Request for Approval under the "Generic Clearance for the Collection of Routine Customer Feedback" (NCI) (OMB Control Number: 0925-0642-03, Expiration Date 9/30/2014)

TITLE OF INFORMATION COLLECTION:

User-centered Testing of Consolidated Cancer Statistics on the SEER Web Site

PURPOSE:

Cancer surveillance research provides the basis for evaluating the impact of efforts in cancer control and helps inform decisions in science and public health. NCI's Surveillance Research Program (SRP) within the Division of Cancer Control and Population Sciences (DCCPS) serves as the most authoritative source of information on cancer incidence, prevalence, mortality, and survival in the United States. Its best-known project is the Surveillance, Epidemiology, and End Results (SEER) Program, which collects and manages high-quality data that provide a means to measure the progress made in reducing the cancer burden. These data are used increasingly to answer questions about cancer burden, etiology, prevention, treatment, and control.

In addition to collecting data, a primary mission of SRP is to communicate cancer statistics to a variety of audiences which include researchers, health professionals, media, and general public. Currently several tools are available on the SEER website which is being used to produce cancer statistics: Cancer Stat Fact Sheets, the Cancer Statistics Review (CSR), FastStats, and CANQUES. There is a large overlap between these tools and it is not transparent to users which are the best tools to obtain the cancer statistics they need. SRP, in collaboration with NCI's Office of Communication and Education (OCE) and DCCPS Health Communication and Informatics Research Branch (HCIB) began a project to consolidate these four tools into a universal tool/design that would stratify cancer statistics in more efficient and easier to understand ways for both researchers and the public. The purpose of this submission is to have the target audiences provide input to the redesign process to ensure that the revised design is intuitive and easy to use. The end goal is to offer a single tool designed to give an experience that is "user-centric" and not "tool-centric".

DESCRIPTION OF RESPONDENTS:

A total of 24 individuals will participate in this project. They are broken down into four user groups as follows:

- Researchers (6) who use cancer statistics for their work.
- Health professionals (6) who work with cancer patients or otherwise have a need to obtain cancer statistics.
- Press and policy participants (3), who require cancer statistics for media publications.
- Members of the general public (9) who have a personal connection to cancer (through a family or friend) and whom express a desire to look for cancer statistics in their search for cancer information.

Participants will be located nationwide. Sessions will be conducted in-person with members of the general public, and by phone and Internet conferencing software with healthcare professionals, the media, and researcher groups. A statement of informed consent will be read to

respondents and consent will be collected verbally when interviews are conducted by phone and with a written consent form when conducted in person (See **Attachment G and H**).

TYPE OF COLLECTION: (Check one)

[ ] Customer Comment Card/Complaint Form
[X] Usability Testing (e.g., Website or Software
[ ] Focus Group
[ ] Customer Satisfaction Survey
[ ] Small Discussion Group
[ ] Other:_____

CERTIFICATION:

I certify the following to be true:

1. The collection is voluntary.
2. The collection is low-burden for respondents and low-cost for the Federal Government.
3. The collection is non-controversial and does not raise issues of concern to other federal agencies.
4. The results are not intended to be disseminated to the public.
5. Information gathered will not be used for the purpose of substantially informing influential policy decisions.
6. The collection is targeted to the solicitation of opinions from respondents who have experience with the program or may have experience with the program in the future.

Name: __Cheryl Burg_____

To assist review, please provide answers to the following question:

Personally Identifiable Information:

1. Is personally identifiable information (PII) collected? [X] Yes [ ] No
   (It is collected temporarily only to provide information to allow us to contact the participant and to receive an incentive. It is then discarded.)
2. If Yes, will any information that is collected be included in records that are subject to the Privacy Act of 1974? [X] Yes [ ] No

3. If Yes, has an up-to-date System of Records Notice (SORN) been published? [X] Yes [ ]No
   During recruitment, PII is collected in the form of name and contact information solely for the purpose of reminding the respondents of the usability test the day before and mailing out the incentive.

A Privacy Impact Assessment (PIA) has been completed and published by HHS on 8/30/2011. The name of the IT system is "NIH NCI OCE Office of Market Research and Evaluation Surveys."

Gifts or Payments:

Is an incentive (e.g., money or reimbursement of expenses, token of appreciation) provided to participants? [X] Yes [ ] No

It is proposed to give the researchers, health care professionals and members of the media who choose to conduct the usability testing in-person $40/per person incentive as a thank you for their time. The general public will also receive $40 for the in-person usability testing. For the

researchers, health care professionals and members of the media who choose to conduct the tests through web-based means, they will receive $35. These incentive amounts are consistent, if not somewhat lower, than other usability testing sessions that NCI has received OMB approval; as well as being in-line OMB's Supporting Statement A. These include usability testing in which:

- Students and general public incentivized at $50 for in-person or on-line responses (0925-0589-04, approved 8/2010, SEER).
- Listserv participants incentivized at the $30 rate for on-line responses (0925-0589-05, approved 8/2010, EGRP).
- Website users and non-website users incentivized at the rate of $60 for on-line responses (0925-0589-08, approved 1/2011; NeXT).

BURDEN HOURS

Category of Respondent	**No. of Respondents**	**Participation Time**	**Burden** (rounded)
Researchers	6	75 minutes	8 hrs
Health Care Professionals	6	75 minutes	8 hrs
Members of the Media	3	75 minutes	4 hrs
Members of the General Public	9	75 minutes	11 hrs
Totals	**24**		**31 Hours**

Total Burden Hours used for IC's to date: 16
Total Burden Hours Approved for IC's under 0925-0642: 8750
Total Burden Hours currently requested: 31

FEDERAL COST: The estimated annual cost to the Federal government is $22,795.
If you are conducting a focus group, survey, or plan to employ statistical methods, please provide answers to the following questions:

The selection of your targeted respondents

1. Do you have a customer list or something similar that defines the universe of potential respondents and do you have a sampling plan for selecting from this universe?
   [ ] Yes [X] No

If the answer is yes, please provide a description of both below (or attach the sampling plan)? If the answer is no, please provide a description of how you plan to identify your potential group of respondents and how you will select them?

NCI will identify potential participants in the fields of researcher, health professional, and members of the media through a variety of sources. All individuals who agree to participate and can be scheduled will be included, up to the maximum number needed in each group.

- Researchers will be identified through NCI's Surveillance Research Program based on published works in PubMed and citation indexes and by posting recruitment notices on various professional listservs and web communities (See **Attachment K**). The researchers and health professionals recruited by NCI will be contacted via the two attached emails (See **Attachment I**).

- Three of the six Health Care Professionals will be identified by NCI's Surveillance Research Program and the remaining three will be identified by the contractor, User-Centered Design, using a screener (**See Attachment A**).
- Press and policy participants will be identified through the NCI Press Office, Communications Specialists within DCCPS, science reporters at the NCI's Cancer Bulletin, and other science press contacts. These participants will be contacted by phone (**See Attachment J**).
- Members of the general public will be identified by the contractor (User-Centered Design) using a screener (**See Attachment B**).

Administration of the Instrument

1. How will you collect the information? (Check all that apply)
   [ ] Web-based or other forms of Social Media
   [X] Telephone
   [X] In-person
   [ ] Mail
   [ ] Other, Explain

2. Will interviewers or facilitators be used? [X] Yes [ ] No

Attachments included below:

Attachment G-H:	Consent Forms
Attachment I:	Email/Letter Invitation
Attachment J:	Phone Script for Media Respondents
Attachment K:	Recruitment-Announcement Script for Researchers and Health Professionals
Attachment L:	Privacy Act memo

Attachments included as separate files:

Attachment A-B:	Survey/Questionnaire to Recruit Respondents
Attachment C:	Moderator's Guide for Public
Attachment D:	Moderator's Guide for Health Care Professionals
Attachment E:	Moderator's Guide for Researchers
Attachment F:	Moderator's Guide for Media

Attachment G:
Informed Consent Form

Identification of Project	**Interviews about Cancer-based Statistical Needs**
Statement of Age of Subject	I state that I am at least 18 years of age, in good physical health, and wish to participate in a program of research being conducted by Office of Market Research and Evaluation of the National Cancer Institute within the National Institutes of Health.
Purpose	The purpose of this research is to determine the needs of various audiences for cancer statistics.
Procedures	Participants will be asked to answer questions about their experience, if any, with cancer statistics and after seeing some samples to describe their preferences. A total of about 24 individuals are being asked to participate in these interviews.
Confidentiality	All information collected in this study will be kept private according to the Privacy Act. I understand that the data I provide will be grouped with data others provide for the purpose of reporting and presentation and that my name will not be used.
Risks	I understand that the risks of my participation are expected to be minimal in nature.
Benefits, Freedom to Withdraw, & Ability to Ask Questions	I understand that this study is not designed to help me personally but that the researchers hope to make the presentation of cancer statistics on the web better for people like me in order to make the experience easier for future users. I am free to ask questions or withdraw from participation at any time and without penalty.
Contact Information of Investigators	Name: Cheryl Burg, MA MS AGS Position: IT Specialist *Telephone: 301 496-0152* *Email: cheryl@mail.nih.gov*

Printed Name of Research Participant _____

Signature of Research Participant _____

Date_____

Attachment H:
Verbal Informed Consent Form for the SEER Interviews

As part of this research, I need to ask you to formally agree to this usability test and interview. As part of a research project for the National Cancer Institute, we are seeking to determine the needs of various groups of users for cancer statistics, and to determine the appropriateness and preferences of some samples. Individuals who we think would have an appropriate background are being asked to participate in these interviews. We are asking a total of about 24 individuals to participate. So we are asking you for about 60 minutes of your time today. Both the monitor used in the usability test and your voice will be videotaped, but your image will not be videotaped.

We won't be asking anything personal and identifying information is only collected so we can send you $35-40 as a token of our appreciation of your time, depending on whether the testing occurs in-person or web-based. Identifying information will not be shared. Any findings will be reported in aggregated form. If you wish that I do so, there is some formal information about your privacy that I can share with you including the OMB number and the authorization authority. Do you want me to read this information to you? Or if you prefer, I can mail you a copy?

Your participation is voluntary, and if you choose not to participate it will not affect your relationship with the National Cancer Institute. You may ask questions at any time during the interview. You are also free to stop the interview at any time without penalty and without any questions being asked of you. Do you have any questions about the process of the interview/usability test?

If you agree to participate, you are saying that you understand what I've told you and that any questions you have were satisfactorily answered. You are also saying that you are at least 18 years old, and that you voluntarily agree to participate. Do you agree to participate in this usability test and interview?

Attachment I: Follow up Email for Public Participants

Dear XXX-

Thank you for your response to the earlier email about helping with interviews about SEER statistics. Based on your responses, we have scheduled you for the following time (Eastern Time Zone):

Xxxday, Date at Time

I need to tell you that the Federal government is concerned that you know about your privacy and the burden that you are accepting. The information reported below gives you more specifics.

OMB No.: 0925-0642-03
Expiration Date: 9/30/2014

PRIVACY ACT NOTIFICATION STATEMENT

The National Cancer Program—Sec. 411 [285a] provides authority for collection of information. (For details about the authority see http://codes.lp.findlaw.com/uscode/42/6A/III/C/1.) Personally identifying information (name, address, phone number, and email) are collected to contact participants and arrange a time of participation and to provide an incentive as a thank you for their time. This information will be shared only with those who need to contact participants about the time or with those who will compensate participants for their time. Providing this information is voluntary although without this information, the participant cannot be scheduled or receive an incentive to participate. This information is not shared further and it is destroyed after it has been used for these purposes.

NOTIFICATION TO RESPONDENT OF ESTIMATED BURDEN

Public reporting burden for this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do

- Please reply to this email and confirm that this is still a satisfactory time for you.

- Please send us a mailing address where we can mail a check for your compensation.

For the interview, you don’t need to do anything in preparation. I will send you information about conferencing software that we will use. We will use it so that we can see your screen as you work on the site. At the time of the test you will need to log onto the conferencing software and have another browser window open to see the site.

Attachment J: Phone Script for Media Participants

Hi. This is _____. I am calling because your name was given to me as a possible participant for interviews that we are conducting about the use of the National Cancer Institute's statistics. In total we are interviewing about 24 individuals.

We plan to conduct one-on-one interviews DATES either onsite at the National Cancer Institute's Offices in Bethesda or via telephone and computer. We are looking for individuals

- Who are members of the media,
- Who write about science for dissemination to the public,
- Who have written or could reasonably be expected to write material that would include statistics or references to statistics, and
- Who are not employed by the federal government

If you participate in this project, we will need your name and email address so that we can contact you to arrange a time for your participation and eventually we will need your address so we can send you a stipend. The National Cancer Program—Sec. 411 [285a] provides authority for collection of information. (For details about the authority, see http://codes.lp.findlaw.com/uscode/42/6A/III/C/1.) Your personal information will not be saved once we have finished using it.

I also need to tell you that the Federal government is concerned that you know about your privacy and the burden that you are accepting. Would you like me to read it to you or e-mail you a copy?

OMB No.: 0925-0642-03
Expiration Date: 9/30/2014

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If you qualify, is there a time during the DATES that we could have 1 hour of your time? Can you come to our offices? If you wish to be interviewed via telephone and computer, we will send you an email with information about how to join a conference via your computer.

Attachment K:
SEER Recruitment-Announcement Script for Researchers and Health Professionals

The National Cancer Institute (NCI) is seeking researchers and health professionals to take part in an hour-long interview about their cancer statistics-related information needs.

NCI is conducting these one-on-one interviews to help make Surveillance, Epidemiology, and End Results (SEER) Program data more accessible and its website more user-friendly to a variety of audiences. The interviews will be carried out (DATES), either on site at the NCI offices in Bethesda, MD, or via telephone and computer. An incentive to participate will be provided to those selected to participate.

Participants:

- must have sought and obtained NCI's SEER Program data in the past, in any form (datasets or summary data)
- cannot be employed by the federal government
- Those who wish to participate remotely must also have access to a computer and Internet connection and a telephone.

If you wish to participate, would like additional information, or have questions, please contact Bill Killam from User Centered Design, the contractor assisting NCI with this project, at bkillam@user-centereddesign.com

DEPARTMENT OF HEALTH & HUMAN SERVICES

0925-0642-03

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

DATE: December 21, 2011

TO: Cheryl M. Burg, BS, MS, MA, AGS
Office of Communications and Education
National Cancer Institute

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: "Formative User-Centered Testing of Consolidated Cancer Statistics on the Surveillance, Epidemiology, and End Results (SEER) Web Site"

I have reviewed the NCI submission to OMB that proposes to re-design cancer statistics to make them more intuitive and easy to use by target audiences. The end goal is to offer a single tool designed to give an experience that is "user-centric" and not "tool-centric".

I have determined that the Privacy Act will apply to this data collection which involves the collection of personally identifiable information such as name, address, phone number, email address, highest level of education completed and employment information from researchers, health professionals, and members of the general public. The collection will solicit opinions from respondents who have experience with the program currently or in the future.

Participants will be located nationwide and will receive monetary incentives for their participation. Sessions will be conducted in-person with members of the general public, and by phone and Internet conferencing software with healthcare professionals, the media, and researcher groups. Study results are not intended to be disseminated to the public.

The data collection is covered by NIH Privacy Act Systems of Record 09-25-0156, "Records of Participants in Programs and Respondents in Surveys Used to Evaluate Programs of the Public Health Service, HHS/PHS/NIH/OD."

If you have any questions, please contact my office at (301) 402-6201.

Karen M. Plá

Attachment: NIH Privacy Act Systems of Record 09-25-0156

cc: Vivian Horovitch-Kelley, Project Clearance Liaison, NCI