Information Collection Request

National Program of Cancer Registries Cancer Surveillance System

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Supporting Statement B

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B. COLLECTION OF INFORMATION EMPLOYING STATISTICAL METHODS

B1. Respondent Universe and Sampling Methods

Respondents are the central cancer registries in 50 states and territories that currently receive CDC funds from the National Program of Cancer Registries (NPCR). Central cancer registries in the four states not supported by CDC report to the NCI SEER Program and those data are combined with NPCR data to provide national cancer incidence statistics. No statistical adjustments for sampling are made since sampling is not conducted. Data collection at the state level is population based and these data are reported biannually 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 (NAACCR) (www.naaccr.org) 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 NPCR central cancer registries. The central cancer registries 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 for older years. An overview of the data collection and flow process is provided in **Attachment 2**.

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

CDC is requesting that once a year, NPCR registries electronically report cumulative cancer data which includes data from the first funding year (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 involves 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 submission, 50 registries report the standard list of data items for the NPCR Cancer Surveillance System (NPCR CSS).

The data items reported are based upon the 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 2a, 2b, and 2c show the data items collected by NPCR awardees for reportable cancers diagnosed starting January 1, 2024, January 1, 2025, and January 1, 2026, respectively. These required status tables are updated annually based upon any changes outlined in the NAACCR Standards for Cancer Registries, Volume II.

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 agencies and 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 registry 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 registries' submission including details of edit errors.

When standards of completeness and quality are met for the NPCR-CSS final submission, CDC aggregates registry 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, geographic area, 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 use 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 requests 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 registries

to comply with the request. There should be few technical difficulties for registries in using these familiar processes. When a central cancer registry has difficulties due to issues such as software or hardware problems, technical assistance is provided on a short-term and long-term basis. If necessary, short extensions are provided to give the central cancer registry additional time to report.

In addition, to ease reporting, there are a number of other reasons for registries 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 cancer registry in the United States Cancer Statistics (https://www.cancer.gov/cancer/uscs) is a point of pride and accomplishment for central cancer registries. Central cancer registries want their state or territory 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. Registries are not required to send additional data to test the system but a few 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 is retained to assist with data management and analysis of NPCR CSS. The CDC unit managing 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 Mary Elizabeth O'Neil, 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) (https://seer.cancer.gov/seerstat).

References:

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6 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.

7 McLaughlin C. Confidentiality protection in publicly released central cancer registry data. *Journal of Registry Management* 2002; 29(3):84-88.

8 National Center for Health Statistics. *NCHS Staff Manual on Confidentiality*. Hyattsville, MD: Centers for Disease Control and Prevention, National Center for Health Statistics; 1997.

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.CINA Explorer: An interactive tool for quick access to key NAACCR cancer statistics based on the Cancer in North America (CiNA) dataset from the North American Association of Central Cancer Registries. Available at www.naaccr.org/interactive-data-on-line/. [Accessed on 2024 Jun 6].