Information Collection Request

Reinstatement

National Program of Cancer Registries Cancer Surveillance System
OMB No. 0920-0469

Supporting Statement: Part B

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B. COLLECTION OF INFORMATION EMPLOYING STATISTICAL METHODS

B1. Respondent Universe and Sampling Methods

Cancer surveillance data is intended to be a complete assessment of all cancer cases diagnosed in a given time period in a given geographic area. This is referred to as population based.

Respondents are the 48 states and territories that currently receive CDC funds from the National Program of Cancer Registries. Central registries in the five states not supported by CDC report to the NCI SEER program and those data are combined with the NPCR data to provide National incidence rates. No statistical adjustments for sampling are made since sampling is not conducted. **Attachment 10** lists the number of cases each state reported to NPCR-CSS in each diagnosis year 1995-2009. Over 20 million incident cases of cancer for this time period were reported to CDC from 45 states and the District of Columbia.

B2. Procedures for the Collection of Information

State Level Procedures

NPCR-funded grantees collect and aggregate data for local public health purposes under the authority of state laws, which require reporting of cancer to the central cancer registry. As depicted in **Attachment 2**, the first step in cancer registration occurs when a physician makes a diagnosis of cancer. Once a definitive diagnosis has been established and treatment planned, the data are entered into a computer, usually with a commercial software package that includes quality control measures to assure high-quality data (step 2). Step 3 on the flow chart occurs when reporting facilities (hospitals, physicians' offices, radiation facilities, freestanding surgical centers, and pathology laboratories) perform additional quality control measures over and above what is performed at data entry. The data are sent to the central cancer registry (step 4). Quarterly submissions to the central registry are common, but larger facilities may report more often, and smaller facilities, less frequently.

After the central cancer registry receives the data, each incoming case must be checked against the existing database to ascertain if it is a new case or has been reported previously. At the same time, additional quality control measures are applied (step 5). Based on this processing, the central cancer registry may return data to the reporting facility for clarification (step 6). All central cancer registries must link state incidence data with state mortality data to obtain cases that are first diagnosed at death (death certificate only cases) and to update vital status information for existing cases. Central cancer registries are encouraged to link state incidence data with National mortality data for additional updated vital status information while the 10 ARRA-funded registries are required to do this linkage. In addition to work that is done within state boundaries,

central cancer registries are funded for inter-state data exchange to obtain cancer data on residents who travel to other states for diagnosis or treatment. Once quality control standards are met and the data are complete, they are ready for use and dissemination by the state and submission to CDC (steps 7 and 8). This standard process conducted by all central cancer registries usually takes 12 to 18 months after the close of the year in which the cancer is diagnosed.

Prior to reporting the data to CDC, central cancer registries run their data through a set of computerized edits. These data edits check the content of data fields against an encoded set of acceptable codes and provide feedback on the quality of the data. There are three types of edits: 1) single-field edits (edits that verify one data item at a time), 2) inter-field edits (edits that verify one data item and its relationship to other related data items), and 3) inter-record edits (edits that compare data recorded across more than one record and is used for patients with multiple tumors). In collaboration with other standard-setting organizations, CDC participates in a working group that modifies and reviews existing edits as well as creates new edits. As with NAACCR Standards for Cancer Registries, Volume II, these edits are continually updated.

Procedures for Reporting to CDC

The data items reported to CDC are based upon the North American Association of Central Cancer Registries (NAACCR) Standards for Cancer Registries, Volume II, which is a comprehensive reference to ensure uniform data collection, to reduce the need for redundant coding and data recording between agencies, and to facilitate the collection of comparable data among groups.

CDC is requesting that once a year, NPCR registries electronically report cumulative cancer data, which includes data from 1995 (for most registries) going forward. These data are considered final for reporting cancer statistics and are often referred to as *24-month data* since they are reported to CDC about 2 years after the year of diagnosis.

CDC requests to add a second electronic data report, considered preliminary, that would involve earlier reporting of the most recent year of data. This additional data submission would be 1 year of data only. These data are referred to as *12- month data* since they will be reported to CDC approximately 1 year after the end of the diagnosis year.

The variables to be reported to CDC do not vary between the preliminary and final data submissions. However, as part of each of these submissions, 38 registries will report the standard list of data items and 10 ARRA funded registries will report an enhanced set of data items, which includes variables that will support patient centered outcomes research.

Attachment 3a is a copy of the submission specifications that were sent to NPCR grantees in August 2012 providing instructions for the reporting of Final (24 month) cancer incidence data to CDC in November 2012. **Attachment 3a** also contains a list of data items for each of the two planned data submissions – preliminary and final. This

table is updated annually based upon any changes outlined in the NAACCR Standards for Cancer Registries, Volume II.

The 10 ARRA funded registries will report an enhanced set of data items during each data submission. **Attachment 3b** contains the list of variables to be reported by the 10 ARRA-funded registries. It includes the standard NPCR variables and the enhance variables that support PCOR.

CDC Data Aggregation and Dissemination

Once the data are reported to CDC, they are processed and data evaluation reports are generated as indicated in step nine on the flow chart. The data evaluation reports include the results of evaluating state data by the data standards for completeness of case ascertainment and data quality as adopted by NPCR for program goals and a report detailing the states' submission including details of edit errors. **Attachment 11** outlines the components of the data evaluation reports. In calendar year 2012, over 20 million incident cases of cancer for diagnosis years 1995-2009 were reported to CDC from 45 states and the District of Columbia.

When standards of completeness and quality have been met, CDC aggregates state data and make them available as pre-calculated rates on the Internet in a format that facilitates obtaining data by sex, race, age, and other common factors of interest**.** Any data published from NPCR CSS in surveillance reports, either in printed copy or on the Internet, are scrutinized to assure that the privacy of the individual is protected. Restricted-access data sets are available with appropriate processes in place to protect security (**Attachment 4**). Current users of the restricted-access NPCR CSS data must sign a data release agreement as outlined in a data release policy that is updated annually.

B3. Methods to Maximize Response Rates and Deal with Non response

CDC is requesting that each registry report data to CDC twice annually. The use of existing data standards and record layouts for electronic submission of data makes it easy for states to comply with the request. Many NPCR states voluntarily submit data to NAACCR and exchange data with neighboring states using these same standards and formats. There should be few technical difficulties for states in using these familiar processes. When a central cancer registry has difficulties due to issues such as software or hardware problems, technical assistance will be provided on a short-term and long-term basis. If necessary, short extensions will be provided to give the central registry additional time to report. The response rate in future years should be 100% or very near 100%.

In addition, to ease reporting, there are a number of other incentives for states to submit data. The incentives include an independent and detailed assessment of data quality and the recoding of important data items such as primary site and histology to national standards used for analysis. Evaluation of awardees has been based on progress toward meeting NPCR standards and not solely on achievement of program standards. In

addition, the inclusion of the data from their central registry in the United States Cancer Statistics is a point of pride and accomplishment for central registries. Central registries want their state represented in reports of Federal statistics and to be recognized as a high-quality registry.

B4. Test of Procedures or Methods to be Undertaken

The electronic reporting system has been in use since 2001. While small modifications have been made since that time, the system has worked well in the past. The plan is to continue to use the same reporting system in the future. Each year the system is tested and refined based on test data from previous years' submissions. States are not required to send additional data to test the system but a few may be asked to volunteer to do so.

B5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

A data contractor, ICF Macro, has been retained to assist with data management and analysis of NPCR CSS. The CDC unit, which manages the NPCR, has a surveillance research team of Masters and PhD level epidemiologists and a statistician to consult on statistical issues as well as cancer registry specialists, which consult on the reporting of data. The current Contracting Officer's Representative is Reda Wilson, Cancer Surveillance Branch, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, CDC.

REFERENCES

1 U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2009 Incidence and Mortality Web-based Report.* Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2013. Available at: www.cdc.gov/uscs.

2 National Heart, Lung, and Blood Institute. *NHLBI Fact Book, Fiscal Year 2008*. Bethesda (MD): National Heart, Lung, and Blood Institute; 2009.

3 Howlader N, Noone AM, Krapcho M, Neyman N, Aminou R, Altekruse SF, Kosary CL, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations), National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2009_pops09/, based on November 2011 SEER data submission, posted to the SEER web site, April 2012.

4 Curry SJ, Byers T, Hewitt M. *Fulfilling the Potential of Cancer Prevention and Control*. Washington (DC): The National Academies Press; 2003.

5 Haynes MA, Smedley BD. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Washington (DC): The National Academies Press; 1999.

6 Tucker TC, Howe HL, Weir HK. Certification of population-based cancer registries. *Journal of Registry Management* 1999; 26(1): 24-27.

7 North American Association of Central Cancer Registries (NAACCR). *Standards for Cancer Registries:* vol. III: *Standards for Completeness, Quality, Analysis and Management of Data*. Springfield (IL): NAACCR; 2000.

8 Menck HR, West DW. Central cancer registries. In: Hutchison CL, Roffers SD, Fritz AG. *Cancer Registry Management: Principles and Practice*. Lenexa (KS): National Cancer Registrars Association; 1997. p. 395-422.

9 Chronic Disease Committee, Council of State and Territorial Epidemiologists. Inclusion of Cancer Incidence and Mortality Indicators in the National Public Health Surveillance System (Position Statement #CD 4). June 1998.

10 Centers for Disease Control and Prevention. *CDC/ATSDR/CSTE Data Release Guidelines for Re-Release of State Data*. Atlanta: Centers for Disease Control and Prevention; 2003 (available upon request).

11 American Statistical Association. Privacy, Confidentiality, and Data Security Web Site. Alexandria, VA: American Statistical Association; 2005. Available at http://www.amstat.org/comm/cmtepc/index.cfm.

12 Doyle P, Lane JI, Theeuwes JM, Zayatz LM (eds). *Confidentiality, Disclosure, and Data Access: Theory and Practical Application for Statistical Agencies*. Amsterdam: Elsevier Science BV; 2001.

13 Federal Committee on Statistical Methodology. *Checklist on Disclosure Potential of Proposed Data Releases*. Available at http://www.fcsm.gov/committees/cdac/cdac.html.

14 Federal Committee on Statistical Methodology. *Report on Statistical Disclosure Limitation Methodology*. (*Statistical Working Paper* 22). Washington (DC): Office of Management and Budget; 1994. Available at http://www.fcsm.gov/working-papers/spwp22.html.

15 McLaughlin C. Confidentiality protection in publicly released central cancer registry data. *Journal of Registry Management* 2002; 29(3):84-88.
16 Stoto M. *Statistical Issues in Interactive Web-Based Public Health Data Dissemination Systems*. Draft report prepared for the National Association of Public Health Statistics and Information Systems, Rand Corporation; September 2002.
17 Havener, L and Thornton, M (editors). Standards for Cancer Registries, Vol II: Data Standards and Data Dictionary, 13th ed. Springfield, Ill: North American Association of Central for Cancer Registries; 2008.
18 North American Association of Central Cancer Registries. *Cancer in North America, 2000-2006:* volumes 1-3. Springfield (IL): North American Association of Central Cancer Registries; 2009. Available at : http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=50
19 National Center for Health Statistics. *NCHS Staff Manual on Confidentiality*. Hyattsville, MD: Centers for Disease Control and Prevention, National Center for Health Statistics; 1997.