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## 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 rephrase 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.
4. [If appropriate] There are also some people from NCI listening to our discussion today because they want to be able to hear directly from you.
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 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?

**HINTS WEB SITE**

[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 among 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?

If yes: Tell me about your experience using this ordering tool.

[If they have not heard of it or used it before: The My Toolkit 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<sup>1</sup>]? 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?

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<sup>1</sup> 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](http://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.

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](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 and 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?

Have you ever reviewed the report “[Cancer Communication Health Information National Trends Survey 2003 and 2005](#)”? [DIRECT INTERVIEWEE TO LINK: [http://hints.cancer.gov/docs/hints\\_report.pdf](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. 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?