National Program of Cancer Registries (NPCR)
Program Evaluation Instrument (PEI)

OMB No. 0920-0706

Change Request to Conduct the
Workload Management Survey

Background and Justification

CDC currently supports the National Program of Cancer Registries (NPCR), a group of central cancer registries in 45 states, the District of Columbia, and 2 territories. The central cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths (National Cancer Program Registries: Cancer Surveillance Systems, OMB No. 0920-0469, exp. 1/31/2010). Program standards for the NPCR establish goals for data quality and include recommendations about staff training and credentials. CDC collects performance indicators for NPCR-funded registries through the web-based Program Evaluation Instrument (PEI) (OMB No. 0920-0706, exp. 12/31/2011). This information is used to evaluate the registries' use of funds, their progress toward meeting objectives, and their infrastructure and operational attributes.

Central cancer registries 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 number of incidence cases that they process as well as their use of information technology. Cancer registries have asked for clear staffing guidelines based on registry characteristics such as size (i.e., number of new cases annually), degree of automation, and registry-specific reporting procedures. At present, there are no standards to help 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 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.

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.

Items of Information to be Collected

CDC proposes to conduct a one-time survey to supplement information collected through the PEI. Although the PEI includes a limited number of questions about program staffing (the largest part of the program budget), the information is not sufficient to address the need for developing standards and guidelines. The information to be collected through the one-time, special-purpose survey will complement the PEI's routinely collected indicator information and will enhance planning for NPCR-funded registries as well as the evaluation of these programs.

The primary information collection instrument will be the Workload Management (WLM) Survey (**Attachment C-1**). Survey responses will be submitted to CDC electronically for analysis. A secondary data collection instrument, the Work Activities Journal (see **Attachments C-2a and C-2b**), will be used to support the primary survey, but will not be submitted to CDC. An overview of the PEI and the proposed Workload Management Survey is included as **Attachment C-3**.

Uses of the Information to be Collected

The information to be collected through the WLM survey will provide a baseline for qualified, credentialed registry staffing. The overall goal is to develop workload and staffing standards for NPCR-funded central cancer registries. Information collected through the WLM survey will enable CDC to assess the workforce necessary for meeting data reporting requirements and answer data requests that are based upon high quality, timely data. Specific guidance will be developed so that cancer registry managers can more effectively measure workload, evaluate the need for staff and staff credentials, and advocate for adequate staffing. The staffing guidelines will be organized in terms of registry characteristics and specific staff activities (eg, case abstraction, auditing, training). The guidelines can thus be used to help central cancer registries determine the appropriate level of staff for activities such as surveillance, data enhancement, and data analysis.

The results of the WLM survey will also help CDC make informed decisions about the future of the NPCR program by estimating the impact on NPCR staffing requirements of proposed changes to cancer surveillance data systems. Although cancer clinical care is constantly changing, significant changes to the NPCR's cancer surveillance data elements (OMB No. 0920-0469) are implemented only once every three years. This restriction on changes increases the efficiency of staff training programs and contains their costs. The next set of changes is being developed for implementation in 2010 and could involve more than 100 new data elements, as well as modifications to existing data elements. The results of the Workload Management Survey will help CDC personnel, as well as managers at NPCR-funded registries, predict the impact of these changes and plan effective staffing support for them. If the proposed changes would result in substantial burden on NPCR-funded registries, CDC might elect to increase the budget for staff, reduce the number of data changes, or identify (some or all of) the changes as voluntary enhancements rather than mandatory requirements.

The Workload Management Survey is a designed as a one-time, special purpose information collection. At this time, CDC plans to discontinue collection of the WLM data elements upon completion of the special-purpose survey, however, the WLM survey will help CDC and NPCR member registries determine whether additional studies might be useful in the future.

Consultation and Coordination

The Workload Management Survey was designed collaboratively with input from the affected parties, including NPCR staff at CDC, representatives from NPCR-funded state cancer registries, SEER, the National Cancer Registrars Association (NCRA), the North American Association of Central Cancer Registries (NAACCR), and experts at the University of California, San Francisco/Center for the Health Professions who have established expertise in the conduct of workload studies. The members of the project advisory committee are listed in **Attachment C-4**. Committee members have been consulted extensively during the development of the information collection plan and the instruments.

A letter of support from NAACCR, which includes and represents the NPCR-funded central cancer registries, is enclosed (**Attachment C-5**). The high degree of support demonstrates the need for the proposed information collection from the perspective of the registries who will serve as respondents for the proposed survey. Because NAACCR's members include additional population-based cancer registries in North America, NAACCR's support also demonstrates interest from the broader cancer surveillance community in the development of staffing standards.

On April 1 and 2, 2009, CDC participated in a meeting of the National Coordinating Council on Cancer Surveillance sponsored by the American Cancer Society (Atlanta, Georgia). Concern about adequate staffing for potential changes to cancer surveillance systems was expressed, along with support for the proposed WLM survey.

Contact: Lori Swain, Executive Director
National Cancer Registrars Association
(770) 299-6620 extension 313
lswain@ncra-usa.org

On April 15 and 16, 2009, CDC also discussed the proposed WLM survey with attendees at the NPCR Program Directors meeting in Atlanta, GA. Several of the Program Directors voiced support of this survey. The Director of the Indiana State Cancer Registry's opinion was typical of the comments. She stated, "I have reviewed the study and feel it would be of great benefit and value to undertake the work force study, which could be used by central cancer registries to justify current and future staffing needs."

Contact: Martha Graves, RHIA, CTR
Indiana State Central Registry
(317) 233-7424
Mgraves@isdh.IN.gov

Respondents

Participation in the Workload Management Survey is voluntary. Respondents will be the 45 state-based programs and the District of Columbia. At present, the two territories funded through the NPCR (Puerto Rico and the Pacific Islands Jurisdiction) are substantially different from the state-based programs (one is still in a planning phase, and does not yet report information through the PEI). For these reasons, the territories will not be asked to participate in the Workload Management Survey at this time.

The proposed information collection does not include five states whose cancer registry operations are funded by the Surveillance, Epidemiology, and End Results (SEER) program, a federal program of regional, state, and national cancer registries. SEER-funded central cancer registries do not submit information to CDC through the PEI. The information collection instruments for the Workload Management Survey will be made available to SEER, which participated in their development, for independent use at SEER's discretion. CDC welcomes the opportunity to share insights and results with SEER, but recognizes the limits to direct comparison of NPCR-funded registries and SEER-funded registries, due to differences in data definitions and data collection procedures.

Estimated Annualized Burden Hours

Respondents will be the 46 NPCR-funded cancer registries in 45 states and the District of Columbia. A designated manager at each registry will complete and submit one Workload Management Survey (**Attachment C-1**) on behalf of the registry. The Workload Management 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 Management Survey will be submitted electronically through a web-based system.

In order to determine the aggregate number of personnel hours that each registry dedicates to specific tasks, each cancer registrar will be asked to maintain a paper-based Work Activities Journal (**Attachments C-2a and C-2b**) for a one-week period. At the end of the week, the registry manager will consolidate the individual journal worksheets, and then submit the aggregate information through the Workload 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 Management Survey.

CDC and the NPCR-funded registries are the primary beneficiaries of the proposed information collection. We estimate that 90-100% of the registries will participate on a voluntary basis.

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
NPCR Registries	Workload Management Survey	46	1	4	184
	Work Activities Journal	368	1	2	736
	Total				920

Burden hours for each instrument were estimated using feedback from our pretesting of the instruments with 7 pre-testers. For registry managers, the burden estimate includes 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.

Estimated Annualized Cost to Respondents

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Hourly Wage	Total Burden (in hours)	Total Cost
NPCR Registries	Workload Management Survey	46	1	$21.97	184	$4,042
	Work Activities Journal	368	1	$21.97	736	$16,170
					Total	$20,212

Information Collection Plan

The WLM survey will be conducted during the summer of 2009 and data analysis will be conducted during the fall of 2009. Each registry will receive an invitation to participate via email (**Attachment C-6**). Registries that do not respond will receive an email reminder (**Attachment C-7**) followed by a telephone reminder (**Attachment C-8**) to encourage participation.

Project Time Schedule

Activity	**Time Schedule**
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

Information collection will be conducted by the Center for the Health Professions, University of California, San Francisco. A list of experts at UCSF is included as **Attachment C-9**. The WLM survey has been approved by UCSF's IRB (**Attachment C-10**). The cost of the data collection contract is $50,000.

CDC Contacts for the PEI:	Division of Cancer Prevention and Control	
	Jean Ewing, MSW, MS Hyg	Telephone 770-488-1062 Email Jean.Ewing@cdc.hhs.gov
	Reda Wilson, MPH, RHIT, CTR	Telephone 770-488-3245 Email Reda.Wilson@cdc.hhs.gov
CDC Contact for WLM:	Division of Cancer Prevention and Control	
	Linda Mulvihill, RHIT, CTR	Telephone 770-488-3246 Email Linda.Mulvihill@cdc.hhs.gov

List of Attachments

C-1. Workload Management Survey
C-2a. Work Activities Journal
C-2b. Work Activities Journal Instructions
C-3. Overview of PEI Elements and WLM Elements
C-4. WLM Project Advisory Committee
C-5. Letter of Support from NAACCR
C-6. Invitation to Participate
C-7. Follow-up Email for Non-Respondents
C-8. Follow-up Telephone Reminder for Non-Respondents
C-9. UCSF Data Collection Team
C-10. UCSF IRB Approval Letter