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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 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.
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. 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 audiotapes 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 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.

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?

What topics do you think are missing from HINTS?

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]. 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]

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 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](#)”? [SHOW REPORT]. 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. 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]. 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]. 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 HINTS Program has recently made available [insert new resource]. Let's take a look at this resource. Tell me your impressions to the [insert new resource name].

The My Toolkit feature allows you to organize and save items from the HINTS website, 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?