Attachment D: Potential Results User Interview Guide

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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 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.
- 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 tapes when writing our report. When we write our report, we will report on what was said, but not on who said it.

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- 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 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.

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?

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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?)

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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?

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/briefs.jsp#briefs]. 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#briefs]. 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: 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.

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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 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?1

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?

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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?