

Cancer Survivorship Needs Assessment for the National Comprehensive Cancer Control Program Grantees

OSTLTS Generic Information Collection Request
OMB No. 0920-0879

Supporting Statement – Section A

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Table of Contents

Table of Contents.....	2
Section A – Justification.....	3
1. Circumstances Making the Collection of Information Necessary.....	3
2. Purpose and Use of the Information Collection.....	7
3. Use of Improved Information Technology and Burden Reduction.....	7
4. Efforts to Identify Duplication and Use of Similar Information.....	8
5. Impact on Small Businesses or Other Small Entities.....	8
6. Consequences of Collecting the Information Less Frequently.....	9
7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5.....	9
8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency.....	9
9. Explanation of Any Payment or Gift to Respondents.....	9
10. Protection of the Privacy and Confidentiality of Information Provided by Respondents.....	9
This information collection is not research involving human subjects.....	10
11. Institutional Review Board (IRB) and Justification for Sensitive Questions.....	10
12. Estimates of Annualized Burden Hours and Costs.....	10
13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers.....	11
14. Annualized Cost to the Government.....	11
15. Explanation for Program Changes or Adjustments.....	11
16. Plans for Tabulation and Publication and Project Time Schedule.....	11
17. Reason(s) Display of OMB Expiration Date is Inappropriate.....	12
18. Exceptions to Certification for Paperwork Reduction Act Submissions.....	12
LIST OF ATTACHMENTS – Section A.....	12

- **Goal of the study:** Assess the cancer survivorship needs of comprehensive cancer control (CCC) program grantees, and to identify the types of activities, resources, and materials that could help the CCC programs address those needs. In addition, this study will assess how the activities undertaken and materials produced by the National Cancer Survivorship Resource Center (NCSRC) have met the survivorship needs of CCC programs.
- **Intended use of the resulting data:** The data will support the Centers for Disease Control and Prevention's (CDC) efforts to ensure that cancer survivors' public health needs are being met, and will inform future survivorship technical assistance and resources provided to CCC programs.
- **Methods to be used to collect data:** Web-based information collection instrument, and telephone-based focus groups.

Section A – Justification

1. Circumstances Making the Collection of Information Necessary

Background

This information collection is being conducted using the Generic Information Collection mechanism of the OSTLTS OMB Clearance Center (O2C2) – OMB No. 0920-0879. The respondent universe for this information collection aligns with that of the O2C2. Data will be collected from 65 cancer prevention and control program directors, acting in their official capacities within state (n=51, including District of Columbia), tribal (n=7), and territorial (n=7) health departments funded by the Centers for Disease Control and Prevention (CDC) through the National Comprehensive Cancer Control Program (NCCCP). The 7 funded tribal health departments include: Alaska Native Tribal Health Consortium; Cherokee Nation; Fond du Lac Reservation; Great Plains Tribal Chairmen's Health Board; Northwest Portland Area Indian Health Board; South Puget Intertribal Planning Agency; Tohono O'Odham Nation. The 7 funded territorial health departments include: American Samoa; Commonwealth of Northern Mariana Islands; Federated States of Micronesia; Guam; Republic of the Marshall Islands; Republic of Palau; Puerto Rico.

This information collection is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241). This information collection falls under the essential public health service(s) of:

- 1. Monitoring health status to identify community health problems
- 2. Diagnosing and investigating health problems and health hazards in the community
- 3. Informing, educating, and empowering people about health issues
- 4. Mobilizing community partnerships to identify and solve health problems
- 5. Development of policies and plans that support individual and community health efforts
- 6. Enforcement of laws and regulations that protect health and ensure safety
- 7. Linking people to needed personal health services and assure the provision of health care when otherwise unavailable
- 8. Assuring a competent public health and personal health care workforce
- 9. Evaluating effectiveness, accessibility, and quality of personal and population-based health services
- 10. Research for new insights and innovative solutions to health problems ¹

Addressing the public health needs of cancer survivors is a priority issue for CDC's Division of Cancer Prevention and Control (DCPC), and one of the six priorities of the National Comprehensive Cancer Control Program (NCCCP)¹. A cancer survivor is a person diagnosed with cancer, from the time of diagnosis throughout the person's lifespan.² Due to the aging U.S. population and improvements in cancer care, the number of cancer survivors has steadily increased during the last 3 decades.³ Nearly 14 million American have been diagnosed with cancer, and the number is expected to increase.⁴ Cancer survivors have long-term adverse physical and psychosocial effects from their diagnosis and treatment, and have a greater risk for additional cancer diagnoses compared with persons without a cancer history.⁵ Cessation of tobacco use, regular physical activity, maintenance of a healthy weight, and routine consultation with health-care providers about follow-up care after a cancer diagnosis (i.e., survivorship care plans) are all evidence-based ways that help improve quality of life following a diagnosis, prevent new cancers or cancer recurrence, and increase survival.⁶

In 2010, DCPC funded the development of a National Cancer Survivorship Resource Center (NCSRC) to support the development, implementation, and evaluation of strategies outlined in the National Action Plan for Cancer Survivorship: Advancing Public Health Strategies.⁷ The National Action Plan charts a course for how the public health community can address cancer survivorship more effectively and comprehensively and focus on improving the quality of life for survivors. The National Action Plan identifies and prioritizes cancer survivorship needs, and proposes strategies for addressing those needs within four core public health components: (1) surveillance and applied research; (2) communication, education, and training; (3) programs, policies, and infrastructure; and (4) access to quality care and services. Among its many activities, the NCSRC was funded to assist NCCCP grantees with addressing the public health needs of cancer survivors in their jurisdictions.

The National Cancer Survivorship Resource Center (NCSRC) is a collaboration between the American Cancer Society, the George Washington University Cancer Institute, and CDC to shape the future of cancer survivorship care and improve the quality of life of cancer survivors. Starting in 2010, the current NCSRC was funded through a 5-year cooperative agreement with CDC to support

the development, implementation, and evaluation of strategies outlined in the National Action Plan for Cancer Survivorship. The NCSRC has developed resources, materials, and tools for three targeted audiences: health care professionals; cancer survivors and their caregivers; and the policy and advocacy community.

The purpose of this information collection is to assess the cancer survivorship needs of comprehensive cancer control (CCC) programs, and to identify the types of activities, resources, and materials that could help the CCC programs address those needs. In addition, this information collection will assess how the activities undertaken and materials produced by the National Cancer Survivorship Resource Center (NCSRC) have met the survivorship needs of CCC programs. Information collected will be used to ensure that cancer survivors' public health needs are being met, and will inform future survivorship technical assistance and resources provided to CCC programs.

Overview of the Information Collection System

Information will be collected from a total of 65 state, tribal and territorial cancer prevention and control program directors (50 states, District of Columbia, 7 tribes/tribal organization, and 7 U.S. affiliated territories/Pacific Islands).

CDC is partnering with Battelle – an independent, non-profit research organization – to conduct this information collection. Battelle is responsible for developing the information collection instruments, data collection, and preparing and delivering data files to CDC. The Battelle team includes a cancer survivorship subject matter expert from the University of North Carolina, Dr. Sarah Birken, who provided consultation on the development of the information collection instruments. The CDC is responsible for contributing to the development of the information collection forms, and analyzing and interpreting the collected data.

Information will be collected via two methods: a web-based assessment and telephone focus groups. Data will be collected using two methods to give the CDC a comprehensive needs assessment, and to ensure that the different methods offer unique but complementary data about the cancer survivorship needs among NCCCP grantees. The web-based information collection instrument (see **Attachment A—Cancer Survivorship Needs Assessment Instrument: Word version** and **Attachment B—Cancer Survivorship Needs Assessment Instrument: Web version**), programmed using Survey Monkey, will allow respondents to complete and submit their responses electronically and at their own convenience. This instrument will be used to gather information from CCC program directors (or their designees) regarding NCCCP grantees' current and future needs for resources that support survivorship programs, as well as their use and satisfaction with existing NCSRC resources and materials. The web-based instrument was pilot tested by 4 public health professionals. Feedback from these individuals was used to refine questions as needed and establish the estimated time required to complete the instrument.

The telephone focus groups will be conducted with a sample of CCC program directors who participated in the web-based information collection. Battelle will conduct three focus groups (see

Attachment C—Telephone Focus Group Interview Guide: Health Care Professional Audience; Attachment D—Telephone Focus Group Interview Guide: Cancer Survivor and Caregiver Audience; and Attachment E—Telephone Focus Group Interview Guide: Policy and Advocacy Audience). Participants will be assigned to a specific focus group based on how they report using NCSRC materials and for which audience (specifically: health care professionals, cancer survivors and caregivers, and policy and advocacy). As is common within focus group design, grouping participants homogeneously often encourages rich yet focused discussion. Such was considered when designing this portion of this study.

Overall, the purpose of the focus groups will be to gather more in-depth qualitative information and feedback on the existing NCSRC resources, and recommendations for improving and/or adding to existing resources. All focus groups will be limited to no more than 90 minutes in order to minimize respondent burden.

Focus groups will be recorded in order to capture the conversation accurately. Verbal permission will be obtained from the participants prior to the beginning of the focus group. The focus group interview guides were pilot tested using one of the three interview guides: Attachment D—Telephone Focus Group Interview Guide Cancer Survivor and Caregiver Audience. One focus group was conducted with 6 public health professionals. Feedback from these individuals was used to refine questions on all three interview guides and establish the estimated time required to complete the interview guide. While there are minor differences between the three focus group interview guides, the number of questions and type of questions are similar.

Items of Information to be Collected

The web-based information collection instrument (see **Attachment A—Cancer Survivorship Needs Assessment Instrument: Word version** and **Attachment B—Cancer Survivorship Needs Assessment Instrument: Web version**) consists of a total of 133 questions (the maximum number possible). The instrument contains skip logic, therefore not all respondents will answer all 133 questions. The web-based information collection instrument contains questions of various types, including multiple response, interval (rating scales), and open-ended. An effort was made to limit questions requiring narrative responses and skip patterns were incorporated to allow for streamlining responses reducing the burden on respondents.

The instrument will collect information on the following:

- Respondent demographic information – including program position or title and length of time working with the programs – for the purposes of controlling for respondents’ programmatic history and knowledge during data analyses
- Audience-specific needs for cancer survivorship resources
- Current awareness and use of NCSRC resources
- Degree to which NCSRC resources are perceived as appropriate, useful, and credible
- Suggestions for improvements and expansion of survivorship resources, and for improving dissemination of the resources to audiences and stakeholders

For the telephone focus groups, there are three separate focus group interview guides (see **Attachment C—Telephone Focus Group Interview Guide: Health Care Professional Audience**; **Attachment D—Telephone Focus Group Interview Guide: Cancer Survivor and Caregiver Audience**; and **Attachment E—Telephone Focus Group Interview Guide: Policy and Advocacy Audience**). Each focus group guide is similar, yet tailored to the specific audience who will participate: health care professionals (14 questions total), cancer survivors and caregivers (14 questions total), and policy and advocacy groups (15 questions total). Similar open-ended questions will be asked during each focus group on the following:

- Current and emerging cancer survivorship needs
- Suggestions for improving communication about and dissemination of the resources
- Feedback on NCSRC resources
- Suggestions for improvements to existing resources
- Recommendations for new resources to address unmet needs
- Final comments/feedback participants would like to share

2. Purpose and Use of the Information Collection

The purpose of this information collection is to assess the cancer survivorship needs of comprehensive cancer control (CCC) programs, and to identify the types of activities, resources, and materials that could help the CCC programs address those needs. In addition, this information collection will assess how the activities undertaken and materials produced by the National Cancer Survivorship Resource Center (NCSRC) have met the survivorship needs of CCC programs. The information collection will identify the unmet cancer survivorship needs of NCCCP grantees and the types of activities, resources, and materials that could fill those gaps.

The findings generated from this information collection will be used to strengthen support provided to cancer survivors by ensuring that current and future needs are met, as well as provide the basis for actionable recommendations for improving training and technical assistance related to cancer survivorship.

3. Use of Improved Information Technology and Burden Reduction

Data will be collected via a web-based information collection instrument (see **Attachment A—Cancer Survivorship Needs Assessment Instrument: Word version** and **Attachment B—Cancer Survivorship Needs Assessment Instrument: Web version**) and telephone focus groups (see **Attachment C—Telephone Focus Group Interview Guide: Health Care Professional Audience**; **Attachment D—Telephone Focus Group Interview Guide: Cancer Survivor and Caregiver Audience**; and **Attachment E—Telephone Focus Group Interview Guide: Policy and Advocacy Audience**).

The web-based information collection allows respondents to complete and submit their responses electronically. This method was chosen to reduce the overall burden on respondents. The

information collection instrument was designed to collect the minimum information necessary for the purposes of this project (i.e., limited to 133 questions). The bulk of questions are of the multiple choice-multiple selection variety and there are limited opportunities for providing open-ended responses except as an “other” response. Furthermore, respondents will be allowed to skip non-applicable questions.

The telephone focus groups were chosen to reduce burden on participants so that they would not have to travel in order to participate. Participants will be able to join their assigned session from a location of their choosing, and the time required will be limited to the scheduled 90 minutes (maximum) for each session. The focus group interview guides were designed to collect the minimum information necessary for the purposes of this project (i.e., limited to 15 questions), and each focus group will have no more than 12 participants in order to provide all participants opportunities to contribute to the discussions. Collecting information via telephone focus groups will also help to minimize the burden on Battelle staff by reducing the time required for follow-up. Battelle staff will be able to verify responses and request clarification in real time as needed during the information collection process.

4. Efforts to Identify Duplication and Use of Similar Information

This information collection will be the first of its kind to systematically assess the current and future needs of NCCCP grantees for cancer survivorship resources, assess NCCCP grantee satisfaction with currently available resources; and generate input from grantees on new and improved resources. Efforts were made to identify duplication and use of similar information, including searches for published literature and programmatic reports. The National Cancer Survivorship Resource Center convened expert panel workgroups in 2011 to identify the informational and resource needs of survivors, health care professionals, and the policy and advocacy community at the national level. However, that effort was not focused on the NCCCP grantees in their unique capacity to monitor and address survivorship needs of all stakeholders at the state and local levels. Information gathered through this data collection is not currently available from other data sources or through other means. The web-based information collection instrument will provide broad, cross-sectional, structured data from across all NCCCP grantees, while the telephone focus groups will provide in-depth, qualitative data. The focus groups will emphasize grantees’ recommendations on how to address unmet needs, and suggestions for improving communication and dissemination of the resources. Because group discussions facilitate new ideas and insights among the participants, the focus group format will provide unique and valuable findings that cannot be achieved with the web-based information collection instrument.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this information collection.

6. Consequences of Collecting the Information Less Frequently

This request is for a one time information collection. There are no legal obstacles to reduce the burden. If no data are collected, CDC will be unable to:

- Develop a targeted and useful strategy to meet the ongoing and changing needs of cancer survivors
- Provide improved technical assistance to cancer survivorship programs
- Ensure that cancer survivorship programs and staff receive up-to-date and useful resources to carry out the programs effectively.

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

There are no special circumstances with this information collection package. This request fully complies with the regulation 5 CFR 1320.5 and will be voluntary.

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

This information collection is being conducted using the Generic Information Collection mechanism of the OSTLTS OMB Clearance Center (O2C2) – OMB No. 0920-0879. A 60-day Federal Register Notice was published in the Federal Register on October 31, 2013, Vol. 78, No. 211; pp. 653 25-26. No comments were received.

CDC partners with professional STLT organizations, such as the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), and the National Association of Local Boards of Health (NALBOH) along with the National Center for Health Statistics (NCHS) to ensure that the collection requests under individual ICs are not in conflict with collections they have or will have in the field within the same timeframe.

9. Explanation of Any Payment or Gift to Respondents

CDC will not provide payments or gifts to respondents

10. Protection of the Privacy and Confidentiality of Information Provided by Respondents

STLT governmental staff will be speaking from their official roles. Although Battelle will collect some individually identifiable information (IIF), used only for follow-up as needed. Focus groups

will be recorded in order to capture the conversation accurately, however verbal permission will be obtained from the participants prior to the beginning of the focus group. All information gathered from participants will be kept secure to ensure protection of information. Battelle will remove all IIF and use only the state name in the dataset sent to CDC. No IIF be distributed publically.

This information collection is not research involving human subjects.

11. Institutional Review Board (IRB) and Justification for Sensitive Questions

No information will be collected that are of personal or sensitive nature.

12. Estimates of Annualized Burden Hours and Costs

The estimate for burden hours for the web-based information collection instrument is based on a pilot test by 4 public health professionals at the CDC. In the pilot test, the average time to complete the instrument including time for reviewing instructions, gathering needed information and completing the instrument, was approximately 30 minutes (range: 25 to 30 minutes). For the purposes of estimating burden hours, the upper limit of this range (i.e., 30 minutes) is used.

The estimate for burden hours for the focus group interview guides is based on a pilot test using one of the three focus group interview guides: Attachment D—Telephone Focus Group Interview Guide Cancer Survivor and Caregiver Audience. One focus group was conducted with 6 public health professionals. The duration of this pilot focus group was approximately 90 minutes. During this time, the moderator reviewed instructions with participants, allowed participants to review NCSRC materials as needed (e.g., website, brochures), and facilitated discussion. Although there are minor differences between the three focus group protocols, the number of questions and types of questions are similar. Therefore, it is expected that the estimated time to complete the focus group of 90 minutes will apply to all focus groups regardless of respondent type.

Estimates for the average hourly wage for respondents are based on the Department of Labor (DOL) Bureau of Labor Statistics for occupational employment for Social and Community Service Managers (http://www.bls.gov/oes/current/oes_nat.htm). Based on DOL data, an average hourly wage of \$30.54 is estimated for all 65 respondents. Table A-12 shows estimated burden and cost information.

Table A-12: Estimated Annualized Burden Hours and Costs to Respondents

Information collection Instrument: Form Name	Type of Respondent	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
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Cancer Survivorship Needs Assessment Web-based Instrument	NCCCP grantee Program Directors	65	1	30/60	33	\$30.54	\$1,008
Telephone Focus Group Guides	NCCCP grantee Program Directors	36 (of the 65 listed above)	1	90/60	54	\$30.54	\$1,649
	TOTALS	65			87		\$2,657

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

There will be no direct costs to the respondents other than their time to participate in each information collection.

14. Annualized Cost to the Government

There are no equipment or overhead costs. Contractors, however, are being used to support development of the assessment tool, data collection, and data analysis. The only cost to the federal government would be the salary of CDC staff and contractors. The total estimated cost to the federal government is \$356,225.60. Table A-14 describes how this cost estimate was calculated.

Table A-14: Estimated Annualized Cost to the Federal Government

Staff (FTE)	Average Hours per Collection	Average Hourly Rate	Average Cost
Epidemiologist (GS 13) CDC project team member and contracting officer's representative	84	\$47.95	\$4027.80
Public Health Advisor (GS 13)- CDC project team member	32	\$47.95	\$1534.40
Public Health Advisor (GS 13)- CDC project team member	32	\$47.95	\$1534.40
Battelle Contract-including UNC Subject Matter Expert			\$349,129
Estimated Total Cost of Information Collection			\$356,225.60

15. Explanation for Program Changes or Adjustments

This is a new information collection.

16. Plans for Tabulation and Publication and Project Time Schedule

For the web-based information collection, Battelle will maintain data in a secured database. Upon completion of data collection, Battelle will download, clean, and de-identify, the data, and send to CDC in Excel format. CDC will conduct a quantitative analysis on all close-ended questions. A qualitative analysis approach will be used to conduct a thematic analysis of responses to the open-ended questions.

For the telephone focus groups, Battelle will maintain audio recordings and transcripts in a secure data base. Focus group participants will be asked not to provide identifying information (such as their name or names of other people) while the focus group is being audio recorded. Upon completion of the telephone focus groups, Battelle will send audio recordings and the de-identified transcripts to CDC. CDC will use a qualitative analysis approach to conduct a thematic analysis of the focus group transcripts.

CDC will create an aggregate summary report from the tabulated data from the web-based information collection and the themes identified from the focus group interviews. Information collected will be used to provide recommendations for improvements and updates needed for program resources and materials and to give insights into how cancer survivorship needs can be met.

Project Time Schedule

- ✓ Design questionnaire and focus group guides (COMPLETE)
- ✓ Develop analysis plan (COMPLETE)
- ✓ Pilot test questionnaire and focus group guide (COMPLETE)
- ✓ Prepare OMB package (COMPLETE)
- ✓ Submit OMB package (COMPLETE)
- OMB approval (TBD)
- Collect data (Assessment open 3 months)
- Code, quality control, and analyze data..... (4 weeks)
- Prepare reports (4 weeks)
- Disseminate results/reports (4 weeks)

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

We are requesting no exemption.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification. These activities comply with the requirements in 5 CFR 1320.9.

LIST OF ATTACHMENTS – Section A

Note: Attachments are included as separate files as instructed.

- A. Attachment A—Cancer Survivorship Needs Assessment Instrument: Word version**
- B. Attachment B—Cancer Survivorship Needs Assessment Instrument: Web version**
- C. Attachment C—Telephone Focus Group Interview Guide: Health Care Professional Audience**
- D. Attachment D—Telephone Focus Group Interview Guide: Cancer Survivor and Caregiver Audience**
- E. Attachment E—Telephone Focus Group Interview Guide: Policy and Advocacy Audience**

REFERENCE LIST

¹ Pollack, L.A., et al., Cancer survivorship: a new challenge in comprehensive cancer control. *Cancer Causes & Control*, 2005. 16(1): p. 51-59.

² Centers for Disease Control and Prevention. A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. April 2004.
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³ Underwood, J.M., et al., Surveillance of demographic characteristics and health behaviors among adult cancer survivors: Behavioral Risk Factor Surveillance System, United States, 2009. 2012: US Department of Health and Human Services, Centers for Disease Control and Prevention.

⁴ Centers for Disease Control and Prevention. Division of Cancer Prevention and Control. *Cancer Survivorship*. Atlanta, GA.

⁵ CDC. A National Action Plan for Cancer Survivorship, op. cit.

⁶ Stovall, E., S. Greenfield, and M. Hewitt, *From Cancer Patient to Cancer Survivor: Lost in Transition*. 2005: National Academies Press.

⁷ CDC. A National Action Plan for Cancer Survivorship, op. cit.