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

(OMB No. 0920-0706)

Request for OMB Approval

Supporting Statement Part A

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National Program of Cancer Registries
Program Evaluation Instrument

This is a revision request for a clearance period of three years. During this period CDC plans to change the data collection frequency from annual to every other year with data collection to occur in odd-numbered years. The project title and the instrument will be modified to reflect the change in data collection frequency (from National Program of Cancer Registries Annual Program Evaluation Instrument (NPCR-APEI) to National Program of Cancer Registries Program Evaluation Instrument (NPCR-PEI)). The current approval expires 12/31/2008.

A. JUSTIFICATION

A1. Circumstances Making the Collection of Information Necessary

The Centers for Disease Control and Prevention (CDC) is requesting OMB approval for a revision request for the National Program of Cancer Registries – Annual Program Evaluation Instrument (NPCR-APEI) **(Attachment 3A)**. This request is to continue the current NPCR-APEI process, change the frequency of data collection, and change the project title to the National Program of Cancer Registries – Program Evaluation Instrument (NPCR-PEI) which will reflect the change in the frequency. A total of 45 states, the District of Columbia, 2 Territories, and the Pacific Island Jurisdictions' unified Central Cancer Registry (CCR) are currently funded by NPCR to assist with the operation of central cancer registries that collect and report cancer incidence data to CDC.

Cancer is a substantial public health burden. In 2007, the American Cancer Society (ACS) estimated that more than 1.4 million Americans will be diagnosed with cancer and approximately 560,000 will die of the disease, more than 1,500 each day[1]. It is estimated that 10.5 million Americans are currently alive with a history of cancer[1]. The National Institutes of Health estimates the overall cost of cancer in 2006 at more than $200 billion including direct costs to treat cancer ($93 billion) and indirect costs in lost productivity due to illness and premature death ($135 billion)[2].

Central Cancer Registries (CCRs) information is required to support cancer prevention and control. Within CDC, the Division of Cancer Prevention and Control (DCPC) plans, directs, and supports cancer control efforts through collaboration with

prevention partners in state health agencies, federal agencies, academic institutions, and with national, voluntary, and private-sector organizations. To obtain a firm basis for such programs, central cancer registries are needed to ensure that high-quality and timely cancer surveillance data are available.

Recognizing the public health value of comprehensive cancer surveillance at the state and national level, Congress mandated the National Program of Cancer Registries (NPCR) in 1992 by enacting the Cancer Registries Amendment Act, Public Law 102-515, and further authorizing NPCR and the data collection for this project in Section 301 of the Public Health Service Act [42 U.S.C. 241] **(Attachment 1)**. This legislation authorizes the CDC to provide funds to states and territories to: 1) improve existing cancer registries; 2) plan and implement registries where none existed; 3) develop model legislation and regulations for states to enhance the viability of registry operations; 4) set standards for data completeness, timeliness, and quality; 5) provide training for registry personnel; and 6) help establish a computerized reporting and data-processing system.

A2. Purpose and Use of Information Collection

The NPCR-PEI is designed to evaluate NPCR-funded registries' use of funds, progress towards meeting program goals and objectives, operational attributes, and computer infrastructure; to collect information about advanced activities (e.g., data linkages, geographic information system usage, collection of additional data items); and to highlight ways registry data is used.

Specific knowledge about operational activities in which NPCR registries are engaged, their use of requested funds, and CDC-recommended activities in which the registries report are not involved, and `are all examples of NPCR-PEI data used to examine NPCR registry operations and their success. The NPCR-PEI data are a complement to existing mechanisms that evaluate the completeness, timeliness, and quality of population-based central cancer registry (CCR) data. CDC encourages CCRs to continue increasing the ways their data is used.

As authorized under the Public Health Service Act, and its subsequent amendments, CDC established standards to indicate the optimum achievement of specific functions and/or activities to be carried out by the CCR. The purposes of these standards are to guide priorities and activities of funded programs, provide objective measures of program progress, and to improve program processes that ultimately affect outcomes. NPCR Program

Standards set measurable outcomes for CCR legislative authority, program administration, electronic data exchange, data content and format, data completeness, timeliness, and quality, data use, and collaborative relationships **(Attachment 7)**.

To assist NPCR in their determination of funded CCRs' progress towards established program standards, the NPCR-PEI is designed to collect information from the following categories of registry operations: 1) staffing, 2) legislation, 3) administration, 4) reporting completeness, 5) data exchange, 6) data content and format, 7) data quality assurance, 8) data use, 9) collaborative relationships, 10) advanced activities, 11) "success stories" that summarize ways in which CCR data are used, and 12) survey feedback.

Examples of information that can be obtained from various questions include, but are not limited to: 1) number of filled staff full-time positions by position responsibility (e.g., CTR Quality Control, CTR Education/Training, Epidemiologist); 2) legislation protecting the confidentiality of CCR data; 3) various data quality control activities; 4) data collection activities as they relate to achieving NPCR program standards for data completeness; 5) whether or not registry data is being used for comprehensive cancer control programs, needs assessment/program planning, clinical studies, or incidence and mortality estimates.

In the National Cancer Prevention and Control funding announcement (CDC announcement #CDC-RFA-DP07-703), grantees are required to complete and submit an annual program evaluation to CDC. In lieu of this annual evaluation, it is intended that once every other year, occurring in odd years, NPCR will deploy the web-based NPCR-PEI for approximately a 4-6 week period at which time grantees will complete the instrument. Each grantee will receive an electronic letter providing information about the procedures for accessing the NPCR-PEI, obtaining technical assistance (**Attachment 3B**), and regarding secure PEI login information (**Attachment 3C**). For years in which the NPCR-PEI is not deployed, a secure web-based data aggregation display system will be deployed to display national results from the previous year's instrument (**Attachment 4**).

In order to continue the current program evaluation process, a contractor, ORC Macro International, Inc. (Macro), will be retained to administer the web-based NPCR-PEI and respond to web-based technical assistance requests by the CCRs. Based on NPCR-PEI submissions, standardized descriptive reports will be

generated by Macro for the CCRs and the CDC. These reports will allow the program to monitor and evaluate the grantees' performance with NPCR program standards and with various attributes of registry operations. NPCR-PEI data will be used by CDC for program planning and improvement and monitoring NPCR's progress toward meeting its own goals and objectives. CDC will provide regular feedback to grantees based on their NPCR-PEI responses, tailoring technical assistance as indicated.

CDC sponsors and supports a wide variety of public health programs in the U.S. designed to monitor and reduce morbidity and mortality from cancer, such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) (Minimum Data Elements for the NBCCEDP are collected under OMB Control No. 0920-0571, exp. 1/31/2010), the National Colorectal Cancer Roundtable, prostate cancer control initiatives, and skin cancer prevention and education initiatives. Increasingly, there is Congressional and public demand for federal agency documentation and accountability of achievement of program objectives and outcomes (e.g., the Government Performance and Results Act of 1993).

NPCR cancer registry operations information collected by the NPCR-PEI is essential to identify areas in which registries may benefit from education and training, technical assistance, and other resources, as well as to evaluate the status of other activities in which the CCRs are involved (e.g., independent and collaborative research, improvements in electronic reporting), and to effectively assist the CCRs with the implementation of changes in the NPCR.

A3. Use of Improved Information Technology and Burden Reduction

The NPCR-PEI is made available to the CCRs on the internet as a user-friendly, web-based instrument. The web-based system facilitates data entry by allowing grantees secure access to the system at any location with an internet connection. Each CCR Program Director is provided a secure login and a secure archive location for their data. The system eliminates software installation and upgrades by respondents, as the questions are formatted so that only 7 of the 62 questions are open-ended and require a text response. The NPCR-PEI allows electronic transmission of the data, an efficient mechanism that minimizes the reporting burden on the states.

To further reduce the burden on CCRs, during the last clearance process, CDC deleted questions from the NPCR-PEI for which

information may be available from other structures. Questions were modified to simplify the required responses, and a small number of questions were added to more easily evaluate all NPCR Program Standards.

A4. Efforts to Identify Duplication and Use of Similar Information

No other program evaluation of NPCR registry operations and data use is currently performed. The NPCR-PEI data collection is unique to national cancer surveillance in providing a national data set that assists the CDC in evaluating the NPCR, implementing improvements and increasing efficiency of cancer registry operations, and complements the existing NPCR-Cancer Surveillance System (NPCR-CSS) (OMB no. 0920-0469, exp. 1/31/2010) activity by evaluating attributes that are not otherwise evaluated. Although the NPCR-PEI places some burden on the CCRs, it also is poised to serve as a program evaluation tool for the CCRs. CCRs usually do not have the means or expertise to evaluate their own programs, and thus are not able to supply CDC with an evaluation of their cancer registry operations.

A5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved.

A6. Consequences of Collecting the Information Less Frequently

The NPCR-PEI will occur biennially to complement the CCRs' NPCR-CSS data submission. The ability of CDC to monitor and improve NPCR's program effectiveness would be compromised if data were collected less frequently because procedures for the collection of cancer data by national standard setters changes frequently. It is essential that CDC evaluate NPCR-funded programs on a regular basis to assess progress towards meeting changing cancer registry data collection standards, to continue to assist the CCRs with their operational needs, and to continue efforts to maximize CCR efficiency. It is also important to provide program information on the NPCR to CDC officials, Congress, constituents, and other Federal, State, and local agencies.

There are no legal obstacles to reduce the burden.

A7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances contained within this application.

A8. 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 June 23, 2008, Vol. 73, No. 121, pp. 35391 **(Attachment 2).** No public comments were received.

B. The Division of Cancer Prevention and Control (DCPC) consulted with staff at Macro regarding various components of the NPCR-PEI. Macro provided consultation regarding implementation and testing of the NPCR-PEI web-based system, and all processes involved in receiving, processing, evaluating, aggregating, and disseminating data from the NPCR-PEI. A list of Macro staff consulted by DCPC is provided in **Attachment 5**.

In addition to consultation with Macro, NPCR program evaluation staff members participated in national conferences, trainings, seminars, and evaluation forums for program evaluation professionals. These activities provided an extended forum for the direct discussion of program evaluation issues and an opportunity for the CDC to engage in consultation with other program evaluation professionals. The meetings and trainings have also provided excellent networking opportunities for NPCR-PEI key staff to share their experiences and ideas.

The CDC maintains a regular forum to discuss and evaluate the NPCR-PEI with funded programs. This mechanism allows input from funded programs to determine the questions appropriate for this type evaluation.

A9. Explanation of Any Payment of Gift to Respondents

No payment or gifts will be made to respondents (grantees) to complete the web-based NPCR-PEI and submit responses to CDC.

A10. Assurance of Confidentiality Provided to Respondents

Staff in the CDC Information Collection Request Office have reviewed this request and have determined that the Privacy Act is not applicable. Respondents are institutional awardees (central cancer registries), not individuals. The information collected pertains to each cancer registry’s activities and attributes.

Protecting privacy is of paramount concern to the NPCR. No data is collected that has the potential for direct or deductive identification of an individual respondent (name, social security number, date of birth, or street address), or geographic location (e.g., county, census tract, zip code) of an individual respondent.

Data will be maintained in a secure location on a dedicated server at Macro for a period of 5 years. The server resides on Macro's local area network (LAN) behind the firewall. Access to the NPCR-PEI server is limited to authorized Macro staff and is password protected on its own security domain. After the first five (5) years, CDC will assume responsibility of maintaining the server and the data will reside on CDC's LAN. Authorized CDC staff will have access to the password protected data.

NPCR-PEI data are submitted electronically to a document server behind Macro's firewall. The data are moved automatically from the document server to the NPCR-PEI server. Each CCR has its own directory location so no CCR has access to another CCR's data.

A11. Justification for Sensitive Questions

No information of a sensitive nature such as race/ethnicity, religious beliefs, or sexual preference will be reported to CDC. Data on race/ethnicity is not needed because respondents are institutions (central cancer registries) and not individuals.

A12. Estimates of Annualized Burden Hours and Costs

A12A. These data are either already collected by or are readily available to the respondents (Central Cancer Registries (CCRs) funded by the National Program of Cancer Registries, n=49). Thus, the only burden on the CCRs involves the time it takes to enter responses on the web-based NPCR-PEI every other year. **Attachment 3A** represents the web-based data collection instrument, which will be updated with the new expiration date upon receipt of OMB approval. Respondents receive an announcement concerning data collection via letter (see **Attachment 3B**). Instructions to respondents are provided in **Attachment 3C**.

The burden estimate for completing the NPCR-PEI was determined in consultation with 3 potential respondents (see **Attachment 6**), who estimated burden ranging from 1 to 2 hours. Their experience served as the basis for the average burden estimate of 1.5 hours per respondent. The burden to respondents should not increase from year to year, and may even decrease as technological

advances are implemented in deployment of the NPCR-PEI. Table 12-A appears to indicate a decrease in the number of respondents. This is due to annualization of responses over the requested three-year clearance period. Data collection will actually occur in 2 of the 3 years approved for this project, 2009 and 2011. This translates into 98 total respondents, combining years 1 (2009) and 3 (2011) (49 respondents/year*2 years), divided by the 3 year period (98/3). In year 2 (2010), respondents will receive an analysis and display of results.

Table 12-A. Estimated Annualized Burden Hours.

Type of Respondents	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
NPCR Grantees	33	1	90/60	50

A12B. The total annualized cost to respondents is estimated to be $1,485. NPCR Program Directors respond on behalf of their cancer registries. Utilizing information from NPCR Continuation Applications, the hourly wage rate was determined for each central cancer registry Program Director funded by NPCR. Due to the wide variation in salaries, the median wage was determined rather than the average, and represents the hourly wage rate shown in Table 12-B.

Table 12-B. Annualized Cost to Respondents.

Type of Respondents	Number of Respondents	Number of Responses per Respondent	Average Burden per Response	Average Hourly Wage Rate	Total Cost
Program Directors for NPCR Grantees	33	1	90/60	$30	$1,485

Source: CDC-RFA-DP07-703 Funding Applications

A13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers

No additional computer hardware or software other than that which is already available to the CCRs (grantees) is needed to enter

responses on the web-based NPCR-PEI, hence no capital or maintenance costs are anticipated.

A14. Annualized Cost to the Government

The estimated annual cost for the contractor for consultation services, technical assistance, and hosting of the NPCR-PEI web application and database is $26,166 per year. The contractor costs are estimated as follows: hourly wage for project staff, approximately 200 hours, average of $42/hour for a total of approximately $8,400; fringe benefits (34% of total wages) for a total of approximately $2,856; labor overhead (38% of total wages) of approximately $3,192; approximately $4,000 in supplies; $2,000 for travel; facilities and administration at 15% for an approximate total of $3,220; miscellaneous $1,017, and fee at 6% for an approximate total of $1,481.

Additional annual costs include personnel costs for federal employees involved in oversight and analysis. The annual staff cost is estimated at $23,000 (25% of a GS-13 public health advisor FTE).

Table A14. Estimated Annualized Cost to the Federal Government.

Contractor	

A15. Explanation for Program Changes or Adjustments

The annualized burden hour estimate during the previous approval period was 74 hours. This estimate was based on an annual data collection schedule (49 respondents * 90/60 minutes per response = 74 hours).

During the next three-year clearance period, the frequency of data collection will change from annual to every other year. Respondents will submit information to CDC in 2009 and 2011, but will not submit information in 2010.

This translates into 98 total respondents, combining years 1 (2009) and 3 (2011) (49 respondents per year*2 years), divided by the 3 year period (98/3 = 33 annualized respondents per year).

The result is a decrease in annualized burden from 74 hours to 50 hours (a net difference of 24 hours).

A16. Plans for Tabulation and Publication and Project Time Schedule

CDC requests a 3-year clearance for the proposed program evaluation instrument. Responses to the evaluation instrument will be received every other year from grantees. The same procedure for completing the instrument and submitting response data will be repeated for each deployment. Transmitted data reflect the CCRs' status at the point in time as of June 30 each year, and this information is transmitted to CDC approximately 60 days later. The schedule for 2009 (Table 16) is anticipated to be:

Table A16. Time Schedule for Instrument Availability, Responding to the Instrument, Generating Data Files, and Creating Descriptive Reports.

Descriptive Reports and data display made available to grantees	

A17. Reason(s) Display of OMB Expiration Date is Inappropriate

There is no request for a date display exemption.

A18. Exception to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.

References

1 American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta (GA): American Cancer Society; 2007.

2 National Heart, Lung, and Blood Institute (NHLBI). *Fact Book, Fiscal Year 2007*. Bethesda (MD): NHLBI; 2007.