

Information Collection Request

Revision

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

Supporting Statement: Part B

Program Official

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REFERENCES

ATTACHMENTS

- 1a Cancer Registries Amendment Act, Public Law 102-515
- 1b Section 301 of the Public Health Service Act [42 U.S.C. 242k]
- 2 Data Collection and Flow Process
- 3a Standard NPCR CSS Submission Specifications
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B. COLLECTION OF INFORMATION EMPLOYING STATISTICAL METHODS

B1. Respondent Universe and Sampling Methods

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. Data collection at the state level is population based and these data will be reported bi-annually to NPCR-CSS. All identified cancer cases are included without sampling.

B2. Procedures for the Collection of Information

NPCR registries have been submitting data to CDC since 2000. The data are submitted electronically in a standardized format established by the North American Association of Central Cancer Registries and used by all cancer registry systems in North America. Because the formats and definitions have been well established for many years, the electronic submission of de-identified data to CDC requires minimal effort by the NPCR CCR. The CCR need time to collect and reconcile records from a variety of sources so that each submission to CDC reflects cancers diagnosed or treated during the previous two to three years, plus any updates. An overview of the data collection and flow process is provided in **Attachment 2**.

In January of each year, NPCR-funded CCRs report preliminary data for the previous diagnosis year to CDC followed in November by updated data. A sub-set of ten NPCR registries were established previously as Specialized Registries and these registries submit an expanded set of data items during the November data submission on cancer treatment for breast, colon, and rectal cancers as well as Chronic Myeloid Leukemia diagnosed in 2011.

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.

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 is also requesting that NPCR registries submit preliminary data, that would involve earlier reporting of the most recent year of data. This additional data submission is one

year of data only. These data are referred to as *12-month data* since they are 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 submission, 38 registries will report the standard list of data items and 10 Specialized Registries will report an enhanced set of data items which includes variables that will support patient centered outcomes research.

The data items reported 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.

Attachment 3a is a copy of the submission specifications that were sent to NPCR grantees in August 2015 providing instructions for the reporting of Final (24 month) cancer incidence data to CDC in November 2015. **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 Specialized Registries will report an enhanced set of data items during each data submission. Not all of these additional variables are NAACCR variables. **Attachment 3b** is a copy of the document that contains a list of standard and enhanced data items that will be reported by the 10 Specialized Registries.

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.

Once the data are reported to CDC, they are processed and data evaluation reports are generated. 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.

When standards of completeness and quality have been met, CDC aggregates state data and make them available in non-confidential, 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 confidentiality of the individual is protected. Current users of the NPCR CSS data must sign a data release agreement as outlined in a data release policy that is updated annually. Restricted-access data sets are available with appropriate processes in place to protect confidentiality and security.

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. 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 of reporting, there are a number of other reasons for states to submit data. They receive 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 is 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.

The current procedures and system have never failed and have proven to be reliable.

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 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. In addition, an IT Team within the unit can assist with computer transmission or software issues. 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.

CDC works closely with the NCI SEER program on statistical methods and uses NCI developed software for incidence rate calculations and survival estimates (SEER STAT).

References:

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- 3 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.
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- 10 North American Association of Central Cancer Registries. *Cancer in North America, 2008-2012: volumes 1-3*. Springfield (IL): North American Association of Central Cancer Registries; 2009. <http://www.naacr.org/DataandPublications/CINAPubs.aspx>