilities/). For assistance with these utility programs, please call ORC Macro at (301) 572-0502.

1. **ICD-O-2 to ICD-O-3 Conversion Program**—(http://seer.cancer.gov/tools/conversion/).

2. **NHIA SAS V2 SAS Program 10.2** —NAACCR has developed and updated a NAACCR Hispanic Identification Algorithm (NHIA) and related NHIA SAS program. All NPCR registries are required to use the Version 2 of the NAACCR NHIA SAS program and record the NHIA variable in the NPCR-CSS 2006 data submission. To download a copy of the SAS program and the associated files required to run the program, please visit the NAACCR Web site under the following link:
   http://www.naaccr.org/index.asp?Col_SectionKey=7&Col_ContentID=312#Hispanic
   Please contact Joe Rogers at (770) 488-4701 for assistance in obtaining and/or running the SAS program.

3. **GenEDITS Plus with the NPCR 2006 Core and Advanced Edits Metafile**—This is an edits program that contains the edits metafiles to run the NPCR 2006 **core** and **advanced** single field and inter-field edits on NAACCR record layout Version 10.2. The program produces summary and detailed reports of core and advanced edit errors.

4. **NPCR-CSS 2006 Edits Metafiles**—For those registries that prefer to use another edits program, this download contains the runtime metafiles for the NPCR 2006 core and advanced single field and inter-field edits.

5. **Inter-Record Edits Standalone Program 2006**—This program runs SEER inter-record edits on NAACCR Record Layout Version 10.2, containing both ICD-O-2 or ICD-O-3 coded cases. The program produces summary and detailed reports of inter-record errors. Once you execute the program, a help file is available that describes how to use the program. **The Inter-Records Edits program should be run after the NPCR 2006 core and advanced edits have been run and errors have been corrected.**

6. **Data Extraction Utility 2006**—This is an executable file that contains the NPCR Data Extraction Utility for the 2006 submission. This program will read NAACCR record layout Version 10.2 and write a new file that contains only data items requested for the 2006 submission. Once you execute the program, a help file is available that describes how to use the program.

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

Attachment 2
Data Items by Diagnosis Year

	Record ID and Demographic Section—(Name and [Number])	Required Status 1995–2004
	Record Type [10]	Y
	Patient ID Number [20] (unique)	Y
	Registry Type [30]	Y
	Registry ID [40]	Y
	NAACCR Record Version [50]	Y
	Address at Dx—State [80]	Y
	County at Dx [90]	Y[1]
	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 [360][2]	Y[2]
	Census Tr Certainty 1970/80/90 [364]	Y
	Census Tr Certainty 2000 [365][2]	Y[2]
	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]
	Computed Ethnicity [200]	As available
	Computed Ethnicity Source [210]	As available
	Sex [220]	Y
	Age at Diagnosis [230]	Y
	Birth Date [240]	Y
	Birthplace [250]	Y
	Occupation Code—Census [270] (if text data have been coded)	Y
	Industry Code—Census [280] (if text data have been coded)	Y
	Occup/Ind Coding System [580]	Y
	Primary Payer at Diagnosis [630][5]	As available[5]

Cancer Identification Section—(Name and [Number])		Required Status 1995–2004
	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][6]	Y[6]
	Behavior Code ICD-O-3 [523][6]	Y[6]
	ICD-O-3 Conversion Flag [2116][6]	Y[6]
Treatment First Course Section—(Name and [Number])		**Required Status 1995–2004**
	Date of Initial Rx—SEER [1260][7]	**As available[7]**
	Date of 1st Crs Rx—COC [1270][7]	**As available[7]**
	Rx Summ—Surg Primary Site [1290][8]	As available[8]
	Rx Summ—Scope Reg LN Sur [1292][8]	As available[8]
	Rx Summ—Surg Oth Reg/Dis [1294][8]	As available[8]
	Reason for No Surgery [1340][8]	As available[8]
	RX Summ--Surg/Rad Seq [1380][8]	As available[8]
	Rx Summ—Chemo [1390][8]	As available[8]
	Rx Summ—Horm [1400][8]	As available[8]
	Rx Summ—BRM [1410][8]	As available[8]
	Rx Summ—Other [1420][8]	As available[8]
	Rad—Regional Rx Modality [1570][8]	As available[8]
	Rx Summ—Transplant/Endocr [3250][8]	As available[8]
Stage/Prognostic Factors Section—(Name and [Number])		**Required Status 1995–2004**
	SEER Summary Stage 2000 [759][9]	Y[9]
	SEER Summary Stage 1977 [760][9]	Y[9]
	Derived SS2000 [3020][10]	**Y[10]**
	Derived SS2000-Flag [3050][11]	**Y[11]**

Follow-Up/Recurrence/Death Section—(Name and [Number])		Required Status 1995–2004
	Date of Last Contact [1750]	Y
	Vital Status [1760]	Y
	Follow-Up Source [1790]	As available
	Cause of Death [1910]	Y
	ICD Revision Number [1920]	Y

Over-Rides/Conversion/System Admin. Section—(Name and [Number])		Required Status 1995–2004
	Over-Ride Age/Site/Morph [1990]	Y
	Over-Ride SeqNo/DxConf [2000]	Y
	Over-Ride Site/Lat/Sequence Number [2010]	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 **core** surveillance data.

Data items new to this submission are noted in **bold.**

The data item names and numbers are those used in NAACCR Volume II, Version 10.2.

Status key: Y = Yes

[1] Leave blank for missing and not reported. 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, the registry may recode all valid county codes to "000."

[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 NHIA SAS Program. See the Submission Specifications document and/or Atachment 1 for more details. Please note that code 9, unknown, is not a valid code for this data item.

[4] Report the results of cases submitted for IHS linkage using codes 0 or 1. See the Submission Specifications document for further details.

[5] This field is currently optional. Submit data as available.

[6] 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.

[7] Submit either the SEER or COC field; for reportable cases diagnosed in 2003 or later, as available.

[8] For reportable cases diagnosed in 2003 or later, as available.

[9] For reportable cases diagnosed in 2000 or before, code using *SEER Summary Staging Guide 1977.* For reportable cases diagnosed in 2001 and later, code using *SEER Summary Staging Manual 2000.*

[10] For reportable cases diagnosed in 2004 and later, this item is the derived "Summary Stage 2000" from the CS algorithm or EOD codes.

[11] 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 or EOD codes.

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Attachment 3
2006 Data Edits

CORE SURVEILLANCE EDITS		
	Single Field Edits	
	Addr at Dx—State	(NAACCR)
	Age at Diagnosis	(SEER AGEDX)
	Behavior ICD-O-3	(NPCR SUBM)
	Birth Date	(NAACCR DATEEDIT)
	Birthplace	(COC)
	Date of Diagnosis	(NAACCR DATEEDIT)
	Derived SS2000	**(CS)**
	Derived SS200-Flag	**(CS)**
	Diagnostic Confirmation	(SEER DXCONF)
	Grade	(COC)
	Histologic Type ICD-O-3	(NPCR SUBM)
	ICD-O-3 Conversion Flag	(NAACCR)
	IHS Link	**(NPCR SUBM)**
	Laterality	(SEER LATERAL)
	Morph Coding Sys—Current	(NAACCR)
	NAACCR Record Version	(NAACCR)
	NHIA Derived Hisp Origin	**(NPCR SUBM)**
	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)
	Record Type	(NAACCR)
	Registry ID	(NAACCR)
	Registry Type	(NAACCR)
	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)

CORE SURVEILLANCE EDITS		
	Inter-Field Edits	
	Age, Birth Date, Date of Diagnosis	(NAACCR IF13)
	Age, Primary Site, Morphology ICD-O-3	(SEER IF15)
	Behavior ICD-O-3, Site, Histology ICD-O-3	(NAACCR)
	Behavior ICD-O-3, Summary Stage 1977	(NPCR SUBM)
	Behavior ICD-O-3, Summary Stage 2000	(NAACCR)
	Birth Date, Date of Diagnosis	(NAACCR IF47)
	Derived SS2000, Date of Dx	**(NPCR SUBM)**
	Derived SS2000-Flag, Derived SS2000	**(CS)**
	Diagnostic Confirm, Seq Num—Central	(SEER IF23)
	Diagnostic Confirmation, Behavior ICD-O-3	(SEER IF31)
	Diagnostic Confirmation, Histology ICD-O-3	(SEER IF48)
	Edit Over-rides	(SEER REVIEWFL)
	Hemato ICD-O-3, Summ Stg 1977	**(NPCR SUBM)**
	Laterality, Primary Site	(NAACCR IF24)
	Laterality, Primary Site, Morphology ICD-O-3	(SEER IF42)
	Lymphoma ICD-O-3, Site, Summ Stg 1977	**(NPCR SUBM)**
	Morphology—Type and Behavior ICD-O-3	(SEER MORPH)
	Primary Site, Behavior Code ICD-O-3	(SEER IF39)
	Primary Site, Laterality	(SEER IF82)
	Primary Site, Morphology—Imposs ICD-O-3	(SEER IF38)
	Primary Site, Morphology—Type ICD-O-3	(SEER IF25)
	Race 1, Race 2, Race 3, Race 4, Race 5	(NAACCR)
	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)
	Registry Type, Registry ID	(NAACCR)
	Registry Type, Sequence Number—Central	(NAACCR)
	Seq Num—Central, Prim Site, Morph ICD-O-3	(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, Rpt Srce	(NAACCR)
	Type of Report Srce (DC/AO), Diag Conf	(SEER IF05)
	Type of Report Srce (DC), Seq Num—Cent, ICD-O-3	(SEER IF04)
	Unknown Site Hist ICD-O-3, Summary Stage 1977	(NPCR SUBM)
	Unknown Site, Laterality	(NAACCR)

CORE SURVEILLANCE EDITS		
	Inter-Record Edits[1]	
	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 Numbers of Primaries Using Age at Diagnosis	(SEER IR03)
	Verify Race Same on All Records for a Patient	(SEER IR04)
	Verify Sex Same on All Records for a Patient	(SEER IR05)
	Verify Sequence Numbers of Primaries Using Dates at Diagnosis	(SEER IR06)
	Verify Sequence Number Not in Conflict With Number of Primaries	(SEER IR07)
	Verify Same Primary Not Reported Twice for a Person	(SEER IR09)
	Verify No Duplicate Bladder Primaries Reported for a Person	(SEER IR13)
	Verify Spanish Surname or Origin Same on All Records for a Person	(SEER IR14)

ADVANCED SURVEILLANCE EDITS		
	Single Field Edits	
	Addr at Dx—Postal Code	(COC)
	Cause of Death	(SEER COD)
	Census Tract 1970/80/90	(SEER TRACT)
	Census Tract 2000	(SEER)
	Census Tr Cert 1970/80/90	(SEER CENSCERT)
	Census Tr Certainty 2000	(SEER)
	Census Cod Sys 1970/80/90	(SEER RESSYST)
	Computed Ethnicity	(SEER COMPETHN)
	Computed Ethnicity Source	(SEER ETHNSRC)
	County at Dx—NPCR[2]	(NPCR)
	Date of 1st Crs Rx—COC[3]	**(NPCR SUBM)**
	Date of Initial Rx—SEER[3]	**(NPCR SUBM)**
	Date of Last Contact	(NAACCR DATEDIT)
	Follow-up Source	(COC)
	ICD Revision Number	(SEER ICDCODE)
	Primary Payer at Dx	**(NPCR SUBM)**
	Rad—Regional Rx Modality	**(NPCR SUBM)**
	Reason for No Surgery	**(NPCR SUBM)**
	RxSumm—BRM	**(NPCR SUBM)**
	RxSumm—Chemo	**(NPCR SUBM)**
	RxSumm—Hormone	**(NPCR SUBM)**
	RxSumm—Other	**(NPCR 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 SUBM)**
	RxSumm—Transplnt/Endocr	**(NPCR SUBM)**
	Vital Status	(COC)

ADVANCED SURVEILLANCE EDITS		
	Inter-Field Edits	
	Age, Histologic Type, COD ICD-O-3	(SEER IF43)
	Age, Primary Site, Morphology ICD-O-3—Adult	(SEER)
	Age, Primary Site, Morphology ICD-O-3—Pediatric	(NPCR)
	Census Tract 1970/80/90, Census Tract Coding Sys	(SEER IF45)
	CompEthn, Date of Diag	(SEER IF71)
	Date of Init Rx—SEER, Date of Dx	**(NAACCR18)**
	Date of Init Rx—SEER, Date Last Cont	**(NAACCR IF35)**
	County at Dx, Addr at Dx—State	(NPCR SUBM)
	Date of 1st Crs Rx—COC, Date of Dx	**(COC)**
	Date of 1st Crs Rx—COC, Date of Last Contact	**(COC)**
	Date of Last Contact, Date of Diagnosis	(NAACCR IF19)
	EthnSrc, Date of Diag	(SEER IF72)
	Follow-up Source, Vital Status	(COC)
	ICD Revision Number, Cause of Death	(SEER IF37)
	ICD Revision, Vital Stat, Date Last Contract	(NPCR)
	Type of Report Srce (DC/AO), COD	(SEER IF09)
	Type of Report Srce (DC/AO), Vit Stat	(COC)
	RxSumm—Scope Reg LN Surg, Prim Site	(SEER IF109)
	RxSumm—Surg Prim Site, Primary Site	(SEER IF108)
	Surgery, Rad, Surg/Rad Seq	**(COC)**
	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)
	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)

NOTES:

Edits new to this submission are noted in **bold.**

See the NPCR-CSS utilities Web site (https://www.npcrcss.org/utilities/) 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] Core inter-record edits are required to be resolved and will be used to assess program standards.

[2] This edit has been modified to allow "000" as a valid code for recode if state law prohibits the release of county codes.

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

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Attachment 4
2006 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
	If you have not done so for your NAACCR Call for Data 2006 submission, identify duplicate records in your database using the *NAACCR Protocol for Assessing Duplicate Cases (1999–2003, 2003).* Otherwise, copy your Duplicate Protocol Assessment results from your NAACCR submission to Attachment 9.
	Run the ICD-O 2 to ICD-O 3 conversion program on cases diagnosed prior to 2001.
	Run the NAACCR NHIA V2 SAS Program 10.2 to assign the derived Hispanic ethnicity to incident cases.
	Update with the Indian Health Service link variable (if applicable).
	Run the edits program using the NPCR-CSS 2006 edits metafiles and resolve single field and inter-field edit errors.
	Run the inter-record edits standalone program 2006 and resolve edit errors.
	Extract the data file; verify that all required diagnosis years are included (i.e., from your NPCR reference year through 2004)*.
	Follow the steps for creating and transmitting data and send the data file to ORC Macro by January 31, 2006.
	Complete Attachment 7-11 and submit via the CSS document server, fax, or mail to ORC Macro.

*** Do <u>not</u> submit your NAACCR Call for Data 2006 submission. The case definition and diagnosis years are not the same as those for the NPCR-CSS submission. Refer to the 2006 NPCR-CSS Submission Specifications for details.**

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

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 ORC Macro will call each program in early December to provide the login, user ID, and password and to answer questions.

If the NPCR-CSS data extraction utility is not used to create the file for submission, it is recommended that each State use PKZIP or WINZIP to compress its files prior to posting them to the 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. Enter your user-specific ID and password and click on the **Login** button.

4. A folder will appear 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 2006 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 **GA95V10** for 1995 Georgia data in Version 10 and **GA9504V10** for 1995–2004 Georgia data in Version 10. Once you have selected the file and entered any descriptive text that you want to include with the submission, click on the **Continue** button.

5. You will receive a confirmation message that the file has been successfully uploaded. Depending on the size of the file and speed of your connection, this may take a few seconds to 30 minutes or more.

6. The file has now been uploaded.

7. Click on **Logout** in the upper right-hand corner, and you will return to the login screen.

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

Attachment 6
Overview of Data Security

The NPCR-CSS project data reside on a dedicated server at ORC Macro. To ensure the security and confidentiality of project data, the following provisions have been incorporated into the ORC Macro 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 ORC Macro'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 ORC Macro's firewall.

- Access to the NPCR-CSS server is limited to authorized ORC Macro project staff (see below). It is password protected on its own security domain. No one, including nonproject staff at ORC Macro, is allowed access to the NPCR-CSS data.

- All ORC Macro 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 ORC 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 will be destroyed when no longer needed.

- A comprehensive security plan has been developed by ORC Macro's security team. The security team consists of June Bray, Managing Director; Kevin Zhang, Project Director; Leo Shen, Data Manager and 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 ORC Macro 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 ORC Macro 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.

ORC Macro
Authorized Project Staff

Staff Member	Position
June Bray, Ph.D.	Managing Director
Kevin Zhang, Ph.D.	Project Director
Leo Shen, M.B.A.	Data Manager/Security Officer
David Radune, B.S.	Database Administrator
Gretchen Stanton, M.S.	LAN and WAN Security Steward
Qiming He, Ph.D.	QA Coordinator/Programmer Analyst
Yuan Ren, Ph.D.	Statistical Programmer/Sr. Analyst
Jonathan Stanger, M.P.A.	SQL Programmer
Shaobin Xu, M.S.	Programmer Analyst

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

Attachment 7
2006 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 3.

Diagnosis Year	(1) Total Number of Records	(2) Number of Excluded Records	(3) Number of DCOs	(4) Death Clearance Conducted (Yes/No)	(5) NHIA Run (S/M/N)	(6) IHS Linkage (Y/N)	(7) Comments	(8) File Name	(9) NAACCR Version	(10) NAACCR Record Type
1995										
1996										
1997										
1998										
1999										
2000										
2001										
2002										
2003										
2004										

Instructions for Completing the 2006 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 2006 data submission.

(1) **Total Number of Records:** Enter the number of records submitted for each year, including death-certificate-only cases. The form is designed for one file for each diagnostic year. If one file is used for all years, indicate that on the form.

(2) **Number of Excluded Records:** Enter the number of records in your database not included in this submission. Reasons for excluding a record may include case-sharing agreements with other registries or facility-specific contract requirements. Please record the reason for excluding cases under Comments.

(3) **Number of Death-Certificate-Only Cases:** Enter the number of DCOs included in the submission for each year.

(4) **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. For details, refer to NAACCR Call for Data 2006, Packet 1 (General Protocols), "Verification of Death Clearance Form" on 1995–2003 Data.

(5) **NHIA Run:** Run the NAACCR Hispanic Identification Algorithm (NHIA) Version 2 and record the derived NHIA variable. For details, refer to NAACCR Call for Data 2006, Packet 5. Enter "S" if the SAS algorithm was run, "M" if done manually, or "N" if not done.

(6) **IHS Linkage:** If linkage was performed between your 1995–2003 incidence data and Indian Health Service files and race data was updated and race reported accordingly, enter "Yes."

(7) **Comments:** Use this space as needed.

(8) **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 10 = GA95V10
- 1995–2002 Georgia data, Version 10 = GA9502V10

(9) **NAACCR Version:** NAACCR Version 10.2

(10) **NAACCR Record Type:** Should be "I," Incidence (length = 1946) or "A," Full Case Abstract (length = 6694), with the Patient Confidential Section blanked out.

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Attachment 8
2006 NPCR-CSS Data Items Transmitted

Registry name: _____

Please write "Yes" or "No" to indicate the transmission status of each data item to CDC. If the data item will not be transmitted, or if the data item is modified prior to transmission, please explain (e.g., data not collected, State law prohibits). For shaded data items, please make a checkmark if the data item is consolidated.[1] Please refer to the notes regarding specific data items.

Record ID and Demographic Section	Transmitted (Yes/No)	Consolidated[1] (✓)	Reason for Not Transmitting or for Modifying Prior to Transmission
Record Type [10]			
Patient ID Number [20] (unique)			
Registry Type [30]			
Registry ID [40]			
NAACCR Record Version [50]			
Addressat Dx—State [80]			
County at Dx [90]			
Addressat Dx—Postal Code [100]			
Census Tract 1970/80/90 [110]			
Census Tract 2000 [130]			
Census Tr Cert 1970/80/90 [364]			
Census Tr Certainty 2000 [365]			
Race 1–5 [160–164]			
Spanish/Hispanic Origin [190]			
NHIA Derived Hisp Origin [191]			
IHS Link [192]			
Computed Ethnicity [200]			
Computed Ethnicity Source [210]			
Sex [220]			
Age at Diagnosis [230]			
Birth Date [240]			
Birthplace [250]			
Occupation Code—Census [270]			
Industry Code—Census [280]			
Occup/Ind Coding System [330]			
Primary Payer at Diagnosis [630]			

Cancer Identification Section	Transmitted (Yes/No)	Consolidated (✓)	Reason for Not Transmitting or for Modifying Prior to Transmission
Sequence Number—Central [380]			
Date of Diagnosis [390]			
Primary Site [400]			
Laterality [410]			
Grade [440]			
Diagnostic Confirmation [490]			
Type of Reporting Source [500]			
Histologic Type ICD-O-3 [522]			
Behavior Code ICD-O-3 [523]			
ICD-O-3 Conversion Flag [2116]			

Treatment First Course Section	Transmitted (Yes/No)	Consolidated (✓)	Reason for Not Transmitting or for Modifying Prior to Transmission
Date of Initial Rx—SEER [1260][2]			
Date of 1st Crs Rx—COC [1270][2]			
Rx Summ—Surg Primary Site [1290][2]			
Rx Summ—Scope Reg LN Sur [1292][2]			
Rx Summ—Surg Oth Reg/Dis [1294][2]			
Reason for No Surgery [1340][2]			
Rx Summ—Surg/Rad Seq [1380][2]			
Rx Summ—Chemo [1390][2]			
Rx Summ—Horm [1400][2]			
Rx Summ—BRM [1410][2]			
Rx Summ—Other [1420][2]			
Rad—Regional Rx Modality [1570][2]			
Rx Summ—Transplant/Endocr [3250][2]			

Stage/Prognostic Factors Section	Transmitted (Yes/No)	Consolidated (✓)	Reason for Not Transmitting or for Modifying Prior to Transmission
SEER Summary Stage 2000 [759][3]			
SEER Summary Stage 1977 [760][4]			
Derived SS2000 [3020][5]			
Derived SS2000-Flag [3050][5]			

Follow-Up/Death Section	Transmitted (Yes/No)	Consolidated (✓)	Reason for Not Transmitting or for Modifying Prior to Transmission
Date of Last Contact [1750]			
Vital Status [1760]			
Follow-Up Source [1790]			
Cause of Death [1910]			
ICD Revision Number [1920]			

[1] When multiple reports for one tumor are received, the same data items are evaluated, and the best values are chosen and stored in a consolidated record.

[2] Transmission requested as available for cases diagnosed in 2003 and 2004.

[3] For cases diagnosed in 2001 through 2003.

[4] For cases diagnosed before 2001.

[5] For cases diagnosed in 2004 and later.

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Attachment 9
2006 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 2006 NPCR-CSS Submission Specifications). The duplicate rates will be used to adjust the completeness of case ascertainment estimates. The 1999–2003 duplicate rate will be used to adjust the 1995–2003 estimates. The 2003 duplicate rate will be used to adjust the 2003 estimate. Please return this form with your data submission.

Diagnosis Year	Criteria	Results
1999–2003	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
2003	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
2006 NPCR-CSS Dataset Participation Agreement

January 2006 Data Submissions
(For more information see NPCR-CSS Data Release Policy)

Registry name _____

Please indicate whether data from your state cancer registry submitted in the January 2006 data submissions may be included in the following NPCR-CSS data sets:
A. Public-Use Data Sets

USCS expanded data set ____ Yes ____ No

USCS county cancer incidence data set. ____ Yes ____ No

B. Restricted-Access Data Sets *(description of restricted access file (RAF) enclosed)*

.

_____ Yes _____ No

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 _____

These attachments are available on the NPCR-CSS utilities Web site (https://www.npcrcss.org/utilities/). You are encouraged to complete and submit these forms to your State folder on the NPCR-CSS document server or you can fax or mail the forms to ORC Macro:

ORC Macro
Attn: Cancer Surveillance Project
7315 Wisconsin Avenue, Suite 400W
Bethesda, MD 20814
Fax: (301) 961-8537

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Attachment 11
2006 Registry Follow-Up Sources

Registry name:_____ Person completing form: _____

Instructions for completing the form are on the next page.

Diagnosis Year	Follow-Up (year, source of follow-up, and cancer sites followed up for vital status)																	
	1995		1996		1997		1998		1999		2000		2001		2002		2003	
	Source	Sites	Source	Sites	Source	Sites	Source	Sites	Source	Sites	Source	Sites	Source	Sites	Source	Sites	Source	Sites
1995																		
1996																		
1997																		
1998																		
1999																		
2000																		
2001																		
2002																		
2003																		

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). The placement and number of characters must reflect the NAACCR version you are using to submit the data (i.e., NAACCR version 6 requires 8 characters, while all later versions require 15 with leading zeros).

   - **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 (v10.2) 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.

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

   You may fax ((301) 961-8537) or mail the forms to ORC Macro. However, forms can also be completed electronically and uploaded with your data submission. If you fax the forms, please notify ORC Macro 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 and fax all changes to NPCR-CSS at (301) 961-8537 or upload the corrected form to the NPCR-CSS Web site. Please notify ORC Macro of any changes.

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.

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

   Your data are transmitted through a secured server and are encrypted during transmission. If you password-protect your files, please notify ORC Macro 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 2004 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. Beginning this year, **core** inter-record edits will be assessed for standards. This is especially important if you want your registry's data to be considered for inclusion in the 2006 Restricted Access File.

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

    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 ORC Macro staff.

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

Reports will be available in early May 2006.

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 ORC Macro server. The user cannot delete a file once it has been uploaded. If you want to have the file deleted, please call the NPCR-CSS Help Line at (301) 572-0502 or e-mail npcr-css@orcmacro.com with an instruction to ORC Macro staff to delete the file. ORC Macro will confirm the deletion of the file by e-mail.