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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). 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 rephrase 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 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 [focus group/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. 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? In 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(s)? From what source(s)?

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 additional data did you need (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 HINTS survey and 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 for which 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) or a specific question that 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?

USE OF HINTS PRODUCTS AND RESULTS: POTENTIAL DATA USERS

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.

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 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?]

The HINTS program has produced a new resource called [INSERT OTHER HINTS RESOURCE, E.G., PRODUCT / FEATURE / REPORT / PUBLICATION¹]? Let's take a look. What are your first impressions of [name of HINTS resource]. Tell me about your experience in using this [product/feature/tool/document].

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](http://hints.cancer.gov/docs/HINTS_Data_Users_Handbook-2008.pdf)"? [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 and 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](http://hints.cancer.gov/docs/hints_report.pdf)"? [DIRECT INTERVIEWEE TO LINK OR SHOW: 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?

HINTS has a place on the website called Research Using HINTS (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?

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. For example, NCI is planning 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, and a way to incorporate data from international survey administrations into the HINTS data repository and onto the HINTS Web site.

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?

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. Would knowing which researchers were conducting research with a particular HINTS question or questions be helpful to you?

FUTURE USE OF HINTS

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?

