August 2010

Process and Needs Assessment Evaluation of the HINTS Program

Final Report

Prepared for

National Cancer Institute
6130 Executive Blvd.
Bethesda, MD 20892-7338

Prepared by

Bridget Kelly, Ph.D., M.P.H.
Linda Squiers, Ph.D.
Marjorie Margolis, B.A.
Julia Kish Doto, Ph.D.
Elizabeth Adams, M.S.
Molly Lynch, M.P.H.
Paula Eguino-Medina, B.S.
Debra Pinkney, M.S., M.P.H.
RTI International
3040 Cornwallis Road
Research Triangle Park, NC 27709

Table of Contents

Appendix

List of Figures

Number **Page**

List of Tables

Number   **Page**

Background/Purpose

The Health Information National Trends Survey (HINTS) is a research program of the National Cancer Institute (NCI), designed to conduct regular surveillance on the American public's knowledge of and attitudes toward cancer and engagement in cancer-related behaviors. HINTS is a nationally representative survey that allows NCI and its partners to gather data about the public's need for cancer information, their preferred and trusted sources of cancer information, and their information-seeking behaviors. The HINTS survey has been conducted three times—in 2003, 2005, and 2007. To date, combined responses total 15,000.

One goal of the HINTS program is to ensure not only that data are used for academic research and to further the fields of cancer communication and health behavior, but also that findings from such research can be used to develop policies, programs, and practices at national, state, and local levels. As such, NCI has developed products such as HINTS Briefs for those who are the "results users" of research findings. NCI has made a considerable effort to ensure that the access to information, data, and results from the HINTS program are easily accessible for different types of users.

To encourage access to and use of the HINTS data, NCI has made the survey questions, data, and results available via the HINTS website (http://hints.cancer.gov/). The website provides background information about the goals of the survey and connects those who use the site to survey questions, documentation (e.g., sampling plan, codebooks), reports, and HINTS data in multiple formats. These components of the website were designed to address the needs of data users.

The current project continues to cultivate this feedback loop by striving to obtain information regarding the reach of and satisfaction with the HINTS program among a variety of different stakeholders. To that end, we conducted focus groups and interviews with data users and results users in various positions, including academics, cancer control planners, graduate students, CDC staff members, and cancer center communication directors. In the following pages, we describe the results of those focus groups and interviews.

Methods

The audience was segmented into two primary user groups: data users and results users (see Figure 2-1). Within these two groups, we gathered input from both current users and potential users. Segmenting each of the groups even further (i.e., current data users, current results users, potential data users, and potential results users), we obtained feedback from the following stakeholder groups:

1. Academic researchers

2. Cancer control planners (including state and local health department staff and advocacy agencies)

3. the communication directors (or staff) from NCI designated cancer centers

4. CDC staff

5. Health communication graduate students.

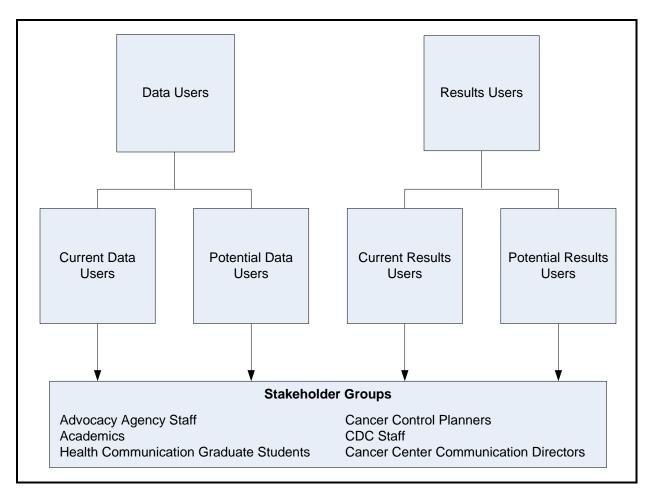Our plan for data collection is described in detail below.

**Figure 2-1.   Audience Segments for HINTS Needs Assessment and Process
Evaluation**

The primary screening criteria for each audience included their awareness of HINTS and their use of HINTS (data or products). For participants who are not currently using HINTS (potential users), we sought a mix of those who are aware of HINTS and those who are not (see Appendix A for screeners).

A detailed research plan depicting the method of recruitment and number of participants in each segment is found in Appendix B.

2.1   Data Collection

Participants were recruited primarily through conferences at which members of the particular audience segment were expected to be in attendance. These included the HINTS Data Users Conference in September 2009; The Public Affairs Network (PAN) Steering Committee Conference in January 2010; the Dissemination Conference in March 2010, and the Leadership Institute Conference in June 2010. In some cases, appeals were made at the conference and names of interested people were collected. In others, we sent e-mails (approved by RTI's Institutional Review Board) to the list of registered participants in order to organize a focus group at a particular conference.

Data were collected using both in-depth phone interviews and focus groups. In each case, trained moderators and interviewers used discussion guides, developed in collaboration with NCI (see Appendix C for discussion guides). Interviews and focus groups were recorded using digital audio recorders, and recordings were transcribed by a professional transcription service.

2.2   Analysis

Transcripts were coded using NVivo Software for qualitative data. RTI developed the coding scheme in collaboration with NCI. Slightly more than 10% of the transcripts (n=5) were double-coded by trained coders, and statistics of agreement were calculated. Across all possible codes, the minimum agreement level was 95%. Data were then analyzed to identify themes. These themes are reported below.

2.3   Respondent Characteristics

There were a total of 22 data users. Of the current data users, 4 were academics, 2 were graduate students at a university in North Carolina, one was a CDC staff member and one worked for a cancer advocacy agency. Of the potential data users, 4 were academics, 6 were cancer control planners, 4 were UNC graduate students and one was a CDC staff member.

There were a total of 46 results users: 14 current results users and 32 potential results users. Of the current results users, 10 were cancer control planners, 2 were UNC health communication students, 1 was a cancer center communication director, and 1 was a CDC staff members. Of the potential results users, 20 were cancer control planners, 2 were UNC students, 7 were cancer center communication directors, and 3 were CDC staff members.

Results

In the following sections we describe the findings. Results that apply to all user groups are presented first, followed by results specific to data users and results specific to results users. We did not find many differences between current and potential users, however, each quote presented is attributed to either a potential or current results or data user. We present key findings in Table 3-1.

Table 3-1.   Key Findings

Overall findings:

- Many users thought there was a lack of awareness about HINTS

- Participants provided detailed suggestions for improvements to the website, including adding tabs.

- Participants provided numerous suggestions for new HINTS topics, including additional types of cancer, issues related to survivorship or end-of-life issues, use of social media, etc.

- Most users said they would be likely to use HINTS again in the future.

- Participants suggested a blog as a way of fostering a research community.

- Most would prefer to receive updates or new results via e-mail newsletter.

- Respondents provided very specific feedback on HINTS products, including several reports, the HINTS Briefs, brochure, fact sheet, and My Toolkit.

Findings from data users:

- Data users thought the communication variables on the survey were unique.

- Data users felt HINTS was easy to access and use.

- Some data users mentioned that they liked the way the questions are displayed on the website.

- Several data users expressed difficulty finding information on weights.

- Several data users discussed challenges with trend analysis, such as changes to question wording over time.

- Data users provided detailed suggestions about additional documentation that could be added.

Findings from results users:

- Results users, who often are information intermediaries, try to reach a very wide range of audiences, from donors and patients, to clinicians, the media, and the general public.

- Results users employ various channels, including broadcast media, mailings, outreach to church groups, and health fairs to reach their target audiences.

- Most results users need data on the incidence and prevalence of cancer by geographic area. Some suggested this can be difficult to find.

- A couple of users identified specific needs for communication-related data.

3.1   Results Across All User Types

3.1.1   General Findings

The general findings were as follows:

- Overall, respondents had positive comments about the HINTS survey.

- Some suggested awareness of HINTS is low.

- Users suggested reorganizing the website into sections for different types of users and placing key findings on the home page.

- Users provided a number of suggestions for additional topics to be added to HINTS, including those related to other types of cancer or health issues and more specific Internet questions.

- Participants suggested adding a blog to the HINTS website to help foster a research community.

- Most would prefer to receive updates via an e-mail newsletter.

- Participants provided specific comments and suggestions for several HINTS products, including two reports, the briefs, the brochure, NCI Cancer Bulletin, and fact sheet and the My Toolkit.

Each of these findings is described in more detail below.

3.1.2 Detailed Findings

Awareness of HINTS/ General Impressions

Most users said they had either heard of HINTS through co-workers or at one of the conferences where we were recruiting for the study. Both data users and results users had positive comments overall, and specifically mentioned liking that the dataset is available to the public, the inclusion of communication variables that cannot be found elsewhere, and specific features, such as the web page that details all of the questions that have been asked.

Several data users liked the fact that HINTS is a free public use dataset that is easy to use:

"The fact that it's a larger, you know, nationally representative sample's really good….Well, of course, the fact that it's easy to get a hold of. You know, you can just download it from the website." (Current data user, academic)

"Getting access to the data was very easy, and I think that's good for like publicly available datasets because a lot of them have just like a lot of channels and lots of people need to get access to the data." (Potential data user, focus group, graduate students)

However, results users suggested that awareness about the HINTS data is low:

"I think, people are just not knowing about it. And so, you know, sending it out to people working in this area of communication is important because all this data, you know, can't be used unless people know how to get to it." (Potential results user, cancer center communication director)

"A lot of people don't know about it," current results user, cancer control planner

"Well, if I hadn't gone to an NCI meeting, I would never have known you existed. So I would just encourage that, from a communication standpoint, to people like myself or to organizations that I belong to, they got to get the word out about this." (Current results user, cancer center communication director)

Suggestions for the HINTS Website

Respondents provided a number of specific suggestions for the HINTS website. Some suggested including new results or findings on the homepage:

"I think maybe having … some key findings or just some kind of really brief, you know, headline type information…little factoids." (Potential data user, CDC staff member)

"I feel like a lot of homepages that I see, a lot of times they have like highlights of the, I know it's just supposed to be about the survey and talking about what the survey's about but a lot of times they'll have highlights on the new findings and stuff at the beginning...." (Potential data user, focus group, cancer control planners)

Others suggested organizing the site in terms of the type of information a particular user might be looking for or adding tabs to make the information easier to find:

"You could put the, you know, questions, 'Do you need preliminary data for your grant?' and, 'Need some data backup to help you inform your policy?' or something, just a couple of, you know, a few major questions." (Potential data user, focus group, cancer control planners)

"To tell you that that was one of the most frustrating parts of it, was that there are no tabs. So you can't get to the homepage by just clicking, you know, to go back to the home. I really had to go down into the *Facts*, the *FAQ*, to find out a lot of the information that I was trying to find." (Current results user, health policy researcher)

"On some sites, they have, for example…, 'This is information for patients. This is for providers. This is for health professionals. This is for the public.' And when I see that, either like in your situation, 'Well, okay, this relates to me on a personal level. This relates to me on a professional level.' You have the ability to go to both sites and you're not locked out of the other one." (Potential data user, focus group, cancer control planners)

Results users specifically commented on the literacy level of some of the web pages and provided specific suggestions for improvement, or sections that could be explained better:

"Well, I just think bulleted information, chunking the information, you know, your basic health literacy, pull out the big ideas and then support those big ideas with text. And even if it's the hypertext so that if I want to learn more about that big idea I can go to it, but I don't have to slog through the whole thing." (Potential results user, cancer center communication director)

"Because that center panel, the thing that I noticed the most when I open a three panel, says, 'HINTS can help survey researchers and social scientists, offers a test bed for new theories of health communication behavior.' I'm like, "What?" (Potential results user, cancer control planners)

They also pointed out that the HINTS brochure is written at a very high literacy level.

Participants in one focus group thought that the site was boring and could be made more interesting with more dynamic programming:

> "I mean, I find it just kind of boring. It's just very static…maybe that's, you know, kind of trying to attract a certain audience but, you know, there's really nothing that exciting about it. There's nothing like flipping or, you know, I see that there's an RFP release, I mean, that seems like that's a big deal that if trying to researchers but, you know, it could blink or something. … like maybe even having a ticker at the top where they're like either giving statistics or the new announcements." (Potential data user, focus group, cancer control planners)

Suggestions for Additional HINTS Topics

Both data users and results users offered a lot of ideas about additional topics that could be included as topics for new questions on the HINTS survey. These included:

- additional types of cancer, such as cervical cancer

- other health topics

- more specific questions related to Internet sites

- social media and health IT

- patient-provider communication

- issues specific to cancer patients (including survivorship end-of-life issues, clinical trials)

- demographic questions, such as immigration status

- use of alternative medicine

- reactions to specific health campaigns.

Participants provided a lot of detail for some of these ideas. Additional information can be found in Table 3-2.

Table 3-2.   Suggestions for Additional Topics for HINTS Survey

Participants had numerous suggestions for additional topics for HINTS survey questions. Following are some specific areas they mentioned.

A number of respondents wanted to see information on additional **types of cancer or other health issues**:
"It'd be good if they had something about hematological cancers and neural cell tumors." (Potential data user, focus group, cancer control planners)

"I would be maybe interested in having more thorough specific information on testicular cancer and perceived risk and screening or self exam be addressed." (Potential data users, focus group, graduate students)

"Well I think it's missing information on…a disease like cervical cancer. It's missing information on hysterectomy …which was previously collected but for some reason is no longer collected. There was also no information on sexual activity and age of onset of first sexual activity, which is very important when you're looking at really anything with regard to cervical cancer screening…" (Current data user, current data user, CDC staff member)

"I think one thing that would be helpful for me is if it had more questions about a wide range of like chronic conditions or co-morbidities in it. And it, just a focus on cancer, but a whole range of, you know, diabetes, high blood pressure, all those sort of like chronic conditions that are [inaudible]." (Current data user, academic)

More specific detail on **where people go on the Internet:**
"More specific information about where they're going on the internet, so, in particular what websites because I think there's, there's so many now. I think it'd be very interesting to track the nature of the sites that are visited." (Potential data user, focus group, cancer control planner)

"…just getting an idea of what internet sites people are likely to trust or act on, you know. Is it a *CNN* news story or is it, I don't know, what kind of things are they looking at?... what types of even online social networks they, if they use that for health information and what their experience has been with it." (Potential data user, focus group, cancer control planner)

"I think it would be very interesting to really understand how people use social networks like Facebook and Twitter and so forth to either engage with other people in the cancer community, or they use it as a place to seek information about cancer or how to select a facility for treatment and that sort of thing. I think there's a whole host of things that would be very interesting to learn how people use that and how they use it by different age cohorts." (Potential results user, cancer center communication director)

Issues specific to **cancer patients**:
"Well, I mean, I'm interested in palliative care/end of life issues so I know there was one or two questions related to that, but … I'm interested in preferences for prognostic information…maybe if there's some, for people who do have cancer some more questions about what concerns they have and some communication issues they have with caregivers and clinicians." (Potential data user, focus group, cancer control planner)

"Like post-treatment stuff, like, you know, some have a chronological piece to it. I don't know diagnosis context again." (Potential data user, focus group, cancer control planner)

"I wish that there were more questions about clinical trials and sort of understanding and trust in the clinical trials enterprise or the Archer healthcare system. And then, and I don't know because I haven't looked at the recent version recently, but if there are things about, if there are questions about electronic health records, I'd be really interested in seeing that." (Current data user, advocacy agency employee)

"I don't see it on here, maybe things like with dealing with how people cope with cancer diagnosis." (Potential data user, focus group, graduate students)

"Survivorship is another area that I think would be very helpful. We're working a lot in that area, and I think that's an area, though, that it's probably even more important to have it in there because it's difficult to find information about survivorship these days. I mean, there is, but it's certainly not nearly the amount of information you could find about certain cancers, etcetera." (Potential results user, cancer center communication director)

Table 3-2. Suggestions for Additional Topics for HINTS Survey (continued)

"Maybe some quality of life measures, I don't know if those are captured here." (Potential data user, focus group, graduate students)

"Interest in alternative therapies—or complementary, yeah, what people turn to and combine with Western medicine." (Potential data user, focus group, graduate students)

Maybe this might be outside of the scope of HINTS but caregiver information, in terms of caregiver decision making and bereavement." (Potential data user, focus group, graduate student)

Some were specifically related to patient-provider communication:
"Another, something I don't see up there is did you feel like your healthcare provider supported you in your decision of how to proceed after a cancer diagnosis, as far as what you're opting for with treatment." (Potential data user, focus group, cancer control planner)

"How are their opinions and their experiences with the hospital and the patient provider communication affected after diagnosis versus pre-diagnosis when maybe they were just seeing their GP and, you know, someone that they've known all their lives versus, you know, coming to a cancer center, a major cancer center and seeing a new oncologist or whatever." (Potential data user, focus group, cancer control planner)

Several mentioned additional **demographic questions**, such as immigrant status, access to care and having children:

"For the demographics, like immigrant status might be interesting, as well. And if that's too sensitive like at least time, like number of years lived in the US." (Potential data user, focus group, cancer control planner)

"I don't want to say immigration status, but, you know, how long folks have been in the United States, where they came from, these type of issues because I know that in many ways the cultural origin, the national origin of individuals can have an impact on how they use both health information and the health care system. I was really impressed with the way the General Social Survey does it, so again, it's probably just a little bit more specific questions." (Current data user, CDC staff member)

"… questions involving like how far do you travel to your healthcare provider? Do you have the resources available? Do you have insurance? Just kind of the whole gamut of, you know, if you have cancer or if you're going to get cancer, like are you able to still receive the, you know, the right care? … Even as far as transportation issues." (Potential data user, focus group, graduate students)

"Something else in the demographic information would be interesting, at least for me, would be whether the respondents have children. Some people are interested in the effects of children in cancer decision making." (Potential data user, focus group, cancer control planner)

Ideas for Fostering a Research Community

Several data users suggested that the HINTS conference is already doing a good job of fostering a research community. In addition, some had other ideas including developing a blog on which data users could ask each other questions or share solutions and reaching out to graduate school professors. Several users suggested that graduate students are often looking for public use datasets for master's theses or doctoral dissertations. Others suggested linking to HINTS from other Department of Health and Human Services (DHHS) websites, including the CDC's National Center for Health Statistics page and NCI's Health Communication and Informatics Branch. One user suggested a user-generated module:

> "I guess, maybe they could more formally ask for people to recommend modules to be added to the dataset. You know, kind of like the GSS sometimes has an open call for people to have proposals to include different special modules. … That might get certain groups of researchers to be interested in trying to do more with the dataset if they could

propose a module of ten questions or something specific to their interest." (Current data user, academic)

Another brought up the idea of a competitive grant:

"If they had some little pool of money people could apply for to write a paper, that would draw a lot of interest, even if it wasn't that much…or an annual award for the best HINTS paper or something like that." (Potential data user, focus group, cancer control planners)

Likely Future Use of HINTS

Asked if they would be likely to use the HINTS data or results in the future, most respondents said they would:

"Sometimes people ask, 'Why did you make that choice to put your ads on TV or put ads on the internet?' 'Well, because 85% of the population use the internet to get health information, or their most preferred media is TV for getting health information.' So that sort of stuff would help me in my marketing planning and strategy." (Current results user, cancer center communication director)

"So in our ad hoc requests it'll be important. If we're doing a disparities, which we do a disparities, or a report, every, every other year. I think this has some very valuable information that could go in there in terms of how to communicate to different groups." (Current results user, health policy researcher)

Preferred Channels for Information from HINTS

Most users said they would prefer e-mail newsletters as a way of learning new information or results from HINTS:

"I would, I would like to get news releases or a link that I could go to via e-mail." (Potential results user, cancer center communication director)

"Maybe if there's a way to tailor what you want to hear about. You know, maybe if you're wanting to hear the latest, you know, breast cancer information, or the, you know, being able to customize what e-mails you get, that might be helpful." (Potential results user, cancer center communication director)

"A newsletter that's mostly headings and links. Not a lot of content but, you know, headings that tell you what to expect to find when you click on the links so I can decide, "Do I want to click on the link or not?" (Potential results user, cancer center communication director)

Others mentioned webinars, conferences on health communication or statistics, and Twitter as preferred channels for learning about HINTS.

Findings Specific to HINTS Products

"Research Using HINTS" Page (List of Publications and Presentations)

Data users said they would use this section of the website to cite papers or to see what analyses have already been done, so as not to duplicate research. Some results users said they would use it for background information. Others could not think of ways it would be helpful to them.

Data users had several suggestions for this page, including making the list searchable by variable or key word, linking to the entry in PubMed, and providing abstracts:

"Yeah, that would be helpful, I mean, especially if you're like thinking about a paper to be able to search on the variables or the respondents or the year, just the key features of the survey." (Potential data user, focus group, academic)

"Going back to the previous page, I would suggest that you turn those links into a link to PubMed so that somebody [can access the abstract] in a setting that has online subscription." (Potential data user, focus group, cancer control planners)

"I went on that earlier and I was real excited to see that because I like that it shows the application of HINTS data and what you can do with it and what people have done with it. I guess I was hoping that I could link to the articles and see them... Maybe an abstract of these articles would be nice, if you could at least see an abstract of it." (Potential data user, focus group, graduate student)

Others thought works in progress should be added to the list, though some suggested this may be difficult to implement:

"Oh, yeah, I think so. I'd be pretty bummed if I, yeah, spent six months working on it and it came out." (Potential data user, focus group, academic)

"I don't know, at what stage you could put that someone's working on something so that you're not working on in the same time and don't know…It'd be a bummer if all of a sudden you saw…something published. And…I had been working on it for the last several months thinking that I was going to publish on it," current data user, academic

Briefs

The results users felt very positively about the briefs:

I clicked on the first one, the *Social Context Influences Interpersonal Health Communication,* and I really loved it. I think it was, you know, just enough information to kind of tell me what, what was learned, and it gave me an idea of how I might think about that, you know, in my, in my work." (Potential results user, cancer center communication director)

"Yes, I love it. And in fact, I wish I'd known about it before because we have done articles about nutrition or exercise. So these graphs especially would be great. Is this the kind of stuff that can be repurposed, or would we have to go through an approval process?" (Potential results user, cancer center communication director)

> "I think you have it laid out really well. You have the *Quick Facts* early enough so someone doesn't say, 'Oh my God, I have to read all that?'" (Potential results user, cancer center communication director)

Several mentioned liking the "quick facts" in particular. Several results users mentioned the importance of topics specific to certain ethnic groups.

Some had suggestions for improvement. A few participants mentioned that they missed the PDF icon and that it should be made more prominent or could include the word "printable." Two communication directors thought the charts were difficult to read and could use more footnotes.

Results users gave a variety of examples for how these briefs are already being used or could be in the future:

> "We've used them as packets and press releases, as part of trainings on how we can use data." (Potential results user, focus group, cancer control planners)

> "Well, if we were writing a story for our patients, for example, and we were talking about melanoma, … I'd pull up some of the statistics. You know, like, According to the HINT Survey, only a certain percentage of people wear hats, and therefore it is important for people to wear hats in the, in the sun." (Potential results user, cancer center communication director)

> "[We used them as handouts]. It was most of the time when we were going and presenting at, you know, Comprehensive Cancer Control meetings or we had display tables at like local, state Public Health Association meetings or, let's see, what else, like at hospital functions sometimes." (Current results user, cancer control planner)

Data users did not have much to add regarding the HINTS briefs.

"Cancer Information National Trends Survey 2003 and 2005" Report

Both data users and results users found this report useful. Several data users said they would take a glance at this report before starting data analyses. For example:

> "Like, if you were interested in differences in use, like in online health seeking by gender or something like that… I imagine there's probably a table in here somewhere that would probably give you an idea of whether or not that's true." (Current data user, academic)

One data user said she would have her students check their analyses against the ones in this report to make sure they are correct. Others said they would probably just conduct the analyses themselves so the report would not be that helpful to them.

Most results users had not read through this report before. A couple vaguely remembered having scanned quickly through it. Those who had not seen it before were asked to spend some time looking at it and then provide their impressions. Results users really liked the charts and maps in the report:

> "I love the maps when you can do stuff that changes over time. So if you're trying to show, like if you've got this kind of thing and you have it for 2003, 2004, 2005 then you

can show a change over time, I think that's great." (Potential results user, focus group, cancer control planners)

"I love the maps that show, I guess, this just shows the penetration of internet usage, the health information. That's really interesting. I love how those were done, that's really cool." (Potential results user, cancer center communication director)

A number of results users said they would use the actual data in this report (regarding media use behavior) to help with planning for advertising or marketing efforts. This was particularly true of cancer center communication directors:

"For us within the hospital what cancer sites we're gonna focus on more, whether it's to increase volume or, to increase the awareness and reputation in that particular area and… I could see this being useful for our advertising folks, too, as to where to put your money. If people are, you know, on the internet more, let's put our money in there. If people are a watching television more, you know, let's put our… monies there." (Potential results user, cancer center communication director)

"I'm really surprised about the statistics about television. I can't believe people actually …put that much credence in what they hear on television. But that's very amazing, and to us it may be, you know, we need to be mindful of that. We need to maybe pay more attention to television than we have been. I think it can be very useful for people in communications." (Potential results user, cancer center communication director)

"The health communications section, that's also good because as we are thinking about how we should present our intervention and which, what mode of communication we could, we should use, is something that will be helpful, just in thinking about even having PSAs or having something in a newspaper." (Current results user, MD at non-profit organization)

"Analytic Methods to Examine Changes Across Years Using 2003 and 2005 Data" Report

Results users did not have much to say about this report. However, data users did find it useful. Comments overall were positive:

"I get really impressed that HINTS does this, you know, they provide this and it's not just a little one paragraph on the website saying, 'Sorry, we understand the problem but oh, well.' And I think it's fantastic just glancing at this that there's code for several different systems in the back, I think that's really great." (Potential data user, focus group, graduate students)

"That book on *Analytic Methods* is very helpful in terms of showing just exactly what kind of code and syntax you need to include in it, in terms of doing some of the analysis and why you need to do it." (Current data user, academic)

One had a suggestion for improvement:

"I guess just since it just talks mainly about being 2 years instead of 3 years, like we're really interested in looking across all 3 years. So, you know, if they can update it where they talk more about methods that compare 2 years and specific methods that you might

try to use to do 3 years or something would be probably kind of useful." (Current data user, academic)

NCI Cancer Bulletin, Brochure and Fact Sheet

For the most part, users could not seem to think of ways they could use the NCI cancer bulletin.

Most said they had not seen the brochure before. Results users, however, particularly cancer center communication directors, felt the brochure would be a good way to disseminate information about HINTS:

"My thought is, if I had a copy of this brochure, I could give it not only to my colleagues in communication, but in other areas at [name of University] that also write about cancer but may not be in the Cancer Center." (Potential results user, cancer center communication director)

I think it would be helpful for people who do communications, public affairs, marketing, people who, you know, deal directly with our patients because it's obviously… all about… understanding how people access information and use of information that's available in all the different ways." (Potential results user, cancer center communication director)

Data users felt the fact sheet was very clear:

"It's a lot clearer from the fact sheet that the focus is a lot on health information and communication, rather than just cancer statistics, which is not that clear from the homepage." (Potential data user, focus group, academic)

"This, I think, is very clear and it answers the questions right away of how can it help me and, and help survey researchers, you know, offers a test for new theories, you know, this kind of stuff I think is really useful." (Potential data user, focus group, academic)

Respondents in one focus group thought the fact sheet would be more useful if it included a snapshot of results (e.g., an example of topics of briefs). A couple of participants mentioned that they would liked to have known more about the details of the data collection (e.g., sample size) in the fact sheet.

My Toolkit

Reviews of the My Toolkit feature were mixed. Some thought it was helpful to be able to collect everything in one place and then download:

"I think it would be useful just because, you know, you wouldn't have to stop and download it. And I could just do it at the end when I'm finished. And then just being able to save it like in one place on my computer, is perhaps easier to do it that way," potential data user, CDC staff member

Others felt the utility was limited:

" I think I have [used it] in the past when I downloaded, like that 2007 dataset or something. But I didn't find that it was that useful because basically there's not that many

different things you're really kind of downloading at any time, you know?" (Current data user, academic)

"So I will tell you my honest opinion, and I'm embarrassed to say this, in theory I think My Toolkit would be awesome. Whether or not I would actually use it is another thing. It's sort of like my online calendar, great, I think it's very helpful, but it does take effort on my part to make sure that I load my meetings in there." (Potential results user, cancer center communication director)

"Yeah. but honestly, the, my impression at this point is, and this is the first time I'm really looking at it, the adding, like adding it to My Toolkit feels like an extra step. Like I'd rather it just say 'Download Now.' [laughter] So I'm looking at the description of My Toolkit on the, on the right box, on the box on the right." (Potential results user, cancer center communication director)

A number of users said it was not clear what My Toolkit was. Some mentioned a limitation is that it only lasts for the one session. So if you leave the HINTS website and come back later, your items have not been saved.

3.2   Results Specific to Data Users

3.2.1 General Findings Specific to Data Users

The general findings from data users were as follows:

- Data users said the communication variables on the HINTS survey are unique.

- Data users mentioned that compared to other surveys, HINTS is easy to use, though there was some concern about quality of the questions.

- Two data users mentioned that HINTS obtains lower response rates than some other surveys.

- Several data users expressed difficulty finding information on weights.

- A number of data users described instances in which they could not find the information they needed and resorted to contacting NCI directly.

- Several data users discussed challenges with examining mode effects, such as different question wording between modes.

- Users described changes in question wording over time as a challenge for trend analysis.

- Data users provide suggestions for additional documentation that could be provided by HINTS, including that related to weights and sampling.

Each of these findings is described in detail below.

3.2.2 Detailed Findings Specific to Data Users

Overall impressions

Overall, data users had very positive comments about the HINTS data. They mentioned specific communication variables as particularly good features of HINTS:

"All the health information seeking is different. Like you can't get that from BRFSS or any of, or NHANES or something where it's, where those questions are maybe about perceptions or health behaviors. You can't get the information seeking behavior anyplace else." (Current data user, cancer advocacy agency)

"My own feelings are, the best features about HINTS are that it has some unique data, you know, specifically on communication factors that then can be related back to behaviors of interest." (Current data user, academic)

"Well, what I find most useful is, I'm kind of really interested, of course, in all the things about different kinds of channels of communication, but specifically the online internet type uses. (Current data user, academic)

Some also mentioned the listing of questions on the website as a particularly useful feature:

"The way they have changed the website now where they have the pages with all the questions listed and stuff, that's very helpful. So you can get a real quick idea of whether or not the variables are in the dataset that you need. That can be really useful. It takes a lot of time to kind of get up to speed on new datasets." (Current data user, academic)

"I thought it was really easy to use and I really liked how under the *HINTS Questions* they had it grouped by different subcategories, but you can also go onto the *Survey Instruments* and find the original instrument, as well." (Potential data user, focus group, graduate students)

Some data users pointed out particular features or tools they found useful:

"The most useful part was being able to sort of keyword search for different things, like maybe smoking, and then have all the things come up. Something that I do love is that when you find a question that you want, and then that you can tab over it when it's a multi-year question and compare the findings year to year right on the same page. That was one of my favorite things about HINTS." (Current data user, cancer advocacy agency)

"Well, what came along later were things like nice tools, like being able to pull out frequencies and things like that really easily." (Current data user, academic)

Comparison to Other Surveys

Several of the data users had only very limited experience with other large-scale datasets so could not make comparisons to HINTS. Of those who had used other surveys, some mentioned that HINTS is easier to use:

"Well, HINTS is smaller than say, like CHIS and NHIS. It has a smaller sample size, but that also makes it more easily, you know, easy to manage…It tends to be a very nice, clean, easy dataset to work with." (Current data user, academic)

Well, it's easier to use than some of the other ones, like the, that National Longitudinal Survey of Youth was really complicated to use because you have to extract your variables online that you want and everything and it's such a huge dataset." (Current data user, academic)

Two data users brought up the lower response rates compared to The National Health Interview Survey (NHIS) and the California Health Information Survey (CHIS).

"NHIS and CHIS both have higher response rates from my understanding." (Potential data user, focus group, graduate students)

"One of the problems with HINTS, in at least '05, were the low response rates. And so, you know, looking at other datasets like NHIS and stuff that have higher response rates, the generalizability factor is of some concern…But in 2007 there was, you know, a dual sampling scheme in order to improve response rates." (Current data user, academic)

Two data users expressed concerns about the quality of the HINTS questions:

"The quality of the data, I don't think is anywhere near what the other national datasets are. And it's just, it's much more a qualitative data I would say. It's very subjective, and the questions are not well tested." (Current data user, academic)

"I really worry sometimes that some of the core questions that are being asked are just way too general. They lack specificity, issues like 'From what source do you get health or, and/or medical information?' just seems way too broad. …It's very easy to conceptualize multiple types of health information that any cluster of individuals might seek." (Current data user, CDC staff member)

The Need for Technical Support from HINTS

Several data users mentioned instances in which they needed to get in touch with NCI directly for technical support. This typically had to do with questions related to weights, but in some cases involved other issues, as well:

"I had my graduate student contacting them via e-mail, they were going to set up a conference telephone call that has never happened. …I'm sure that there's an answer somewhere, but I think this is what happens with all national datasets and secondary analyses. You never really get to a point of totally understanding how the weights were created, and that's a frustration I find with all secondary analyses." (Current data user, academic)

"We had some pretty advanced statistical questions that we had to approach [NCI] directly about … In particular, we could not decipher how the weights were computed for the dataset, and the problem was pretty straightforward. We figured it out, but we weren't sure, and until we were sure, we were very uncomfortable." (Current data user, CDC staff member)

"It looked like there were duplicates of each record, and so we were very confused for a while …But what we realized… like each person in the household had the same ID or something like that. Or … I think there wasn't a patient identifier or a respondent identifier. There was more of a household identifier, and I think it overlapped. And you had to look for secondary information to find out which pieces were unique… I mean, we really had to go digging for that information, and I think we wound up e-mailing somebody at HINTS to get that." (Current data user, CDC staff member)

Challenges to Analyzing Mode Effects

Not many of the data users had ever attempted to analyze mode effects. Of those who had, several described challenges, however there were no common challenges. They ranged from different questions across modes to classic mode differences and the lack of Internet as an option:

"The phone and the mailed survey had different fruit and vegetable questions, so you can't really determine whether it's mode effects or the difference in the items or if it was difference of question." (Current data user, academic)

"I mean, it was really clear, though, that the telephone data for HINTS suffers tremendously from sort of bipolar responding. People answered on the extremes. Questions that were intended to assess a range of responses would end up coming out pretty much, you know, on the poles of 'yes' or 'no' and not a great deal of variability in the middle." (Current data user, CDC staff member)

"One of the criticisms that I've already received on some of the work is…why wasn't there an internet option? Why did we choose mail and telephone and not also offer folks an opportunity to log in to a secure server and complete the questionnaire online? And I think there's an awful lot of interest in that as that type of functionality has increased..." (Current data user, CDC staff member)

Trends Analysis

Most data users had not tried to conduct trend analyses. A few had, though. Of those, some mentioned changes in questions as a barrier to conducting trend analyses:

"Well, it's complicated because…questions vary from year to year. So either …they're either not the same questions, or you have them one year and you don't have them another year." (Current data user, academic)

"HINTS has kind of played around a lot with the questions they've asked, rephrased them and reworded them, and then that causes some problems if you're trying to do some sort of, like trend analysis." (Current data user, academic)

Two respondents mentioned other unique challenges they encountered, but these were not mentioned by other data users:

"From a survey methodology standpoint… from '05 to '07, '03 and '05 were, were CATI. They were telephone by RDD, and then '07 has a different, did a different sampling, which was the phone and the mail. And so you just have to be able to account for that sort of stuff and take it, and there were certain biases associated with each approach." (Current data user, academic)

Well, just recently we were talking about doing a trend analysis across the three waves, and then in that *Analytical Methods* book it talked about how to do it across two waves, but of course it didn't cover three waves. …if they really have it just spelled out, it kind of reduces, I guess, any kind of confusion or possibility for error that other researchers might have, if they have it actually spelled out specifically." (Current data user, academic)

Suggestions for Additional Documentation

Data users had several suggestions for additional documentation, however these did not overlap. These primarily had to do with sampling and weighting:

"I think it might be worth the investment in … developing a few more methodological bulletins that look at these issues, provide guidance about analysis and weighting and under what conditions it's better to just stratify or [inaudible] whereas when we take the full larger respondent and weight it in proportion." (Potential data user, focus group, cancer control planners)

"It might be helpful if they could do some sort of analysis to try to justify or look more at the survey's representativeness. If they publish some methodological papers about that in terms of the sample characteristics. That would be helpful, especially if they had them published somewhere that could be cited to help other researchers then when they come along trying to publish papers, to be able to cite." (Current data user, academic)

"I have trouble with the mail survey. The way it was described … the sampling is a cluster analysis based on the individual, the clusters are the individual homes. And if you read the documentation, it clearly states that surveys were mailed to each household and that every adult in the household was supposed to take the survey. But only three surveys actually were mailed to a household. And therefore, if a household had more than three adults in it, they really had no way of conducting the survey and it never, there's never any documentation that I have found … how they compensated for the fact that there were so many households only had one survey returned or some households had two surveys returned…And therefore you have clusters of size one, you have clusters of size two ….and no one has been able to answer my question on that, or has been willing to answer my question on that." (Current data user, academic)

3.3 Results Specific to Results Users

3.3.1 General Findings Specific to Results Users

The general findings from results users were as follows:

- Results users have a very wide range of audiences, from donors and patients, to clinicians, the media and the general public

- Results users employ various channels, including broadcast media, mailings, outreach to church groups, and health fairs to reach their target audiences

- Several results users said they think there is low awareness of HINTS among people in their line of work.

- Most results users need data on the incidence and prevalence of cancer by geographic area. Some suggested this can be difficult to find.

- A couple of users did mention needs for communication-related data

Each of these findings is explained in detail below.

3.3.2 Detailed Findings Specific to Results Users

Results Users Primary Audiences and Methods of Outreach

Results users were asked about their target audiences for information. They mentioned a very broad range of audiences, including, but not limited to:

- donors to their respective cancer centers

- patients

- caregivers

- survivors

- clinicians

- minorities and underserved populations, including African American, Latino, Arab American, and Native American populations and those of lower SES

- the media

- the general public.

Results users, especially cancer center communication directors, varied widely in their main methods of outreach to patients and other audiences. Some methods they mentioned included: radio, web-based seminars, church groups, printed, educational materials, presentations, posters and flyers in exam rooms, mailings, health fairs, and phone calls.

Data Needs

Asked about their specific data needs, many results users expressed needs for data on the incidence and prevalence of cancer in different geographic areas:

> "Sometimes I have queries from reporters… 'Tell me about cancer in my, in my county or in my area, in my geographic region.'" (Potential results user, cancer center communication director)

> "…I would say I personally look at [geographic] data probably every month or two, and the reason we do is that, you know, I'm responsible for business development and marketing. So, you know, if we know that we have a, … higher incidence of disease in a certain market over another that may direct where we choose to advertise or where we choose to do community events…to try to impact either preventing the disease or, you

know, making sure that people who get that disease know what treatment options are available." (Potential results user, cancer center communication director)

"I think when we're talking to people in [state name], they want to know about what's going on in [state name]…They really, like they want that data, they really want to know how [state name] stands against what's happening in other states." (Potential results user, focus group, cancer control planner)

But some said this type of data can be difficult to find:

"We, we love area specific, like statewide [data]. I mean, it's one thing to say across the United States, but to have, you know, numbers specifically for [state name] and even drill down even more for, you know, the [area name], we try and look for that, but that's not always out there." (Potential results user, cancer center communication director)

"In order for us to get the media to care or want to write a story, we need local information. So we need to be able to find it for [state name] or for the metropolitan [city name] area, you know, as easily as we can. And frankly, it's really not that easy to find. I don't have real good luck finding stuff on the NCI website." (Current results user, cancer center communication director)

Some results users did mention needs for communication-related data specifically:

"What would be helpful for us to have is things that kind of match the data on health literacy with, with formats that are useful for people at different levels of health literacy, related particularly to medical decision making and compliance. Because …it's not until … you screw up your drugs, that we know you didn't get it." (Potential results user, focus group, cancer control planner)

"I think the topic areas would be communication on all the varieties of individuals both in terms of direct in-person patient and also mediated through various technology, health technology, by going to the internet or using a healthometer, messaging, all kinds of different media." (Current results user, health policy researcher)

Results users said the primary sources of data they use currently include NCI, the American Cancer Society, Cancer Control PLANET or SEER data. Others mentioned national health surveys such as NHIS, BRFSS, and NHANES, state departments of health and state cancer registries. Asked about preference for formats for that data, responses were very mixed. Some preferred text, others graphs, and some a combination of the two.

Recommendations and Summary

Overall, comments regarding the HINTS survey and website were predominantly positive. Respondents provided interesting feedback and important suggestions. Asked whether they would be likely to use the HINTS data in the future, most users said "yes."

4.1 Recommendations

Based on the findings, RTI makes the following recommendations to NCI for improvement to HINTS and the HINTS website:

4.1.1 Recommendations Overall

- Increase outreach about HINTS by contacting graduate schools in communication, public health, and statistics about the availability of this free public-use dataset. Also consider adding links to HINTS from other DHHS websites or advertising at public health conferences and on popular health websites (e.g., WebMD.com). Another option is to create web widgets, that users could place on their own websites to keep updated on HINTS findings or news. The HINTS program might also work to create partnerships to promote HINTS on the sites we know users visit, such as cancercontrolplanet.cancer.gov or the ACS website.

- Consider reorganizing the HINTS website and inserting tabs to make specific sections easier to find. One option would be to organize content according to the target audience. For example, a section for "data users" could include the datasets and codebooks, while a section "for cancer center communication directors" might include the brochure, briefs, and recent findings. Other tabs could include "FAQs" or "Reports."

- Use plain language principles for those web pages most relevant to results users in order to ensure the literacy level is not too high. Some pages might include subheads with less text. Users could then click on the subhead in which they are interested to get more information on a particular topic. Briefs and other products most likely to be used by results users should be kept at a lower literacy level.

- Add a blog to the website where users could share information about data analysis methods and other topics. This blog could be monitored periodically by an NCI staff member who could intervene to correct any misinformation.

- Consider adding a feature to engage users more in content generation. This might involve a submission system, with which users could submit ideas for new topic modules or questions for the next HINTS survey.

- Add dynamic features to the website to give it a more updated feel. (Consider a running ticker across the top with new findings or news).

- Provide a subscription-based e-mail newsletter with updates or new results from HINTS analyses. This tool could also be used to more actively target specific types of users with the

HINTS products most useful to them (e.g., the Cancer Trends Report for cancer center communication directors; updated documentation on weighting to the data users). When they subscribe they could answer questions about type of data user and stakeholder group (e.g., cancer control planner vs. academic) so that a newsletter could be tailored accordingly.

- Continue developing HINTS Briefs and consider other ways to use the Quick Facts feature elsewhere on the website or in other HINTS products or publications.

- Rename the My Toolkit to make it more clear what this feature is for (e.g., "my documents" or "my items for download") or add to the website the capability of directly downloading documents without needing to use My Toolkit.

- Consider adding questions to HINTS on topics such as additional cancer types, use of more specific Internet sites, use of social media and topics specific to cancer patients (e.g., survivorship issues, end-of-life issues).

4.1.2 Recommendations Specific to Data Users

- Provide more documentation on weighting of the sample and the sampling methods more generally or where documentation already exists, simply make it more prominent. Documentation on sampling should specifically detail how the cluster sampling was dealt with (multiple respondents in one household).

- Consider providing more documentation on reliability and validity of HINTS items.

- Strive for consistency in question wording on future iterations of HINTS and across modes, when possible.

- Update the trend report to include methods for analysis across three time periods. Continue to include code for SAS and STATA for analyzing across all three time periods.

- As response rates are of concern, add information about trends in response rates for different survey methods and other national surveys to provide context to HINTS response rates.

- Make the list of publications and presentations searchable by key word or HINTS question. Make it more obvious that clicking on the links will take the user to the to the citation on PubMed. It may also be useful to add works in progress.

4.1.3 Recommendations Specific to Results Users

- Make clear the reasons why collecting local data is not feasible given the sample of the HINTS survey.

- Consider placing some results, quick facts, or highlights on the home page of the HINTS website. Topics could rotate to keep results users interested in returning to the site.

- Consider the wide range of audiences listed by results users when deciding upon new topics for HINTS briefs.

- Revise briefs so that "quick facts" are closer to the top in the HTML versions and add footnotes to clarify charts and graphs. Make it more obvious that briefs are printable in PDF form.

- Develop a communication plan for each of the different target audiences which would include specific dissemination channels and strategies relevant for the audience.

- Consider using current target audiences in promotional strategies and efforts. For example, the HINTS program could disseminate copies of HINTS brochures or briefs to members of the PAN steering committee and other results users, who can pass them out to others in their cancer centers and other work places. Graduate students could become HINTS ambassadors, charged with disseminating information about HINTS to classmates via social media and word of mouth.

4.2   Summary

The focus groups and interviews provided valuable data on current and future uses of HINTS. Overall, impressions of HINTS were very positive. However, both current and potential users had numerous ideas for improvements to the data, the documentation, the website, and presentation of results.

As changes are made to the HINTS website in the future, it will be important for NCI to continue soliciting feedback from all of these types of users. Some ways HINTS could make this feasible would be to add a link on the website on which users could click to send an e-mail providing comments or suggestions. Alternatively, NCI might initiate periodic web surveys to solicit suggestions (these could pop up when a user visits the site). An additional idea might be to recruit a panel of users that could meet annually to provide feedback or pretest new ideas. Ideally, such a panel would include both current and potential users of both data and results and would include representation from many of the different subsegments (e.g., academics, cancer control planners, cancer center communication directors, students, federal employees).

Appendix A: Recruitment Screeners

Original Screener Questions

[Note to Interviewer: Code appropriate group based on recruiting location or strategy: If unknown, ask question in italics]

1. **How would you best describe your occupation or career? [READ CATEGORIES]**
   - Cancer control planner (that is, someone who works at the Federal, state, or regional level to plan cancer education, prevention, screening, or treatment programs)

   - CDC and/or other federal agency staff

   - Academic (professor, researcher at University, etc.)

   - Student in the UNC Health Communication Certificate Program

   - Cancer Center Communication director

   - Cancer advocacy organization director

   - Other:_____

2. **What is your highest level of education? [FOR DESCRIPTIVE PURPOSES ONLY]**
   - Some College or less

   - College Graduate

   - Master's level

   - PhD

   - MD or other professional degree

3. **What do you consider to be your field or your area of expertise?**

4. **Do you use the Internet in your day to day work?**
   - Yes

   - No *[END = Ineligible]*

The Health Information National Trends Survey (HINTS) is a national, biennial survey designed to collect nationally representative data on the American public's need for, access to, and use of cancer-related information. HINTS was developed by the National Cancer Institute (NCI) and was created to monitor changes in the rapidly evolving field of health communication.

5. Before today, have you ever heard of the HINTS?

    – Yes (GO TO 6)

    – No (GO TO 5a)

    5a. In thinking about HINTS, which of the following do you think would be MOST USEFUL to you in your work? [RESPONDENTS NEED TO CHOOSE ONE OR THE OTHER]

    – Analyzing the data yourself for research or evaluation studies [code as POTENTIAL DATA USER and skip remaining questions; GO TO END]

    – Seeing or using reports or other publications that summarize the results of the survey [code as POTENTIAL RESULTS USER and skip remaining questions; GO TO END]

    – I would not use data or findings from a national health survey *[END = Ineligible]*

6. Have you ever analyzed, or been part of a research team that analyzed, data from HINTS?

    – Yes [Code as Current Data User] [Go to Q7]

    – No [GO TO Q8]

7. On this team, did you personally use a statistical program like SAS, SUDAAN, OR SPSS to analyze HINTS data? [QUESTION ASKED FOR DESCRIPTIVE PURPOSES ONLY]

    – Yes [SKIP REMAINING QUESTIONS; GO TO END]

    – No [SKIP REMAINING QUESTIONS; GO TO END]

8. Have you ever used or reviewed any of the following HINTS program resources? Check all that apply.

    – HINTS background information (e.g., fact sheet) [Code as any, go to Q9]

    – HINTS Web site [Code as any, go to Q9]

    – Survey questions and frequencies found on the Web site [Code as any, go to Q9]

    – HINTS Briefs [Code as any, go to Q9]

    – Publications or presentations using HINTS data [Code as any, go to Q9]

    – HINTS technical reports and documentation (e.g., The Analytic Methods to Examine Change Across Years report; final reports on methods; survey instruments) [Code as any, go to Q9]

    – I have *NEVER* reviewed or used any HINTS resources [Code as never, go to Q9]

Q9. **Which of the following do you think would be MOST USEFUL to you in your work?**
[RESPONDENTS NEED TO CHOOSE ONE OR THE OTHER]

- Analyzing the data yourself for research or evaluation studies **[code as Potential Data User]**

- Seeing or using reports or other publications that summarize the results of the survey

- I would not use data or findings from a national health survey *[END = Ineligible]*

END OF SCREENER QUESTIONS

IF INDIVIDUAL IS ELIGIBLE

You are eligible to participate in this study, which is funded by the National Cancer Institute. The purpose of this study is to gain insight about the reach of and satisfaction with the HINTS Program, a research tool funded by the NCI used to gather and disseminate information on cancer and cancer-related behaviors. NCI is interested in gathering feedback from a variety of different users regarding the relevance, quality and scope of the data collected. The research study is being conducted by RTI International, a non-profit social science research organization whose headquarters are in Research Triangle Park, North Carolina.

For Focus Group: We will be having a focus group [insert date and location]. The focus group will last approximately 90 minutes. You will be asked about your experience and satisfaction with the HINTS data and to provide feedback and suggestions about the HINTS program. Participants in the focus group will only use a first name to identify themselves. The focus group will be audio-taped. Your participation in this study is completely voluntary. By participating, you may gain knowledge of the HINTS program that will aid you in your future research. There are no other direct benefits to you from participating in this study. The study results may help RTI improve its evaluation of the HINTS Program by identifying ways to improve the protocol guides to accurately tap users' insight.

[If non-Federal employee]: In appreciation for your time, you will receive a $50 gift certificate to Amazon. You will receive the gift certificate by email after the focus group is completed.

Are you interested and available to participate in this focus group?

❏ No ❏ Yes   [If yes]: Great. Please let me get your correct contact information so I may send you a consent form, directions, and a reminder about the date and time of the focus group.

For Triad Interviews: We will be having a small group interview with 3 people on [insert date and location]. The interview will last approximately 90 minutes. You will be asked about

your experience and satisfaction with the HINTS data and to provide feedback and suggestions about the HINTS program. Participants in the interview will only use a first name to identify themselves. The interview will be audio-taped. Your participation in this study is completely voluntary. By participating, you may gain knowledge of the HINTS program that will aid you in your future research. There are no other direct benefits to you from participating in this study. The study results may help RTI improve its evaluation of the HINTS Program by identifying ways to improve the protocol guides to accurately tap users' insight.

[If non-Federal employee]: N/A – TRIADS should all be Federal employees.

Are you interested and available to participate in this focus group?

❑ No ❑ Yes   [If yes]: Great. Please let me get your correct contact information so I may send you a consent form, directions, and a reminder about the date and time of the focus group.

For Individual Interviews: We will be having interviews between [insert dates]. The interview will last approximately 60 minutes. You will be asked about your experience and satisfaction with the HINTS data and to provide feedback and suggestions about the HINTS program. On the day of your interview, you will need to have access to a computer with the Internet as we will be asking you to review some specific web pages while we are talking. During your interview, we will use your first name only. The interview will be audio-taped. Your participation in this study is completely voluntary. By participating, you may gain knowledge of the HINTS program that will aid you in your future research. There are no other direct benefits to you from participating in this study. The study results may help RTI improve its evaluation of the HINTS Program by identifying ways to improve the protocol guides to accurately tap users' insight.

[If non-Federal employee]: In appreciation for your time, you will receive a $50 gift certificate to Amazon. You will receive the gift certificate by email after the interview is completed.

Are you interested and available to participate in this interview?

❑ No
❑ Yes

[If yes]: Great. Please let me get your correct contact information so I may send you a consent form, directions, and a reminder about the date and time of the interview.

IF INDIVIDUAL IS INELIGIBLE

I'm sorry, but based on your answers you are not eligible to participate in this study. Thank you so very much for taking the time to answer these questions and for your interest in the

HINTS Program. If you would like more information about HINTS, please go to:
http://hints.cancer.gov/.

**IF INDIVIDUAL IS ELIGIBLE BUT FOCUS GROUP/INTERVIEW SLOTS ARE
FULL**

You are eligible to participate in this study, however right now we have filled our quota of
individuals whose background and experience are similar to yours. Should someone cancel,
would you be interested in participating in [a focus group / interview]?

❑ No   ❑ Yes

[If yes]: Great. Please let me get your correct contact information so I may contact you if we
have a cancellation.

**Screener Questions (Revised for Leadership Institute Conference-to allow for users who
are both data user and results user)**

[Note to Interviewer: Code appropriate group based on recruiting location or strategy: If
unknown, ask question in italics]

9. *How would you best describe your occupation or career? [READ CATEGORIES]*

    – Academic (professor, researcher at University, etc.)

    – Cancer control planner

    – UNC Health Communication Certificate Program Student

    – Cancer Center Communication director

    – Cancer advocacy organization director

    – CDC and/or other federal agency staff

    – Other:_____

10. *What is your highest level of education?[FOR DESCRIPTIVE PURPOSES ONLY]*

    – Some College or less

    – College Graduate

    – Master's level

    – PhD

    – MD or other professional degree

11. *What do you consider your field or your area of expertise to be?*

12. *Do you use the Internet in your day to day work?*

    – Yes

    – No *[Ineligible]*

The Health Information National Trends Survey (HINTS) is a national, biennial survey designed to collect nationally representative data on the American public's need for, access to, and use of cancer-related information. HINTS was developed by the National Cancer Institute (NCI) and was created to monitor changes in the rapidly evolving field of health communication.

13. *Before today, have you ever heard of the HINTS?*
    – Yes (GO TO 6)

    – No (GO TO 5a)

5a. *In thinking about HINTS, which of the following do you think would be MOST USEFUL to you in your work? (Choose the one that best describes you)*
    – Analyzing the data yourself for research or evaluation studies **[Code as Potential Data User]** *[END = Ineligible]*

    – Seeing or using reports or other publications that summarize the results of the survey **[Code as Potential Results User]**

    – **Both [analyzing the data and seeing or using reports and publications that summarize the survey results] [Code as BOTH Potential Data User and Potential Results User –** *new category of user***]**

    – I would not use data or findings from a national health survey *[END = Ineligible]*

14. *Have you ever analyzed, or been part of a research team that analyzed, data from HINTS?*
    – Yes [Go to Q7] [nothing coded with this option]

    – No [GO TO Q8]

15. *On this team, did you personally use a statistical program like SAS, SUDAAN, OR SPSS to analyze HINTS data? [QUESTION ASKED FOR DESCRIPTIVE PURPOSES ONLY]*
    – Yes [Go to Q8]

    – No [Go to Q8]

16. *Have you ever used or reviewed any of the following HINTS program resources? (IF YES TO ANY, Code as Current Results User).*
    – HINTS background information (e.g., fact sheet)

    – HINTS Web site

    – Survey questions and frequencies found on the Web site

    – HINTS Briefs

    – Publications or presentations using HINTS data

- HINTS technical reports and documentation (e.g., The Analytic Methods to Examine Change Across Years report; final reports on methods; survey instruments)

- I have never reviewed or used any HINTS resources [GO TO Q9]

> If Q5 (ever heard of HINTS) = Yes AND Q6 (ever analyzed data) = No
> AND Q8 (ever used HINTS resources) = never, ask Q9.
>
> If Q5 (ever heard of HINTS) = Yes AND Q6 (ever analyzed data) = Yes
> AND Q8 (ever used HINTS resources) = Code as both Current Data User and Current Results User – new category of user.

Q9. *In thinking about national health surveys, **which of the following do you think would be MOST USEFUL to you in your work?** [RESPONDENTS NEED TO CHOOSE ONE OPTION](Choose the one that best describes you)*

- Analyzing the data yourself for research or evaluation studies *[code as Potential Data User] [INELIGIBLE]*

- Seeing or using reports or other publications that summarize the results of the survey *[code as Potential Results User]*

- **Both [analyzing the data and seeing or using reports and publications that summarize the survey results] [Code as BOTH Potential Data User and Potential Results User –** *new category of user*]

- I would not use data or findings from a national health survey *[END = Ineligible]*

IF INDIVIDUAL IS ELIGIBLE

You are eligible to participate in this study, which is funded by the National Cancer Institute. The purpose of this study is to gain insight about the reach of and satisfaction with the HINTS Program, a research tool funded by the NCI used to gather and disseminate information on cancer and cancer-related behaviors. NCI is interested in gathering feedback from a variety of different users regarding the relevance, quality and scope of the data collected. The research study is being conducted by RTI International, a non-profit social science research organization whose headquarters are in Research Triangle Park, North Carolina.

For Focus Group: We will be having a focus group [insert date and location]. The focus group will last approximately 90 minutes. You will be asked about your experience and satisfaction with the HINTS data and to provide feedback and suggestions about the HINTS program. Participants in the focus group will only use a first name to identify themselves. The focus group will be audio-taped. Your participation in this study is completely voluntary. By participating, you may gain knowledge of the HINTS program that will aid you in your future research. There are no other direct benefits to you from participating in this study. The study results may help RTI improve its evaluation of the HINTS Program by identifying ways to improve the protocol guides to accurately tap users' insight.

[If non-Federal employee]: In appreciation for your time, you will receive a $50 gift certificate to Amazon. You will receive the gift certificate by email after the focus group is completed.

Are you interested and available to participate in this focus group?

❑ No ❑ Yes   [If yes]: Great. Please let me get your correct contact information so I may send you a consent form, directions, and a reminder about the date and time of the focus group.

IF INDIVIDUAL IS INELIGIBLE

I'm sorry, but based on your answers you are not eligible to participate in this study. Thank you so very much for taking the time to answer these questions and for your interest in the HINTS Program. If you would like more information about HINTS, please go to: http://hints.cancer.gov/.

IF INDIVIDUAL IS ELIGIBLE BUT FOCUS GROUP/INTERVIEW SLOTS ARE FULL

You are eligible to participate in this study, however right now we have enough individuals with your background and experience. Should someone cancel, would you be interested in participating in [a focus group / interview]?

❑ No   ❑ Yes

[If yes]: Great. Please let me get your correct contact information so I may contact you if we have a cancellation.

Appendix B: Research Plan

Research Plan

Groups Represented	Current		Potential		Format of Data Collection and Location	Recruitment Strategy
	Data Users	**Results Users**	**Data Users**	**Results Users**		
Segments	*Interpreting experience / analysis experience*	*Limited experienced*	*Familiar / unfamiliar with HINTS*	*Familiar / unfamiliar with HINTS*		
Academic (N=12)	4				4 IDIs (phone)	Users' conferences (9/2009)
			4		1 FG (in-person)	Dissemination Conference (March 2010)
Cancer control planners (e.g., state health dept staff) (N=24)			(6 completed FG) but 5/6 were closer to potential data users than results users so we'll count them here		2 FG (in person)	Dissemination Conference (March 2010)
		4		20		Leadership Institute conference (June 2010)
		6			8 IDI (phone)	Recruited from Webinar, Dissemination Conference or Leadership Institute (March – June 2010)
UNC Health Communication Certificate Program Students (n=10)	2	2	4	2	1 FG (in person at UNC)	University of North Carolina
Cancer center communication directors (N=8)		1		7	8 IDIs (telephone) post-meeting	NCI Public Affairs and Marketing Steering Committee Meeting (1/2010)
Cancer advocacy organizations (N=8)	1				8 IDIs (telephone)	Referral from NCI (email invitations telephone calls)
CDC and/or other federal agency staff (N=12)	1	1	1	3	4 triads (in person) Atlanta, GA	Referral from agency contacts (email invitations / telephone calls)
TOTAL OF COMPLETES	8	14	15	32	6 FG (n=44) 0 triads 24 IDIs	
GOAL TOTAL (N=74)	9 (12%)	17 (23%)	15 (20%)	33 (44%)	4 FGs (n=34) 4 triads (n=12) 28 IDIs	-

Key: FG = focus group, IDI = in-depth interview. Notes: 62 nonfederal employees and 12 federal employees = 74 individuals.

Appendix C: Discussion Guides

Student Focus Group Guide

Welcome and Ground Rules

Thank you very much for taking part in this interview. We would we'd like to learn about your opinions on issues related to the Health Information National Trends Survey (HINTS). Your ideas and opinions are very important to us.

I'm _____ and I'll be conducting the interview today. _____ will be helping me and taking notes during the group. We're both from RTI, International a non-profit organization that conducts health-related research.

Group Objectives

We are holding these interviews for the National Cancer Institute (NCI). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Our goal today is to get your opinions about how HINTS could be helpful to you in your work and/or studies. HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years. This interview will last between 60 - 90 minutes.

Please let me review some basics with you:

1. First of all, there are no right or wrong answers. We want to know your honest ideas and opinions. We are here to learn from you.

2. If you do not understand a question that I ask, please let me know. I'll try to re-phrase it or explain what we are trying to get at with the question. We will be audiotaping this interview. No one except project staff will hear the audiotapes. We will be writing a summary report of the findings from all the discussions we conduct and will refer to the tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

3. Your identity outside this group and anything you say here will remain private. Your name, address, and phone numbers will not be given to anyone, and no one will contact you after this group is over. During the interview, please only use your first name.

4. The opinions expressed by participants should remain confidential and not be discussed outside of this focus group.

5. Because we are audiotaping, it is important that you try to speak up.

6. Please turn your cell phones to silent or vibrate.

7. Should you need a break at any point during the interview, please let me know.

8. Please don't hold back from giving me your honest opinions. If you have something negative to say, that's all right. Sometimes the negative things are the most helpful. Remember, there are no right or wrong answers. We just want to hear your opinions.

Do you have any questions before we start?

Obtain Informed Consent
[REVIEW FOLLOWING KEY POINTS FROM CONSENT]

- Your participation today is voluntary. If any question makes you feel uncomfortable, you do not have to answer it. You can also choose to end your participation at any time.
- We will write a summary report of the findings from all the discussions we conduct. Your name will not be used.
- You will receive a $50 gift card as a thank you for your time today. [Exclude this statement when interviewing Federal employees].
- If you have any questions regarding this interview after it is over, there are telephone numbers at the bottom of the consent form that you can call. [Leave respondents with a copy of the consent.]

Introduction
To get us started, let's just go around the room and have each of you tell us your name, what you are studying and your particular areas of interest related to cancer.

Probes: You can also tell us whether you use cancer information for coursework, teaching, for a thesis or dissertation or as part of a research fellowship or other job (or some combination of these).

On what cancer topics have you worked in the past? What particular cancer topics are you most interested in?

★Are there any particular target audiences in which you are particularly interested?[Probe: rural/urban; low SES; cancer patients; specific subgroups such as Hispanics, African Americans?)

How many of you have ever heard of HINTS? Have you used the HINTS survey in previous work? How? How did you first learn about HINTS?

How does HINTS compare to other surveys with which you work? [PROBE: in terms of ease of use, relevancy of data, technical support, documentation – WHAT ELSE?]

☒ What do you like about these other surveys? What do you not like so much?

☒ If you have not used HINTS before, do you have some ideas about how you might incorporate HINTS data or results into your future work?

★ What do you think HINTS has to offer someone like you?

GENERAL USE OF HEALTH OR CANCER RESULTS

Tell me about the specific data needs you have in your work or studies.

What kind of data or information do you find yourself needing most frequently?

Where do you most often look for such information? What do you like about this source? What do you not like? How is the information, data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you not like? What do you like about this method of presentation?

☒ What other sources do you turn to for cancer-related data? [Suggest if necessary: BRFSS, NHIS, American Cancer Society]. What do you like about these sources? What do you not like? How are the

data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you like about this method of presentation? What do you not like?

What cancer-related data or information do you often need, but can't find or have difficulty finding from any source? What specific information do you need? How would you like that information presented (text, graphs, charts, press release, tables of data, news articles or briefs?)

★   HINTS collects data about many different cancer and health topics. [SHOW LIST on paper]. For what other cancer topics would you like to have more results, information, or data? How would you use this information?

When you need data, how frequently do you need it broken down geographically? When you need data broken down, how do you need it (by region, state, county, Zip Code, something else?)

☒ Are there specific subgroups or subpopulations for which you often find yourself needing data (for example: age groups, sex, race or ethnicity)?

Additional probes: income, health insurance status

HINTS WEB SITE

Let's take a look at the HINTS home page together (http://hints.cancer.gov/)

Who do you think this website is designed for? (Probe: Researchers? Health educators? Students? Other types of people?)

Where would you first go on this site and why?

What specifically would you be looking for?

What recommendations would you make to make the site more useful or inviting to students like you? ☒ [If not mentioned: What are your thoughts about making maps or data by geographic region available on the site? Here are [2 or 3] different examples of how geographic data could be presented for [insert topic]. What are the advantages of each example? What are the disadvantages? Which example do you prefer?

USE OF HINTS PRODUCTS AND RESULTS

☒   Have you ever tried to export the charts on the HINTS website that display findings into a document? How easy or difficult was that process? What could be done to improve the process?

★   Have you used HINTS data to examine changes from year to year or trends over time?
        ★If yes: Describe your experience in analyzing data from year to year? What type of technical support did you need to do these analyses?

        ★If no: What has prevented you from analyzing HINTS data from year to year? What type of technical support would you need to do these analyses?

[ASK ONLY IF SOME OF GROUP HAS USED HINTS DATA]" [SHOW REPORT: http://hints.cancer.gov/docs/HINTS_Data_Users_Handbook-2008.pdf].
Have you ever reviewed the report, "**Analytic Methods to Examine Changes Across Years Using HINTS 2003 & 2005 Data**"? [SHOW REPORT: http://hints.cancer.gov/docs/HINTS_Data_Users_Handbook-2008.pdf]. It is a handbook that provides instructions on how to combine the data files, includes sample SAS/SUDAAN and STATA code for carrying out the procedures. Tell me about your experience using this report. What was most useful? What was least useful? What was not included in this report that you wish had been?

[SHOW REPORT]. Have you ever reviewed the report "**Cancer Communication Health Information National Trends Survey 2003 and 2005**"? http://hints.cancer.gov/docs/hints_report.pdf].
It is described as offering "a snapshot at two different points in time of how the American public (18 years and older) is responding to changes in the health information environment, as well as a suggestive look at how the public responds within that environment to questions about cancer prevention, diagnosis, and treatment." Tell me about your experience using this report. What was most useful? What was least useful? What was not included in this report that you wish had been?

Now let's talk about the special issue of the Journal of Health Communication that showcased a variety of studies that used HINTS data. [Show hardcopy journal] The topics in this issue included cancer-related risk perceptions, disparities in cancer knowledge, information seeking, and impact of communication on cancer-relevant behavior. If NCI were to sponsor a future special journal issue or supplement of HINTS research, should the issue have a particular focus? What should it focus on?

[ASK ONLY IF SOME HAVE USED DATA]:
☒   The 2007 HINTS survey was administered by both phone and by mail. As a result, researchers are encouraged to assess mode effects, that is, how responses to the same item differ by survey mode. Have you ever analyzed mode effects for any type of survey data before? What methods did you use? Did you analyze data from the 2007 survey? If yes: Did you examine mode effects? If no, what barriers did you face in examining mode effects?

[ASK ONLY IF SOME HAVE USED DATA]:
★   When you download 2007 data, you also get documentation and information on how to analyze mode effects. Have you ever read through the information on mode effects? How easy or difficult was it for you to understand the information presented? In what other way could this information be presented for it to be most useful to you?

☒   Have you ever looked at the spreadsheet **HINTS Items Across Years** (http://hints.cancer.gov/instrument.jsp) ? If so, describe your experience in using this spreadsheet.

HINTS has a variety of different materials that describe the survey such as a brochure, fact sheet, update in the NCI Cancer Bulletin. [SHOW MATERIALS – BULLETIN LINK: http://www.cancer.gov/ncicancerbulletin/012610]. Have you ever used any of these HINTS materials? How might you use them in the future?

HINTS also has a variety of different materials that showcase findings from different studies using HINTS. For example, NCI has developed HINTS briefs. [SHOW MATERIALS: http://hints.cancer.gov/briefs.jsp]. Let's look at one of them together. What are your impressions of this resource? Does it contain the type of information that would be useful to you in your work? How could these Briefs be improved? On what particular topics would you like to see HINTS Briefs developed in the future?

HINTS has a place on the website called Research Using HINTS (http://hints.cancer.gov/results.jsp) that lists the presentations that have been made and papers which have been published using HINTS data. What are your impressions of this page? What makes it useful? What could improve it?

If the list of publications could be searched, what features would you most like to search on? For example, keywords, journal name, author, year?

What else either on or off the website could help you connect to research findings using HINTS data? The site only shows publications or presentations that have been completed. ☒ Should manuscripts under review be listed? Why or why not? Would knowing which researchers were conducting research with a particular HINTS question or questions be helpful to you? In what way would this help you?

How do you feel about displaying different results or a "HINTS fact" or "HINTS finding" on the home page as a way to connect users to the results?

The MyToolkit feature allows you to organize and save items from the HINTS Web site, including resources, materials, survey instruments, and data in one place as you navigate around the site. Then you can just go to My Toolkit when you're finished to download and save your choices. Do you think you might use this feature in the future? Why or why not?]

FUTURE USE OF HINTS:

Now that we have looked at the HINTS website and talked about HINTS, do you think you would be likely to use HINTS results or data in the future? How do you anticipate that you might use HINTS information or results in the future? (PROBE for a class assignment; for a conference paper or publications; thesis/dissertation; research assignment, etc.)

When new information about HINTS or findings from HINTS studies become available, how would you like to find out about them? [PROBE: Press release, E-mail newsletter, RSS feed, Widget]

What could be done to make the survey and its results more useful to students like you?

☒   There have been discussions at NCI about linking HINTS data to other national and regional datasets so that results from both can be viewed together. The proposed efforts aim to provide the shared data and system compatibility to allow for integrated data resources for research in cancer control. What other data sets should HINTS link to? How would you use these combined data or their results?

What final recommendations do you have to offer the HINTS program?

Current Data Users Guide

Welcome and Ground Rules

Thank you very much for taking part in this interview. We would like to learn about your opinions on issues related to the Health Information National Trends Survey (HINTS). Your ideas and opinions are very important to us.

I'm _____ and I'll be conducting the interview today. _____ will be helping me and taking notes during the group. We're both from RTI, International a non-profit organization that conducts health-related research.

Group Objectives

We are holding these interviews for the National Cancer Institute (NCI). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Our goal today is to get your opinions about how HINTS might be helpful to you in your professional position. HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years. This interview will last between: 45 and 60 minutes.

Please let me review some basics with you:

1. First of all, there are no right or wrong answers. We want to know your honest ideas and opinions. We are here to learn from you. We are not NCI employees and did not develop HINTS, so anything critical you might say about HINTS will not offend us.

2. If you do not understand a question that I ask, please let me know. I'll try to re-phrase it or explain what we are trying to get at with the question. We will be audiotaping this interview. No one except project staff will hear the audiotapes. We will be writing a summary report of the findings from all the discussions we conduct and will refer to the tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

3. Your identity outside this group and anything you say here will remain private. Your name, address, and phone numbers will not be given to anyone, and no one will contact you after this group is over. During the interview, please only use your first name.

4. The opinions expressed by participants should remain confidential and not be discussed outside of this focus group.

5. Because we are auditaping, it is important that you try to speak up.

6. Please turn your cell phones to silent or vibrate.

7. Should you need a break at any point during the interview, please let me know.

8. Please don't hold back from giving me your honest opinions. If you have something negative to say, that's all right. Sometimes the negative things are the most helpful. Remember, there are no right or wrong answers. We just want to hear your opinions.

Do you have any questions before we start?

Obtain Informed Consent
[REVIEW FOLLOWING KEY POINTS FROM CONSENT]

- Your participation today is voluntary. If any question makes you feel uncomfortable, you do not have to answer it. You can also choose to end your participation at any time.
- We will write a summary report of the findings from all the discussions we conduct. Your name won't be used.
- You will receive a $50 gift card as a thank you for your time today. [Exclude this statement when interviewing Federal employees].
- If you have any questions regarding this interview after it is over, there are telephone numbers at the bottom of the consent form that you can call.

[Interviewer, please have respondent sign and return consent form. Leave respondent with a copy of the consent.]

Introduction
Can you tell me a little about what you do in your current job?

What percentage of your work time would you say is devoted to research? How much of your research are you conducting secondary data analysis? If any, ask: Are you receiving funding to conduct [this/these] secondary data analysis project? From what source?

For Individual Interviews Only

How did you first learn about HINTS?

How long ago did you start working with HINTS data?

★ How did you first access the HINTS data (download it from the website?) In what version? (SAS, SPSS, STATA) How easy or difficult was it to download the data? Did you have any problems or difficulties using the data?

Both Individual Interviews and Focus Group

Tell me about the ways you have used the findings from your analyses of HINTS data?
[If not mentioned, probe the following: Funding request? Reports? Journal articles? Presentations?]

★ When you first started working with HINTS data, what type of additional information or support did you need? Were you able to get the information or support that you needed? How did you get this additional information or support?

What do you consider to be the best features of HINTS?

What do you think HINTS has to offer other professionals [or students] like you?

★Have you conducted secondary data analysis projects with surveys other than HINTS? If so, which ones?

How does HINTS compare to other surveys with which you work? [PROBE: in terms of ease of use, relevancy of data, technical support, documentation – WHAT ELSE?]

What do you like about these other surveys? What do you not like so much?

☒ What topics do you think are missing from HINTS?

<u>HINTS WEB SITE</u>

[NOTE TO MODERATOR: LOG ONTO WEBSITE, NEED PROJECTOR]

Let's take a look at the HINTS home page together (http://hints.cancer.gov/)

Who do you think this website is designed for? (Probe: Researchers? Health educators? Other types of people?)

When you go to the HINTS website, what section or page do you most frequently go to and why?

What do you find most useful in this section and why is it useful?

★ What section of the website do you not go to very often? Why do you not go to this section?

★ What information have you looked for on this site, but were unable to find?

What would make it easier for you to find the information you need on this site?

Individual Interviews Only

If you were looking to find specific questionnaire items you could use on another survey, where would you go?

If you were looking to find out whether or not the survey had data on the use of mammography, where would you go? Is there anywhere else on the site you might look?

If you wanted to find out how to conduct trends analyses using HINTS data, where would you go?

If you wanted to find out the sample size for each administration of HINTS, where would you go?

☒ If you wanted to find out if a specific question was asked on the 2003, 2005, and 2007 surveys, where would you look?

If you wanted to find presentations that had used HINTS data where would you go? How about publications? How about reports?

Both Individual and Focus Group Interviews

HINTS has a place on the website called Research Using HINTS (http://hints.cancer.gov/results.jsp) that lists the presentations that have been made and papers which have been published using HINTS data. Have you ever been to this section of the website? What were you looking for? Did you find it? How did you use that information? (PROBE: cite it in a paper; use as a reference for HINTS methods, etc.)

What else either on or off the website could help you connect to research findings using HINTS data? The site only shows publications or presentations that have been completed. ⊠ Should manuscripts under review be listed? Why or why not? Would knowing which researchers were conducting research with a particular HINTS question or questions be helpful to you? In what way would this help you?

If the list of publications could be searched, what features would you most like to search on? For example, keywords, author, journal, year?

⊠ NCI is interested in fostering collaborations between researchers. One possible way to do this is to give data users the option of having their contact information and their research topics listed on the website? What are your thoughts about this idea? Do you think this would help HINTS researchers connect to each other? Would you do it? Why or why not?

How easy or difficult would it be for someone like you be able to find information that you need on this site?

★ What recommendations would you make to NCI to make the site more useful to someone like you? How could the website be made more inviting to someone like you?

USE OF HINTS PRODUCTS AND RESULTS

Have you ever used "My Toolkit" to order HINTS materials? http://hints.cancer.gov/dataset.jsp
If yes: Tell me about your experience using this ordering tool. (Note to interviewer: It can be explained as an on-line shopping cart).

[If they have not heard of it or used it before: The MyToolkit feature allows you to organize and save items from the HINTS Web site, including resources, materials, survey instruments, and data in one place as you navigate around the site. Then you can just go to My Toolkit when you're finished to download and save your choices. Do you think you might use this feature in the future? Why or why not?]

Have you ever used [INSERT OTHER HINTS PRODUCT / FEATURE / REPORT / PUBLICATION[1]]? Tell me about your experience in using this [product/feature/tool/document].

⊠ Have you ever tried to export the charts on the HINTS website that display findings into a document? How easy or difficult was that process? What could be done to improve the process?

★ Have you used HINTS data to examine changes from year to year or trends over time?
        ★ If yes: Describe your experience in analyzing data from year to year? What type of technical support did you need to do these analyses?

        ★If no: What has prevented you from analyzing HINTS data from year to year? What type of technical support would you need to do these analyses?

★ Have you ever reviewed the report, "**Analytic Methods to Examine Changes Across Years Using HINTS 2003 & 2005 Data**"? [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/HINTS_Data_Users_Handbook-2008.pdf]. It is a handbook that provides instructions on how to combine the data files, includes sample SAS/SUDAAN and STATA code for carrying out the procedures. Tell me about your experience using this report. What was most useful? What was least useful? What was not included in this report that you wish had been?

---

[1] NCI is in the process of developing a few new features and products that may be operational by the time we are ready to conduct interviews. These names and description of these new features/products would be inserted. They may include the following: A Web site (communities.nci.nih.gov/hints) for suggesting and discussing items for upcoming HINTS surveys; a Wiki for suggesting and providing feedback on translations of HINTS items; a way to incorporate data from international survey administrations into the HINTS data repository and onto the HINTS Web site.

★ Have you ever reviewed the report "**Cancer Communication Health Information National Trends Survey 2003 and 2005**"**?** [DIRECT INTERVIEWEE TO LINK: [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/hints_report.pdf]]. It is described as offering "a snapshot at two different points in time of how the American public (18 years and older) is responding to changes in the health information environment, as well as a suggestive look at how the public responds within that environment to questions about cancer prevention, diagnosis, and treatment." Tell me about your experience using this report. What was most useful? What was least useful? What was not included in this report that you wish had been?

The 2007 HINTS survey was administered by both phone and by mail. As a result, researchers are encouraged to assess mode effects, that is, how responses to the same item differ by survey mode. Have you ever analyzed mode effects for any type of survey data before? What methods did you use? Did you analyze data from the 2007 survey? If yes: Did you examine mode effects? If no, what barriers did you face in examining mode effects?

When you download 2007 data, you also get documentation and information on how to analyze mode effects. Have you ever read through the information on mode effects? How easy or difficult was it for you to understand the information presented? In what other way could this information be presented for it to be most useful to you?
Have you ever looked at the spreadsheet **HINTS Items Across Years** (http://hints.cancer.gov/instrument.jsp) ? If so, describe your experience in using this spreadsheet.

HINTS also has a variety of different materials that showcase findings from different studies using HINTS. First, the HINTS briefs. http://hints.cancer.gov/briefs.jsp How have you used the HINTS Briefs? Which Briefs did you use? How was your experience using them? How could these Briefs be improved? On what particular topics would you like to see HINTS Briefs developed in the future? Would it be helpful to have a Brief focused on methodological issues (e.g., Mode effect testing; trend testing)?

Now let's talk about the special issue of the Journal of Health Communication that showcased a variety of studies that used HINTS data. How have you used this special issue in your work? The topics in this issue included cancer-related risk perceptions, disparities in cancer knowledge, information seeking, and impact of communication on cancer-relevant behavior.

If NCI were to sponsor a future special journal issue or supplement of HINTS research, should the issue have a particular focus? What should it focus on?

FUTURE USE OF HINTS:

☒ When new information about HINTS or findings from HINTS studies become available, how would you like to find out about them? [Probe: Press release,
E-mail newsletter, RSS feed, Widget]

The HINTS survey will likely be administered again in the near future. What changes in the survey would you like to see?

What new content areas or questions would you like to see on the survey?

What new documentation or support materials would you like to see?

HINTS has tried to foster a research community by offering information on its website and by hosting a Data Users Conference. What other things could NCI do to foster a research community?

☒ HINTS has the potential to be a data source to many different types of organizations and professionals. Which organizations and types of professionals could benefit the most from analyzing HINTS data?

☒ What organizations could benefit the most from seeing findings from HINTS studies?

☒ There have been discussions at NCI about linking HINTS data to other national and regional datasets so that results from both can be viewed and analyzed together The proposed efforts aim to provide the shared data and system compatibility to allow for integrated data resources for research in cancer control.

What other data sets should HINTS link to? How would you use these combined data or their results?

What final recommendations do you have to offer the HINTS program?

Closing
Those are all of the question I have.

I would like to thank you for participating in this interview. Your thoughts and opinions will be very useful to NCI in addressing the needs of HINTS users and potential users.

You will be receiving your incentive in the mail. Please feel free to contact me at xxx-xxx if you do not receive it within the next 2 weeks.

Potential Data Users Guide

Welcome and Ground Rules

Thank you very much for taking part in this interview. We would like to learn about your opinions on issues related to the Health Information National Trends Survey.
 (HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years.). Your ideas and opinions are very important to us.

I'm _____ and I'll be [conducting the interview/facilitating the focus group] today. _____ will be helping me and taking notes during the group. We're both from RTI, International a non-profit organization that conducts health-related research.

Group Objectives

We are holding these [interviews/focus groups] for the National Cancer Institute (NCI). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Our goal today is to get your opinions about how HINTS might be helpful to you in your professional position. HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years. [This interview will last between 45 and 60 minutes. This focus group will last 90 minutes].

Please let me review some basics with you:

1. First of all, there are no right or wrong answers. We want to know your honest ideas and opinions. We are here to learn from you. We are not NCI employees and did not develop HINTS, so anything critical you might say about HINTS will not offend us.

2. If you do not understand a question that I ask, please let me know. I'll try to re-phrase it or explain what we are trying to get at with the question. We will be audiotaping this [interview/focus group]. We want to give you our full attention and not have to take a lot of notes. No one except project staff will hear the audiotapes. We will be writing a summary report of the findings from all the discussions we conduct and will refer to the tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

3. Your identity outside this gruopand anything you say here will remain private. Your name, address, and phone numbers will not be given to anyone, and no one will contact you after this group is over. During the interview, please only use your first name.

4. The opinions expressed by participants should remain confidential and not be discussed outside of this focus group.

5. Because we are audiotaping, it is important that you try to speak up.

6. Please turn your cell phones to silent or vibrate.

7. Should you need a break at any point during the interview, please let me know.

8. Please don't hold back from giving me your honest opinions. If you have something negative to say, that's all right. Sometimes the negative things are the most helpful. Remember, there are no right or wrong answers. We just want to hear your opinions.

Do you have any questions before we start?

Obtain Informed Consent
[REVIEW FOLLOWING KEY POINTS FROM CONSENT]

- Your participation today is voluntary. If any question makes you feel uncomfortable, you do not have to answer it. You can also choose to end your participation at any time.
- We will write a summary report of the findings from all the discussions we conduct. Your name won't be used.
- You will receive a $50 gift card as a thank you for your time today. [Exclude this statement when interviewing Federal employees].
- If you have any questions regarding this [focus group/interview] after it is over, there are telephone numbers at the bottom of the consent form that you can call. [Leave respondent with a copy of the consent.]

[Interviewer, please have respondent sign and return consent form. Focus group facilitator, please ask if everyone signed and returned their consent when signing in.]

Introduction
For Focus Group: Everyone in this group has something in common – you [TAILOR FOR SPECIFIC GROUP – e.g., you all have said that you have an interest in analyzing data from the Health Information National Trends Survey]. To start things off, let's go around and have you all introduce yourselves to everyone. Please tell us your first name, where you're from, and how you typically use health or cancer-related data or statistics in your work.

Thanks for introducing yourselves.

GENERAL USE AND IMPRESSIONS OF HINTS AND HINTS DATA

So let's get started by sharing a little about what you do in your current job.

What percentage of your work time would you say is devoted to research? How much of your research are you conducting secondary data analysis?

★ If any, ask: Are you receiving funding to conduct [this/these] secondary data analysis project? From what source?

Tell me about the specific data needs you have in your position.

What information do you find yourself needing frequently?

What source do you turn to most often for that information? What do you like about this source? What do you not like? ⊠ How are the data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you like about this method of presentation? What do you not like?

⊠ What other sources do you turn to for cancer-related data? [Suggest if necessary: BRFSS, NHIS, American Cancer Society]. What do you like about these sources? What do you not like? How are the data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you like about this method of presentation? What do you not like?

What cancer-related data or information do you often need, but can't find from any source? What specific information do you need? How would you like that data presented (text, graphs, charts, press release, tables of data, news articles or briefs?)

HINTS has data on many different cancer and health topics. [SHOW LIST]. For what other cancer topics would you like to have more data or information? How would you use these data or information?

When you need data, how frequently do you need it broken down geographically? When you need data broken down, how do you need it (by region, state, county, Zip Code, something else?)

⊠ Have you conducted secondary data analysis projects with surveys other than HINTS? If so, which you often find yourself needing data (for example: age groups, sex, race or ethnicity) ones? Additional probes: income, health insurance status

What do you like about these other surveys? What do you not like?

⊠ How did [you/each of you] first learned about HINTS?

What have you heard about the survey and HINTS data?

HINTS WEB SITE: POTENTIAL DATA USERS

Let's take a look at the HINTS home page together (http://hints.cancer.gov/). How many of you have seen this page before? Take a moment and write down the words to describe your very first impression of this page. Let's all go around and share your first impressions. *Review Impressions with Group*

Based on your impressions, who are the intended users of this site?
Tell me why you say that. [Who do you think this website is designed for?
- (Probe: What specific aspects of the site lead you to think [FILL IN RESPONSES] are the intended users? (Researchers? Health educators? Other types of people?)

Where would you first go on this site and why?

What specifically would you be looking for?

⊠ If you were looking to find out what methods Americans used to search for health information, where would you go?

For Individual Interviews Only

⊠ If you were looking to find out whether or not the survey had data on the use of mammography, where would you go?

Where would you go if you needed to find a general description of the survey?

If you wanted to find out when HINTS had been administered, where would you go?

If you wanted to find out how HINTS worded questions on a particular topic (for example, tobacco use) where would you go? Is there anywhere else on the site you might look?

If you were looking to find specific questionnaire items you could use on another survey, where would you go?

If you were looking to find out whether or not the survey had data on the use of mammography, where would you go? Is there anywhere else on the site you might look?

★ If you wanted to find out how to conduct trends analyses using HINTS data, where would you go?

If you wanted to find out the sample size for each administration of HINTS, where would you go?

☒If you wanted to find out how HINTS worded questions on a particular topic (for example, tobacco use) specific question was asked on the 2003, 2005, and 2007 surveys, where would you go? Is there anywhere else on the site you might look?

If you wanted to find out how a variable had been coded, where would you go?

If you wanted to find presentations that had used HINTS data where would you go? How about publications? How about reports?

For Both Individual Interviews and Focus Groups

Based on what you have seen so far, what do you think HINTS might have to offer someone like you? How would you use this information in your work?

☒How easy or difficult would it be for someone like you be able to find information that you need on this site?

★ What recommendations would you make to NCI to make the site more useful to someone like you? How could the website be made more inviting to someone like you?

<u>USE OF HINTS PRODUCTS AND RESULTS: POTENTIAL DATA USERS</u>

Each of you has indicated that you have little or no experience using HINTS materials or data. HINTS has a variety of different materials that describe the survey. Let's first take a look at the HINTS Fact Sheet [show fact sheet: http://hints.cancer.gov/docs/HINTS_Fact_Sheet_accessible.pdf .

When you look at this fact sheet, do you think that this survey provides data that are relevant to your work? After reading it, what questions do you still have about the survey? What additional information would help you understand what HINTS has to offer? How else would you like to learn about HINTS?

☒ Now let's talk about the special issue of the Journal of Health Communication that showcased a variety of studies that used HINTS data. How have you used this special issue in your work? The topics in this issue included cancer-related risk perceptions, disparities in cancer knowledge, information seeking, and impact of communication on cancer-relevant behavior**.** If NCI were to sponsor a future special journal issue or supplement of HINTS research, should the issue have a particular focus? What should it focus on?[If they have not heard of it or used it before:

The MyToolkit feature http://hints.cancer.gov/dataset.jsp allows you to organize and save items from the HINTS Web site, including resources, materials, survey instruments, and data in one place as you navigate around the site. Then you can just go to My Toolkit when you're finished to download and save

your choices. Do you think you might use this feature in the future? Why or why not?] (Note to interviewer: It can be explained as an on-line shopping cart).

☒ With HINTS data, you could examine changes on a variable from year to year or trends over time. Have you ever conducted any trends analyses? Why or why not? What type of technical support do you think you would need to conduct trends analyses using HINTS data?

Let's take a look at the report, "**Analytic Methods to Examine Changes Across Years Using HINTS 2003 & 2005 Data"?** "? [DIRECT INTERVIEWEE TO LINK OR SHOW: http://hints.cancer.gov/docs/HINTS_Data_Users_Handbook-2008.pdf]. It is a handbook that provides instructions on how to combine the data files, includes sample SAS/SUDAAN and STATA code for carrying out the procedures. Take a quick look at the report. What do you think will be most useful? What is not included in this report that you wish had been?

Now take a look at the report "**Cancer Communication Health Information National Trends Survey 2003 and 2005"? "?** [DIRECT INTERVIEWEE TO LINK OR SHOW: [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/hints_report.pdf]]. It is described as offering "a snapshot at two different points in time of how the American public (18 years and older) is responding to changes in the health information environment, as well as a suggestive look at how the public responds within that environment to questions about cancer prevention, diagnosis, and treatment." What were your impressions of this report? What do you think would be most useful? What is not included in this report that you wish had been?

The 2007 HINTS survey was administered by both phone and by mail. As a result, researchers are encouraged to assess mode effects, that is, how responses to the same item differ by survey mode. ★ Have you ever analyzed mode effects for any type of survey data before? What methods did you use? Did you analyze data from the 2007 survey? If yes: Did you examine mode effects? If no, what barriers did you face in examining mode effects?

☒ Now let's look at the spreadsheet **HINTS Items Across Years** (http://hints.cancer.gov/resultsinstrument.jsp). What are your impressions of this spreadsheet? What could make it more useful?

HINTS has a place on the website called Research Using HINTS (http://hints.cancer.gov/results.jsp) that lists the presentations that have been made and papers which have been published using HINTS data. Have you ever been to this section of the website? What were you looking for? Did you find it? How did you use that information? (PROBE: cite it in a paper; use as a reference for HINTS methods, etc.)

If the list of publications could be searched, what features would you most like to search on? For example, keywords, author, journal, year?

☒ NCI is interested in fostering collaborations between researchers. One possible way to do this is to give data users the option of having their contact information and their research topics listed on the website? What are your thoughts about this idea? Do you think this would help HINTS researchers connect to each other? Would you do it? Why or why not?

How easy or difficult would it be for someone like you be able to find information that you need on this site?

☒ What else, either on or off the website could help you connect to research findings using HINTS data? [For example: conferences, webinars, using social media]. The site only shows publications or presentations that have been completed. Would knowing which researchers were conducting research with a particular HINTS question or questions be helpful to you?

<u>**FUTURE USE OF HINTS**</u>

Do you think you will develop a secondary data analysis project using HINTS data? Why or why not?

☒ For what purpose do you think you would analyze HINTS data? Do you think the information found on the website will give you all the information and tools you need to learn about the data and how to analyze it?

☒ What new content areas or questions would you like to see on the survey?

★What documentation or support materials do you think are needed?

What could be done to make the survey and its results more useful to you?

★HINTS has tried to foster a research community by offering information on its website and by hosting a Data Users Conference. What other things could NCI do to foster a research community?

☒ HINTS has the potential to provide results to many different types of organizations and professionals. Which organizations and types of professionals could benefit the most from results from HINTS studies?

☒ There have been discussions at NCI about linking HINTS data to other national and regional datasets so that results from both can be viewed and analyzed together. The proposed efforts aim to provide the shared data and system compatibility to allow for integrated data resources for research in cancer control. What other data sets should HINTS link to? How would you use these combined data or their results?

When new information about HINTS or findings from HINTS studies become available, how would you like to find out about them? [Probe: Press release, E-mail newsletter, RSS feed, Widget]

What final recommendations do you have to offer the HINTS program?

Closing
Those are all of the question I have.

I would like to thank you for participating in this interview. Your thoughts and opinions will be very useful to NCI in addressing the needs of HINTS users and potential users.

For Interviews:
You will be receiving your incentive in the mail. Please feel free to contact me at xxx-xxx if you do not receive it within the next 2 weeks.

For Focus Groups:
You will receive your gift card as you leave.

Current Results Users Guide

Welcome and Ground Rules

Thank you very much for taking part in this interview. We would we'd like to learn about your opinions on issues related to the Health Information National Trends Survey (HINTS). Your ideas and opinions are very important to us.

I'm _____ and I'll be conducting the interview today. _____ will be helping me and taking notes during the group. We're both from RTI, International a non-profit organization that conducts health-related research.

Group Objectives

We are holding these interviews for the National Cancer Institute (NCI). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Our goal today is to get your opinions about how HINTS could be helpful to you in your professional position. HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years. This interview will last between: IDI - 45 and 60 minutes / 60-90 minutes FG.

Please let me review some basics with you:

1. First of all, there are no right or wrong answers. We want to know your honest ideas and opinions. We are here to learn from you.

2. If you do not understand a question that I ask, please let me know. I'll try to re-phrase it or explain what we are trying to get at with the question. We will be audiotaping this interview. No one except project staff will hear the audiotapes. We will be writing a summary report of the findings from all the discussions we conduct and will refer to the tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

3. Your identity outside this group and anything you say here will remain private. Your name, address, and phone numbers will not be given to anyone, and no one will contact you after this group is over. During the interview, please only use your first name.

4. The opinions expressed by participants should remain confidential and not be discussed outside of this focus group.

5. Because we are audiotaping, it is important that you try to speak up.

6. Please turn your cell phones to silent or vibrate.

7. Should you need a break at any point during the interview, please let me know.

8. Please don't hold back from giving me your honest opinions. If you have something negative to say, that's all right. Sometimes the negative things are the most helpful. Remember, there are no right or wrong answers. We just want to hear your opinions.

Do you have any questions before we start?

Obtain Informed Consent
[REVIEW FOLLOWING KEY POINTS FROM CONSENT]

- Your participation today is voluntary. If any question makes you feel uncomfortable, you do not have to answer it. You can also choose to end your participation at any time.
- We will write a summary report of the findings from all the discussions we conduct. Your name will not be used.
- You will receive a $50 gift card as a thank you for your time today. [Exclude this statement when interviewing Federal employees].
- If you have any questions regarding this interview after it is over, there are telephone numbers at the bottom of the consent form that you can call.
  Leave respondent with a copy of the consent.

Introduction
Can you tell me a little about what you do in your current job?
Probes; Are you responsible for developing health promotion or cancer education materials?

If yes, on what topics have your materials focused on in the past? On what topics will you be developing materials in the next year or two?

☒ What educational formats have you used? For example, have you developed print materials, materials for the web, trainings, or other types of formats?

★ Who do you consider to be your main target audiences, or for those for whom you develop special initiatives? [Probe: rural/urban; low SES; cancer patients; specific subgroups such as Hispanics, African Americans?]

What do you consider to be your main methods of outreach to these groups? [Probe: How do you communicate with these groups most frequently?]

GENERAL USE OF HEALTH OR CANCER RESULTS

Tell me about the specific data needs you have in your position.

   ★ What kind of data or information do you find yourself needing most frequently?

Where do you most often look for such information? What do you like about this source? What do you not like?
   ★ How is the information, data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you not like? What do you like about this method of presentation?

☒ What other sources do you turn to for cancer-related data? [Suggest if necessary: BRFSS, NHIS, American Cancer Society]. What do you like about these sources? What do you not like? How are the data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you like about this method of presentation? What do you not like?

★What cancer-related data or information do you often need, but can't find or have difficulty finding from any source? What specific information do you need? How would you like that information presented (text, graphs, charts, press release, tables of data, news articles or briefs?)

HINTS collects data about many different cancer and health topics. [SHOW LIST]. For what other cancer topics would you like to have more results, information, or data? How would you use this information?

When you need data, how frequently do you need it broken down geographically? When you need data broken down, how do you need it (by region, state, county, Zip Code, something else?)

Are there specific subgroups or subpopulations for which you often find yourself needing data (for example: age groups, sex, race or ethnicity)?

Additional probes: income, health insurance status

HINTS WEB SITE

Let's take a look at the HINTS home page together (http://hints.cancer.gov/)

Who do you think this website is designed for? (Probe: Researchers? Health educators? Other types of people?)

What recommendations would you make to make the site more useful or inviting to someone in your profession? [If not mentioned: What are your thoughts about making maps or data by geographic region available on the site?
          ☒ Here are [2 or 3] different examples of how geographic data could be presented for [insert topic]. What are the advantages of each example? What are the disadvantages? Which example do you prefer? What other features would you like to see?

USE OF HINTS PRODUCTS AND RESULTS

HINTS has a variety of different materials that describe the survey such as a brochure, fact sheet, update in the NCI Cancer Bulletin). [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/brochure.pdf
http://hints.cancer.gov/docs/brochure.pdf
http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_022205/page3

Have you ever used any of these HINTS materials? How might you use them in the future?

HINTS also has a variety of different materials that showcase findings from different studies using HINTS. For example, NCI has developed HINTS briefs. [DIRECT INTERVIEWEE LINK: http://hints.cancer.gov/briefs.jsp]. Let's look at one of them together. What are your impressions of this resource? Does it contain the type of information that would be useful to you in your work? How could these Briefs be improved? On what particular topics would you like to see HINTS Briefs developed in the future?

Now let's look at the report "**Cancer Communication Health Information National Trends Survey 2003 and 2005**"? [DIRECT INTERVIEWEE TO OR SHOW LINK: [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/hints_report.pdf]]. It is described as offering "a snapshot at two different points in time of how the American public (18 years and older) is responding to changes in the health information environment, as well as a suggestive look at how the public responds within that environment to

questions about cancer prevention, diagnosis, and treatment." Can you page through this report and share your impressions of it? Does it contain information that would be useful to you in your work? How could this report be improved for someone like you.

HINTS has a place on the website called Research Using HINTS (http://hints.cancer.gov/results.jsp) that lists the presentations that have been made and papers which have been published using HINTS data. What are your impressions of this page? What makes it useful? What could improve it?

If the list of publications could be searched, what features would you most like to search on? For example, keywords, journal name, author, year?

☒ What else either on or off the website could help you connect to research findings using HINTS data? How do you feel about displaying different results or a "HINTS fact" or "HINTS finding" on the home page as a way to connect users to the results?

The MyToolkit feature http://hints.cancer.gov/dataset.jsp
allows you to organize and save items from the HINTS Web site, including resources, materials, survey instruments, and data in one place as you navigate around the site. Then you can just go to My Toolkit when you're finished to download and save your choices. Do you think you might use this feature in the future? Why or why not?] (Note to interviewer: It can be explained as an on-line shopping cart).

FUTURE USE OF HINTS:

Now that we have looked at the HINTS website and talked about HINTS, do you think you would be likely to use HINTS results or data in the future? How do you anticipate that you might use HINTS information or results in the future? (PROBE media reports; technical reports; grant application)

When new information about HINTS or findings from HINTS studies become available, how would you like to find out about them? [PROBE: Press release,
E-mail newsletter, RSS feed, Widget]

What could be done to make the survey and its results more useful to you?

☒ HINTS has the potential to provide results to many different types of organizations and professionals. Which organizations and types of professionals could benefit the most from results from HINTS studies?

☒ There have been discussions at NCI about linking HINTS data to other national and regional datasets so that results from both can be viewed together. The proposed efforts aim to provide the shared data and system compatibility to allow for integrated data resources for research in cancer control. What other data sets should HINTS link to? How would you use these combined data or their results?

What final recommendations do you have to offer the HINTS program?

Closing
Those are all of the question I have.

I would like to thank you for participating in this interview. Your thoughts and opinions will be very useful to NCI in addressing the needs of HINTS users and potential users.

For Interviews:
You will be receiving your incentive in the mail. Please feel free to contact me at xxx-xxx if you do not receive it within the next 2 weeks.

For Focus Groups:
You will receive your gift card as you leave.

Potential Results Users Guide

Welcome and Ground Rules

Thank you very much for taking part in this interview. We would like to learn about your opinions on issues related to the Health Information National Trends Survey (HINTS). Your ideas and opinions are very important to us.

I'm _____ and I'll be conducting the interview today. _____ will be helping me and taking notes during the group. We're both from RTI, International a non-profit organization that conducts health-related research.

Group Objectives

We are holding these interviews for the National Cancer Institute (NCI). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

Our goal today is to get your opinions about how HINTS could be helpful to you in your professional position. HINTS is a nationally representative survey about how Americans use cancer-related information and is administered every 2-4 years. This interview will last between: IDIs: 45 and 60 minutes / FG: 60-90 minutes.

Please let me review some basics with you:

1. First of all, there are no right or wrong answers. We want to know your honest ideas and opinions. We are here to learn from you.

2. If you do not understand a question that I ask, please let me know. I'll try to re-phrase it or explain what we are trying to get at with the question. We will be audiotaping this interview. No one except project staff will hear the audiotapes. We will be writing a summary report of the findings from all the discussions we conduct and will refer to the tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

3. Your identity outside this group and anything you say here will remain private. Your name, address, and phone numbers will not be given to anyone, and no one will contact you after this group is over. During the interview, please only use your first name.

4. The opinions expressed by participants should remain confidential and not be discussed outside of this focus group.

5. Because we are taping, it is important that you try to speak up.

6. Please turn your cell phones to silent or vibrate.

7. Should you need a break at any point during the interview, please let me know.

8. Please don't hold back from giving me your honest opinions. If you have something negative to say, that's all right. Sometimes the negative things are the most helpful. Remember, there are no right or wrong answers. We just want to hear your opinions.

Do you have any questions before we start?

Obtain Informed Consent
[REVIEW FOLLOWING KEY POINTS FROM CONSENT]

▪ Your participation today is voluntary. If any question makes you feel uncomfortable, you do not have to answer it. You can also choose to end your participation at any time.
▪ We will write a summary report of the findings from all the discussions we conduct. Your name will not be used.
▪ You will receive a $50 gift card as a thank you for your time today. [Exclude this statement when interviewing Federal employees].
▪ If you have any questions regarding this interview after it is over, there are telephone numbers at the bottom of the consent form that you can call. [Leave respondents with a copy of the consent.]

Introduction
Can you tell me a little about what you do in your current job?
Probes: Are you responsible for developing health promotion or cancer education materials?

If yes, on what topics have your materials focused on in the past? On what topics will you be developing materials in the next year or two?

☒ What educational formats have you used? For example, have you developed print materials, materials for the web, trainings, or other types of formats?

★ Who do you consider to be your main target audiences, or for those for whom you develop special initiatives? [Probe: rural/urban; low SES; cancer patients; specific subgroups such as Hispanics, African Americans?)

What do you consider to be your main methods of outreach to these groups? [Probe: How do you communicate with these groups most frequently?

GENERAL USE OF HEALTH OR CANCER RESULTS

Tell me about the specific data needs you have in your position.

★ What kind of data or information do you find yourself needing most frequently?

Where do you most often look for such information? What do you like about this source? What do you not like?

★ How is the information, data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you not like? What do you like about this method of presentation?

☒ What other sources do you turn to for cancer-related data? [Suggest if necessary: BRFSS, NHIS, American Cancer Society]. What do you like about these sources? What do you not like? How are the data or statistics presented (text, graphs, charts, press release, tables of data, news articles or briefs?) What do you like about this method of presentation? What do you not like?

What cancer-related data or information do you often need, but can't find or have difficulty finding from any source? What specific information do you need? How would you like that information presented (text, graphs, charts, press release, tables of data, news articles or briefs?)

★ HINTS collects data about many different cancer and health topics. [SHOW LIST OF HINTS QUESTIONS: http://hints.cancer.gov/questions/index.jsp]. For what other cancer topics would you like to have more results, information, or data? How would you use this information?

When you need data, how frequently do you need it broken down geographically? When you need data broken down, how do you need it (by region, state, county, Zip Code, something else?)

☒ Are there specific subgroups or subpopulations for which you often find yourself needing data (for example: age groups, sex, race or ethnicity)?

Additional probes: income, health insurance status

HINTS WEB SITE

Let's take a look at the HINTS home page together (http://hints.cancer.gov/)

Who do you think this website is designed for? (Probe: Researchers? Health educators? Other types of people?)

☒ What recommendations would you make to make the site more useful or inviting to someone in your profession? [If not mentioned: What are your thoughts about making maps or data by geographic region available on the site?

☒ [FG ONLY]: Here are [2 or 3] different examples of how geographic data could be presented for [insert topic]. What are the advantages of each example? What are the disadvantages? Which example do you prefer? What other features would you like to see on maps?

USE OF HINTS PRODUCTS AND RESULTS

HINTS has a variety of different materials that describe the survey such as a brochure, fact sheet, update in the NCI Cancer Bulletin). [DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/brochure.pdf

http://hints.cancer.gov/docs/HINTS_Fact_Sheet_accessible.pdf

http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_022205/page3

 Have you ever used any of these HINTS materials? How might you use them in the future?

No

HINTS also has a variety of different materials that showcase findings from different studies using HINTS. For example, NCI has developed HINTS briefs. [DIRECT INTERVIEWEE LINK: http://hints.cancer.gov/briefs.jsp]. Let's look at one of them together. What are your impressions of this resource? Does it contain the type of information that would be useful to you in your work? How could

these Briefs be improved? On what particular topics would you like to see HINTS Briefs developed in the future?

Now let's look at the report "**Cancer Communication Health Information National Trends Survey 2003 and 2005**"? [[DIRECT INTERVIEWEE TO LINK: http://hints.cancer.gov/docs/hints_report.pdf]. It is described as offering "a snapshot at two different points in time of how the American public (18 years and older) is responding to changes in the health information environment, as well as a suggestive look at how the public responds within that environment to questions about cancer prevention, diagnosis, and treatment." Can you page through this report and share your impressions of it? Does it contain information that would be useful to you in your work? How could this report be improved for someone like you.

☒ Now let's talk about the special issue of the Journal of Health Communication that showcased a variety of studies that used HINTS data. The topics in this **issue** included cancer-related risk perceptions, disparities in cancer knowledge, information seeking, and impact of communication on cancer-relevant behavior.**.** If NCI were to sponsor a future special journal issue or supplement of HINTS research, should the issue have a particular focus? What should it focus on?

☒ HINTS has a place on the website called Research Using HINTS (http://hints.cancer.gov/results.jsp) that lists the presentations that have been made and papers which have been published using HINTS data. What are your impressions of this page? What makes it useful? What could improve it?

☒ If the list of publications could be searched, what features would you most like to search on? For example, keywords, journal name, author, year?

What else either on or off the website could help you connect to research findings using HINTS data? How do you feel about displaying different results or a "HINTS fact" or "HINTS finding" on the home page as a way to connect users to the results?

The MyToolkit feature: http://hints.cancer.gov/dataset.jsp
allows you to organize and save items from the HINTS Web site, including resources, materials, survey instruments, and data in one place as you navigate around the site. Then you can just go to My Toolkit when you're finished to download and save your choices. Do you think you might use this feature in the future? Why or why not?] (Note to interviewer: It can be explained as an on-line shopping cart).

FUTURE USE OF HINTS:

Now that we have looked at the HINTS website and talked about HINTS, do you think you would be likely to use HINTS results or data in the future? How do you anticipate that you might use HINTS information or results in the future? (PROBE media reports; technical reports; grant application)

When new information about HINTS or findings from HINTS studies become available, how would you like to find out about them? [PROBE: Press release, E-mail newsletter, RSS feed, Widget]

What could be done to make the survey and its results more useful to you?

☒ HINTS has the potential to provide results to many different types of organizations and professionals. Which organizations and types of professionals could benefit the most from results from HINTS studies?

☒ There have been discussions at NCI about linking HINTS data to other national and regional datasets so that results from both can be viewed together. The proposed efforts aim to provide the shared

data and system compatibility to allow for integrated data resources for research in cancer control. What other data sets should HINTS link to? How would you use these combined data or their results?

What final recommendations do you have to offer the HINTS program?

Closing
Those are all of the question I have.

I would like to thank you for participating in this interview. Your thoughts and opinions will be very useful to NCI in addressing the needs of HINTS users and potential users.

For Interviews:
You will be receiving your incentive in the mail. Please feel free to contact me at xxx-xxx if you do not receive it within the next 2 weeks.

For Focus Groups:
You will receive your gift card as you leave.