



National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

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To: Office of Management and Budget (OMB)

Through: Seleda Perryman, DHHS Report Clearance Officer
Marilyn Tuttleman, NIH Project Clearance Officer, OPERA
Vivian Horovitch-Kelley, NCI OMB Project Clearance Liaison, OMAA

From: Linda Squiers, Project Director, RTI International, and
Richard Moser, Project Officer,
Division of Cancer Control and Population Sciences,
National Cancer Institute/NIH
Nina Goodman, Project Officer
Office of Communications and Education (OCE), National Cancer
Institute/NIH

Subject: **Generic Sub-Study, "Evaluation and Needs Assessment of the HINTS Program" (OMB No. 0925-0046-17; Expiration Date: 1/31/2010)**

The National Cancer Institute (NCI) proposes a formative research study designed to collect and analyze feedback from different stakeholders regarding NCI's Health Information National Trends Survey (HINTS) program. Conducting this formative research is critical to ensuring that NCI products and tools are meeting the needs of their target audiences. Results will be used to improve the HINTS program by informing the development messages, materials, and dissemination strategies that meet the needs of both current and potential users of HINTS data and results.

The HINTS program is one of the most important research tools through which NCI conducts regular surveillance on the American public's attitudes toward and behaviors relating to cancer. NCI strives to support the needs of researchers who analyze and interpret the data (data users) as well as those who use the findings to educate the community (results users). Through the HINTS program, NCI primarily supports the needs of data users by making survey questions, data, results, and background of the survey available in multiple formats via the HINTS website. NCI also sponsors a HINTS Data Users Conference to foster a research community around the HINTS program. To address the needs of results users, HINTS creates and publishes *HINTS Briefs* showcasing results to ensure that findings from HINTS research can be used to develop policies, programs, and practices at the national, state, and local level.

Through the proposed formative research, NCI seeks to determine if current dissemination strategies are reaching and supporting the target audiences of this NCI resource. NCI has previously gathered some preliminary feedback about HINTS from current data users to discover new ways to improve the program through different means, such as usability testing and the creation of an advisory committee. NCI seeks to go beyond usability testing of its website, by conducting formative research with new audiences to determine if HINTS is perceived to be

accessible and relevant to its users. In addition, this research will help determine if these target audiences perceive that the support materials (e.g., *Briefs*, the website, technical documentation and reports) are credible, increase their understanding of and self-efficacy in using HINTS data and results, and increase their intention to use data and findings. NCI will use the findings from this research to design resources that will more effectively promote awareness and support the use of HINTS data and results in order to increase the longevity and relevance of the HINTS program. RTI International will implement this formative research study for NCI.

Participants. NCI has identified six target audiences of interest for this investigation: academic researchers, cancer control planners, cancer center communication directors, graduate students, cancer advocacy organizations, and staff at the Centers for Disease Control and Prevention (CDC) and other federal agencies. These audiences will be segmented into four different types of HINTS Users: Potential Data Users, Current Data Users, Potential Results Users, and Current Results Users.

Data Collection Methods. We will gather feedback regarding their experience with and perceptions of the HINTS program through a combination of 3 focus groups, 4 triad interviews, and 36 in-depth interviews. Table 1 presents the data collection methods that will be used for each audience segment. In-depth interviews will be conducted via telephone, and in a few cases in-person. Focus groups will be conducted at the CPCRN conference or at the University of North Carolina at Chapel Hill. Triad interviews will be conducted with CDC and/or other federal staff on-site at their place of work or in RTI's Atlanta, GA, or Rockville, MD offices.

Each in-depth interview, focus group, and triad interview will have an interviewer and an assistant who will take notes, manage administrative details, gather informed consent forms, and work with NCI staff on recommended changes to the discussion guides or process. The interviewer will be experienced in working with stakeholders on cancer-related research topics. NCI staff will listen to or observe the interviews as desired. In addition to having the assistant take notes, RTI will audio-tape and transcribe the interviews and focus groups. Non-federal employees will be compensated \$50.00 for their time. Federal employees will not be compensated for their time.

Interview Guides. RTI has reviewed all planned and existing HINTS products and developed semi-structured interview guides, adapted as needed for focus groups. The guides were appropriately adapted to address unique needs and interests of each of the four categories (current data users, potential data users, current results users, potential results users). The following questions are addressed in the guides (**see Attachments A-E**):

- How are cancer-related data used in their current work?
- What sources are currently used, and what are the likes/dislikes about these sources?
- What cancer-related data and statistics do they frequently need, and what data do they frequently have difficulty finding?
- How do users prefer to have data broken down or segmented (e.g., by geographic region, age, sex, race, ethnicity, income level, health insurance status)?
- How have current users, how learned about the HINTS website, when did they start using it, and how do they use it in their work?

- How do potential users find the information on the HINTS website relevant to their work, what do they see HINTS offering to their work, and, after reviewing HINTS content, do they anticipate using HINTS information or results?
- What recommendations do they have for NCI to improve the HINTS website and HINTS products?

Participants will review the HINTS website during the focus groups and interviews and provide feedback on questions such as the following:

- How user friendly do they find the site, and how easily can they locate information and results that are important to them?
- When prompted, are they able to locate specific topics or research areas on the site?
- What do they see this website offering them in their professional work?

Participants will be asked to provide opinions and feedback on the relevance and usefulness of HINTS products, such as the Facts about the Health Information National Trends Survey sheet, the HINTS brochure, *HINTS Briefs*, and the section of the HINTS website that lists current publications and presentations based on HINTS data.

Recruitment of Target Audiences. To reach the 6 different target audiences, we will use a variety of different recruitment strategies including email invitations, in-person invitations from NCI staff at professional meetings, and telephone calls to individuals to whom research staff are referred from NCI staff. (See Table 1).

Email Invitations to Registered Conference Attendees. Email invitations (**see Attachment F**) will be sent to individuals who have registered for the Spring 2010 conference of the Cancer Prevention and Control Research Network (CPCRN) and attendees of the Fall 2009 HINTS Users Conference. Where appropriate, we will telephone those individuals who do not respond to the e-mail (**see Attachment F**) and leave a toll-free telephone number at which they can contact a member of our research team.

Email Invitations through Organizational Contacts. The University of North Carolina graduate program in health communication has agreed to send out an email invitation to graduate students. Staff from NCI's Cancer Advocates in Research and Related Activities (CARRA) have also agreed to send out an email invitation for this study to cancer advocacy organizations. Staff from NCI's Cancer Information Service Partnership Program, NCI's Division of Cancer Control and Population Sciences, and CDC's National Center for Health Marketing have agreed to forward an email invitation to colleagues who work in cancer control planning or health communication. The email invitation will ask that interested parties contact a member of the research team through a toll-free telephone number.

In-Person Invitations. NCI staff will be conducting a presentation on HINTS to the NCI Public Affairs and Marketing Steering Committee Meeting in early January 2010. At this meeting, NCI staff will update the committee on the HINTS program and invite attendees to participate in the formative research. They will be given a written invitation with the same contact information found on the email invitation.

When interested individuals call this toll-free number, recruitment staff will explain the purpose of the project, eligibility criteria, and what is involved in participating. Interested individuals will be screened (**see Attachment G**) and, if appropriate, invited to participate in the focus group. A reminder e-mail will be sent to eligible individuals who have agreed to participate 2 weeks before the interview or focus group (**see Attachment H**). Study staff will telephone participants 1–2 days prior to the interview or focus group or interview reminding them of their appointment (**see Appendix H**). We will provide a gift card in the amount of \$50.00 to non-Federal employees who choose participate. Federal employees will not be eligible for any monetary compensation.

Prior to the in-depth telephone interviews, participants will sign and mail/fax an informed consent form. For the focus groups and trial interviews, recruited participants will be asked to arrive 15 minutes prior to their scheduled appointment to complete the informed consent form (**see Attachment I**).

Table 1. HINTS Needs Assessment Data Collection Plan

Method	Target Audience	Number	Recruitment Strategy	Data Collection Venue
Focus Group	Academic Researchers (<i>Potential Data Users</i>)	8	Email invites to registered attendees of the CPCRn conference	Conference room at the CPCRn conference
	Cancer Control Planners (<i>Potential Results Users</i>)	8	Email invites to registered attendees of the CPCRn conference	Conference room at the CPCRn conference
	Graduate Students (<i>Mix of all user types</i>)	10	Email invites through UNC professor	University of North Carolina conference room
In Depth Interviews	Academic Researchers (<i>Current Data User</i>)	4	Email invites to attendees of HINTS Users' Conference	Telephone
	Cancer Control Planners (<i>Potential and Current Results Users</i>)	16	Email invites to attendees of HINTS Users' Conference, snowball sample through CIS Partnership Program staff; Email invites to registered attendees of CPCRn conference	Telephone or in-person interviews at conference room at CPCRn conference
	Cancer Center Communication Directors (<i>Potential Results Users</i>)	8	In-person invitation at Steering Committee meeting	Telephone
	Cancer Advocacy Organizations (<i>Potential Results Users</i>)	8	Referral to organization from NCI staff	Telephone
Triad Interviews	Federal Employees (<i>Mix of all user types</i>)	12	Referral from agency contacts. (email invites)	In person at CDC, NCI, or RTI offices

Total: 3 focus groups: 26 individuals; 36 in depth interviews; 12 triad interviews

Data Analysis. Once the data are collected, we will conduct a thematic analysis of the data collected to discover and understand participants' perceived needs regarding HINTS data and communication products in as rigorous and detailed a manner as possible. In analysis, we will code the content in terms of frequency of themes and whether the themes vary by audience or type of user. This process will involve analysis and generation of coding schemes, checks on inter-rater reliability, and revision of the coding scheme to capture emerging themes. RTI will prepare a detailed report describing the purpose, methods, findings, and recommendations from the focus groups, triad interviews, and in-depth interviews. Findings will be organized around the research questions, and recommendations will be tailored to each type of user and audience.

Respondent Burden and Costs. Table 2 displays the burden estimates for each type of respondent and for the total data collection effort. We anticipate screening 100 individuals and recruiting a total of 74 individuals. We expect to have 26 individuals to participate in the in-depth interviews. Each interview will last 60 minutes. We expect to have a total of 12 people to participate in four triad interviews that will last 60–90 minutes each. We expect to have 36 people participate in focus groups varying in size from 8 to 10 people per group. Each focus group will last 90 minutes. We will have 62 non-federal employees and 12 federal employees for a total of 74 participants. The total respondent burden for this effort is estimated to be 103 hours.

Table 2. Estimates of Hour Burden and Respondent Cost

Types of Respondents	Number of Respondents	Frequency of Response	Average Time per Response (Hours)	Annual Hour Burden	Hourly Wage Rate	Annual Respondent Cost
Screeener for Data and Results Users	100	1	0.1 (6 minutes)	10.0	\$34.49	\$344.90
In-Depth Interview	36	1	1 (60 minutes)	36.0	\$34.49	\$1241.64
Focus Group	26	1	1.5 (90 minutes)	39.0	\$34.49	\$1345.11
Triad Interview	12	1	1.5 (90 minutes)	18.0	\$34.49	\$ 620.82
Total	174			103		\$3,552.47

Note: Based upon the average wages, "National Compensation Survey: Occupational Wages in the United States, May 2008," U.S. Department of Labor, Bureau of Labor Statistics.

http://www.bls.gov/oes/current/oes_nat.htm#b29-0000. 19-3099 Social Scientists and Related Workers.

The full generic study, approved on January 26, 2007, requested a total of 2010 burden hours. There have been 16 previous sub-studies approved by OMB under this umbrella submission, totaling 1688 burden hours requested to date. Approval by OMB of this sub-study would bring the total burden hour requested to date for 0925-0046 to 1791; well below the original request of 2010 hours.

Thank you for your consideration of this proposed sub-study #0925-0046-17.

List of Attachments

- A: Current Data User Guide
- B: Potential Data User Guide
- C: Current Results User Guide
- D: Potential Results User Guide
- E: Student Guide
- F: Invitations - E-mail and Telephone
- G: HINTS Screener Questions
- H: Reminders - E-mail and Telephone
- I: Informed Consents for:
 - Interview
 - Interview with Federal Employees
 - Focus Group
 - Focus Group with Federal Employees
 - Triad Interview