

# **Workload Management Study of Central Cancer Registries**

## **Supporting Statement: Part A**

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## **Abstract**

The Centers for Disease Control and Prevention (CDC) administers the National Program of Cancer Registries (NPCR), which provides funding and technical assistance to central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Islands. CDC requests OMB approval for one year to collect information from NPCR-funded registries. Information collected through this new, one-time project will be used to support the development of workload and staffing standards. Guidelines will be developed to help central cancer registries determine how many staff are needed for surveillance, data enhancement, and data analysis activities, and to assess the true costs and benefits of providing an adequate level of staffing. Information will be collected electronically through a web-based Workload and Time Management (WLM) survey.

## **Section A: Justification**

### **A.1 Circumstances that Necessitate the Data Collection**

The National Program of Cancer Registries (NPCR) was established in 1992 to support the coordination of national statistics on cancer, including cancer trends and cancer patterns in various populations. Cancer surveillance information reported through the NPCR is used to monitor cancer trends over time; advance clinical and epidemiologic research; help set priorities for allocating health resources; and evaluate the effectiveness of cancer prevention and control programs. The NPCR is administered by the Centers for Disease Control and Prevention (CDC), which currently provides funding and technical support to central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Islands. Central cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths. Central registries employ a variety of methods to obtain information from medical facilities--including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories--and report selected variables to CDC (National Program of Cancer Registries: Cancer Surveillance System, OMB No. 0920-0469, exp. 11/30/2012). Participating registries vary in terms of their staffing and operational characteristics.

The first major workforce study of the cancer registry field in the United States was undertaken in 2004 by the Center for the Health Professions, University of California, San Francisco. Among the major findings of this 15-month study were that the field of cancer registry and the importance of cancer registry data are not well understood by healthcare administration, even in the arena of health information technology. Most key informants interviewed for the workforce study identified staffing shortages as a major impediment to meeting standards for data quality and timeliness. Informants consistently expressed a need for tools such as workload and staffing standards to help them advocate for more staff, both to improve working conditions and the quality and timeliness of their reporting. Development of workload and staffing standards for cancer registries was one of the key recommendations of the cancer registry workforce study.

CDC proposes to contribute further to the understanding of cancer registration by sponsoring a workload analysis study of NPCR-funded cancer registries which builds on prior research in the

field. Central cancer registries continue to report that they are chronically understaffed, and many registries are concerned about the impact of staff shortages on data quality standards. Staffing patterns are known to vary widely from registry to registry, and registries differ greatly in the volume of incidence cases that they process as well as their use of information technology. For example, we know that some cancer registrars tend to be engaged primarily in case abstracting and follow-up, while others tend to be engaged in quality assurance, data analysis, and administrative activities. Based on this finding, two broad categories of cancer registrars can be identified. A systematic analysis of time spent on various tasks could inform the process of staffing cancer registries and provide clearer guidelines for workload management, training, compensation, and the development of a career ladder for cancer registrars. Without adequate staffing, cancer registries will continue to have difficulty meeting cancer registry reporting requirements in a timely fashion, and the quality of national cancer data may be compromised.

CDC is authorized to conduct the information collection by the Public Health Service Act (**Attachment A**). OMB approval is requested for one year.

### Privacy Impact Assessment

#### *Overview of the Data Collection System*

Central cancer registries in 45 states and the District of Columbia will be asked to participate in a one-time study. Central cancer registries in territories will not be asked to participate in this data collection. A designated manager from each participating registry will submit a web-based Workload and Time Management (WLM) Survey to CDC (see **Attachment C-1**). Each registry's WLM survey will include general information about the registry as well as information compiled from Work Activities Journals maintained by the registry's registrars (see **Attachment D-1**). A Work Activities Journal will be completed by an average of eight registrars in each central registry. The Journals will only be used to inform completion of the WLM Survey. The individual Journals will not be submitted to CDC.

#### *Items of Information to be Collected*

Each registrar's Work Activities Journal will collect information about the number of hours and minutes dedicated over a one-week period to routine tasks in the areas of case finding, records abstraction, follow-up, and quality assurance. The Work Activities Journal will also be used to record the estimated number of hours and minutes dedicated to activities that occur less frequently than daily, but should be accounted for on a monthly or annual basis, such as auditing, database management, training, travel, and death clearances. No personal information in identifiable form (IIF) will be collected.

The WLM survey for each registry will be used to report information about registry characteristics, caseload size and composition, staffing, administration, reporting, procedures, data management and automation, and the registry manager's professional judgments about registry management and resources needed. The WLM survey will also be used to report aggregated information obtained by compiling all of the Work Activities Journals completed by each participating registrar in that registry. No personal IIF will be collected.

## *Identification of Website(s) and Website Content Directed at Children Under 13 Years of Age*

The WLM survey is a web-based survey. There is no website content directed at children under 13 years of age.

### **A.2 Purpose and Use of Information Collection**

Timely and accurate surveillance information about cancer is critical to the efforts of the CDC and other public health institutions to reduce cancer incidence and mortality and improve quality of life for cancer patients. Lack of understanding of cancer registry operations underlies a lack of support for meeting registry staffing needs. At present, there are no standards to help registry managers estimate the number of cancer registrars needed for a registry's workload, align tasks according to staff credentials, or design continuing education requirements for staff. The information to be collected through the WLM survey will be used to analyze the workload and staffing patterns of central cancer registries and their relationships to registry characteristics. The analysis will inform the development of workload and staffing standards for central cancer registries, which they believe will be of substantial benefit. Ultimately, the development of workload and staffing standards will contribute to more consistent position descriptions, more consistent training and preparation for those positions, more efficient use of limited resources, and improved timeliness and quality of cancer surveillance data. Finally, because the data elements for surveillance change over time in response to changes in cancer diagnosis and cancer care, the existence of task-specific workload and staffing standards will help registry managers anticipate the effects of changes to cancer surveillance data elements, and manage staff resources accordingly.

#### Privacy Impact Assessment Information

Cancer registries have asked for clear staffing guidelines based on registry characteristics such as size, degree of automation, and registry-specific reporting procedures.

The WLM survey includes basic questions about registry characteristics such as organizational affiliation and number of staff (full-time, part-time, permanent, contractors, etc.). The WLM also asks for information about the caseload for the registry (the number of new cancer cases reported annually), the sources of case information, whether case information is collected utilizing manual or electronic methods, and the type of software employed for electronic collection. Because many tasks can be performed manually or using electronic methods, and because cancer coding systems are frequently revised to reflect changes in cancer diagnosis and care, the WLM survey asks registry managers to identify training needs that would improve registry productivity, and to provide comments about other resource needs and management issues.

The WLM study is designed to produce quantitative estimates of the amount of staff time dedicated to specific, itemized tasks such as case finding, abstraction of records, follow-up, and quality assurance. However, for a variety of reasons, tasks may not be distributed evenly among registrars within a central registry. To obtain a more accurate profile of tasks and time commitments for each registry as a whole, information from multiple registrars will be collected

and reported in aggregate form. Completion of the WLM survey will include input from an average of eight registrars at each central registry.

The issues of appropriate credentials and continuing education for staff are critical concerns for cancer registries, since staff must be informed about changes in data management systems and information technology, as well changes in data items that reflect changes in cancer clinical care. The WLM survey thus includes questions about training needs for each registry.

### **A.3 Use of Improved Information Technology and Burden Reduction**

The WLM survey will be web-based. Measures we will take to ease the burden include providing a data collection sheet with guidance on how to define data items that are required as survey responses, and a glossary that defines the terms used in the survey. In addition, questions on the survey instrument include references to corresponding items on the data collection sheet, by row number. That is, the row numbers of items on the data collection sheet appear next to the relevant questions on the survey instrument, so that the survey respondent can easily locate the correct data and transfer it from the collection sheet to the survey instrument.

### **A.4 Efforts to Identify Duplication and Use of Similar Information**

NPCR registries participate in three ongoing information collections. Information about the incidence of cancer is collected under OMB No. 0920-0469, NPCR: Cancer Surveillance System (exp. 11/30/2012). Information necessary for progress reporting and monitoring is collected under OMB No. 0920-0706, the NPCR Program Evaluation Instrument (PEI, exp. 12/31/2011). Information necessary for conducting an economic analysis of the NPCR is collected under OMB No. 0920-0812, Economic Analysis of the NPCR (exp. 6/30/2012). The WLM study will not duplicate information collected through other NPCR-specific clearances. **Attachment E** provides an overview of the WLM and the PEI data collections.

Cancer surveillance in the United States is a collaborative effort involving the NPCR administered by HHS/CDC, the Surveillance, Epidemiology, and End Results (SEER) program administered by HHS/NIH/NCI, central registries, and professional associations such as the National Cancer Registrars Association (NCRA) and the North American Association of Central Cancer Registries (NAACCR). Representatives of these organizations and others participated in the Advisory Group for the WLM study, and confirmed that the WLM study does not duplicate their efforts. The NCRA produced a staffing and compensation manual in 2001, which was based on the percentage of time spent on various tasks as a measure of workload. This manual is now out of date. The WLM survey differs from the previous NCRA effort in that the WLM survey will provide actual measures of time dedicated to specific tasks.

### **A.5 Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this data collection.

## **A.6 Consequences of Collecting the Information Less Frequently**

There are no legal obstacles to reduce the burden. This is a one-time data collection. Without this data collection cancer registries will remain in a position of not having the tools to do effective analyses of their workload and staffing patterns, or to advocate for the funds to achieve adequate staffing. Thus, potential gains in quality and timeliness of our national cancer data that are the purpose of this study will be forgone.

## **A.7 Special Circumstances Relating to the Guidelines of 5 CFR 1320.5**

This request fully complies with the regulation by 5 CFR 1320.5.

## **A.8 Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency**

**A.** A 60-day Federal Register Notice was published in the *Federal Register* on May 26, 2010, vol. 75, No. 101, pp. 29550-29551 (**Attachment B**). CDC received one request for additional information, which was provided (see **Attachment B-2**).

**B.** Our project advisory committee and technical advisory committee have provided extensive external consultation. We have held more than 30 conference calls with the project advisory committee, and had a face-to-face meeting with the technical advisory committee. Additional meetings and conference calls are planned as the project progresses. A list of Advisory Committee members is included as **Attachment F**. A letter of support from the NAACR is included as **Attachment G**.

## **A.9 Explanation of Any Payment or Gift to Respondents**

There will be no remuneration for participating registries; however, cancer registrars may apply for Continuing Education credits through the National Cancer Registrars Association.

## **A.10 Assurance of Confidentiality Provided to Respondents**

- A.** Privacy Act Determination. This information collection request has been reviewed by staff in CDC's Information Collection Review Office, who determined that the Privacy Act does not apply. The information collected is not personal or sensitive in nature.
- B.** Safeguards. All data collected for this study will be treated in a secure manner and findings will be reported only in the aggregate. Respondents will not be identified by name, position, or employer in any study reports. Electronic datasets will be kept on password-protected computers and will be accessible only by project staff. If any respondents choose to submit completed hard copies of the survey instead of electronic responses, the hard copies will be stored in locked files that are only accessible to project staff.



- C. Consent. Written consent is not required for the WLM survey. Consent is implied by participation. This project has received IRB approval from the UCSF IRB (**Attachment H**). The UCSF human subject rights and confidentiality protocol will be posted on the survey website and acknowledgement of these will be required to access the survey itself.
- D. Nature of Response. Participation is entirely voluntary, as explained in the cover email (**Attachment C-2**).

### **A.11 Justification for Sensitive Questions**

Questions asked in this survey will pertain only to job activities in cancer registries. Some questions will be in reference to the registries themselves, and some will be in reference to the job activities of individual staff, but there will be no questions asked about sensitive issues pertaining to individual staff.

### **A.12 Estimates of Annualized Burden Hours**

Respondents are NPCR-funded central cancer registries in 45 states and the District of Columbia. The NPCR also funds two central cancer registries for Puerto Rico and the Pacific Islands, however, these registries will not be asked to participate in the WLM study. Because the territory-based central registries are relatively new and procedures are still being established, CDC wishes to minimize burden to these registries.

A designated manager at each participating registry will complete and submit one Workload and Time Management Survey (**Attachment C-1**) on behalf of the registry. The survey will involve a single data collection in a one year only, with an estimated burden per response of 4 hours. The Workload and Time Management (WLM) Survey includes (a) questions about overall characteristics of the registry, and (b) an aggregate summary of the number of personnel hours dedicated to specific tasks over a one-week period. Responses to the Workload and Time Management Survey will be submitted electronically through a web-based system. We estimate that 90-100% of the registries will participate on a voluntary basis. Potential respondents will be contacted once for data collection (**Attachment C-2**); non-responders will receive a follow-up email reminder (**Attachment C-3**). Registries that do not respond to the initial solicitation or the follow-up email will be contacted with a brief telephone reminder call (**Attachment C-4**) to encourage participation and determine the best method for reaching the appropriate manager.

In order to determine the aggregate number of personnel hours that each registry dedicates to specific tasks, each cancer registrar in a participating registry will be asked to maintain a paper-based Work Activities Journal (**Attachment D-1**) for a one-week period, utilizing instructions provided (**Attachment D-2**). The estimated burden per response is 2 hours (for the one-week data collection period). The Journal will not be submitted to CDC, but will be used by the registry manager to complete the WLM survey. At the end of the week, the registry manager will consolidate all information from the individual Work Activities Journals, and then submit the aggregate information through the Workload and Time Management Survey. Because each registry employs an average of 8 cancer registrars, we estimate that a total of 368 Work

Activities Journal worksheets (46 x 8) will be completed to support the Workload and Time Management Survey.

The total estimated burden to respondents is 921 hours.

**Table A.12.A Estimated Annualized Burden Hours**

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
NPCR Managers	Workload and Time Management Survey	46	1	4	184
	Telephone Reminder	15	1	3/60	1
NPCR Staff Registrars	Work Activities Journal	368	1	2	736
Total					921

Burden hours were estimated using feedback from our pretesting of this survey with 7 respondents.

For registry managers, the estimates of burden hours include time to explain the data collection to their cancer registrars, aggregate their time and task data, obtain their most recent annual report, and enter the data at the survey website. For cancer registrars, the estimates of burden hours include time to record their work activities for one week, and to complete the work activities journal.

**Table A.12.B Estimated Annualized Costs to Respondents**

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Total Burden (in hours)	Average Hourly Wage Rate	Total Cost
NPCR Managers	Workload and Time Management Survey	46	1	184	\$21.97	\$4,042
	Telephone Reminder	15	1	1	\$21.97	\$22
NPCR Staff Registrars	Work Activities Journal	368	1	736	\$21.97	\$16,170
Total						\$20,234

Cost to respondents was estimated using estimated burden hours and salary data about cancer registrars. In 2004, the median hourly wage for all cancer registrars, including those who

perform some management duties, was \$21.97.<sup>1</sup> The total estimated annualized cost to respondents is \$20,234.

### **A.13 Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers**

There will be no capital or start up costs for respondents because of this data collection. They will be provided with data collection forms and will need no special tools to measure the data they report.

### **A.14 Annualized Cost to the Government**

Total costs include the cost of CDC project oversight; contractual costs associated with data collection, management, and analysis; and costs of technical support. Overall project management will be provided by the Research Triangle Institute (RTI) (\$8,000). Data collection, processing and analysis will be conducted through a subcontract to the University of California San Francisco (UCSF) (\$38,179). The technical support contractor, the National Cancer Registrars Association (NCRA), is funded at an annual cost of \$3,821 to provide subject matter expertise on registry operations. CDC personnel costs are estimated at \$6,428 annually for 0.05 full time public health advisor who serves as the technical monitor for the project. The total estimated annualized cost to the Federal government is \$56,428. The following table summarizes the estimated Federal Government cost distribution.

Distribution of Estimated Annualized Cost to the Federal Government:

Cost Category	Annualized Cost
RTI project management and oversight contract	\$ 8,000
NCRA Technical Support Contractor	\$ 3,821
UCSF Data Mgmt. Contractor	\$38,179
CDC personnel	\$ 6,428
Total	\$56,428

### **A.15 Explanation for Program Changes or Adjustments**

This is a new, one-time data collection.

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<sup>1</sup> *Frontline Workers in Cancer Data Management: Workforce Analysis Study of the Cancer Registry Field: Final Report*; June 2006. National Cancer Registrars Association.

## **A.16 Plans for Tabulation and Publication and Project Time Schedule**

### **A.16.1 Project Time Schedule**

<b>Activity</b>	<b>Time Schedule</b>
Introductory e-mails sent to respondents	Immediately upon OMB approval
Field questionnaire	2-6 weeks after OMB approval
Follow up on non-responders	6-8 weeks after OMB approval
End survey/data collection	2-3 months after OMB approval
Validate data	3-4 months after OMB approval
Conduct analyses	4-8 months after OMB approval
Publication	8-16 months after OMB approval

### **A.17 Reason(s) Display of OMB Expiration Date is Inappropriate**

Display of OMB expiration date is appropriate.

### **A.18 Exceptions to Certification for Paperwork Reduction Act Submissions**

No exceptions to the certification are requested.