The Health Information National Trends Survey (HINTS): Development, Design, and Dissemination

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Little is known about access, sources, and trust of cancer-related information, or factors that facilitate or hinder communication on a populationwide basis. Through a careful developmental process involving extensive input from many individuals and organizations, the National Cancer Institute (NCI) developed the Health Information National Trends Survey (HINTS) to help fill this gap. This nationally representative telephone survey of 6,369 persons aged ≥18 years among the general population was first conducted in 2002–2003, and will be repeated biennially depending on availability of funding. The purpose of creating a population survey to be repeated on a cyclical basis is to track trends in the public’s rapidly changing use of new...
communication technologies while charting progress in meeting health communication goals in terms of the public’s knowledge, attitudes, and behaviors. The HINTS survey instrument was built upon extant models of health communication and behavior change, taking into account the rapidly changing communication environment. Questions in the survey were drawn from an overall theoretical framework that juxtaposed the “push” aspects of traditional broadcast media against the “pull” aspects of new media. HINTS data will be made widely available for researchers and practitioners; it will help further research in health communication and health promotion and provide useful information for programs, policies, and practices in a variety of settings.

Introduction

To say that there is an ongoing, worldwide revolution in health information is a vast understatement. It is not uncommon today for health information consumers to hear of a breaking story in the news, research it on the Internet, and then show up at their physicians’ office armed with printouts, photocopies of news stories, and lots of questions (Cline & Haynes, 2001; Fox & Rainie, 2002; Murray et al., 2003; NCI, 2000). Estimates compiled from different sources suggest that the number of people who had direct access to the Internet in the United States and Canada alone as of September 2003 has grown to 182.67 million, while the international on-line community has grown to an estimated 605.60 million (NUA Internet Surveys, 2002). From a survey of Internet users in the United States (Fox & Fallows, 2003), an estimated 93 million Americans had reported searching for one of 16 major health topics on-line, making health information searching the “third most popular online activity after email (93%) and researching a product or service before buying it (83%)” (p. i). Of those who have searched for medical information on-line, 68% have suggested that the on-line information had at least “some impact” on decision making either for themselves or their loved ones (Fox & Rainie, 2002).

At all stages of disease, from prevention to diagnosis, to treatment, to end of life, effective health communication can empower people to make informed health-related decisions and to engage in behaviors that can improve their health. Indeed, the results from 25 years of health communication research have begun to have a noticeable impact on mortality rates from diseases such as cancer, as recipients of health communication messages have begun to adopt healthier lifestyles and engage in routine preventative screenings (Hiatt & Rimer, 1999). One critical mission of the NCI is to facilitate the process by which cancer research findings are communicated effectively to the public (Kreps & Viswanath, 2001; NCI, 1999, 2000, 2001). Traditionally, such communications have relied heavily on passive diffusion strategies, such as presentations to health care providers at scientific meetings or publications in professional journals, activities of the NCI Cancer Information Service (CIS) national network of telephone and computer information systems, distribution of publications, or the use of the conventional mass media, such as newspapers or television. Individuals seeking information about cancer or other health issues, however, now have access to multiple information sources including a host of on-line resources (Neuhauser & Kreps, 2003). For NCI and other organizations and individuals involved in the control of cancer, it is essential to maximize the effectiveness of communication, whether such communications occur in physicians’ offices, through the Internet, or are transmitted internationally through the mass media.

Developing and communicating messages for the public about cancer prevention, detection, diagnosis, treatment, and survivorship requires a good understanding of individuals’ sources of and access to cancer-related information; perceived trust in sources and information received; knowledge about cancer and other health information; and
factors that facilitate or hinder communication. The NCI developed the HINTS to gather such information. This nationally representative survey (with oversampling of ethnic-minority populations) provides baseline data about cancer communication practices, information preferences, risk behaviors, attitudes, and cancer knowledge across the country, with data collection repeated routinely to monitor trends.

The purpose of this article is to describe the development of the HINTS research program and uses for HINTS data and information. It addresses the origin and rationale for the survey, its conceptual framework, the questionnaire development process, sample design, data collection, information about respondents, and its dissemination plan.

**Origin and Rationale**

The formal genesis for HINTS grew out of a 1998 conference on risk communication. Attendees included persons trained and experienced in the areas of psychology, communication, health education/health behavior, public health, journalism, and medicine. Past research was reviewed and recommendations made for future research in risk communication. Individual papers from the conference were published in a 1999 supplement to the *Journal of the National Cancer Institute* (Klausner, 1999). At the meeting, researchers and practitioners alike lamented the paucity of population level data about health information variables, and encouraged NCI to develop and launch a regular national communication survey. Such a survey could provide baseline and follow-up data to assess cancer information needs and especially to help us understand the information needs of particular population subgroups.

The call for a national cancer communication survey coincided with a restructuring of organizational resources within the NCI. The restructuring precipitated the development of a new framework from which to guide cancer control research as embodied in a 1999 review article published in the journal of *Cancer Epidemiology, Biomarkers & Prevention* (Hiatt & Rimer, 1999). The framework identified human behavior as a major determinant of cancer control (i.e., in accordance with the biobehavioral model espoused by Anderson, 1998), but also recognized that cancer-related behaviors are inherently multifactorial in nature. Building also on a framework for research activity adopted by the Advisory Committee on Cancer Control of the National Cancer Institute of Canada (Advisory Committee on Cancer Control, 1994), the NCI launched a proscribed set of initiatives designed to advance the science of cancer control through fundamental research (i.e., basic science), surveillance, knowledge synthesis, and program delivery. Chief among these activities was an *Extraordinary Opportunity in Cancer Communication* as identified in the NCI’s fiscal year 2001 (NCI, 1999) budget.

The identification of cancer communications as an *extraordinary opportunity* led the NCI to invest heavily in scientific research that would advance the discipline of cancer communication against a backdrop of a rapidly changing array of media choices. A cornerstone of the initiative was the HINTS. The acronym suggests its purpose: to provide important insights (hints) into the health information needs and practices of the American public. Building on the recommendations of the 1998 risk communication conference, the NCI developed a general population survey to be repeated on a routine basis designed to provide researchers with a continuing source of surveillance data from which to compare trends in health information usage over time. Following the framework articulated by Hiatt and Rimer (1999), the survey would also provide health communication scientists with periodic opportunities to conduct fundamental research into the basic relationships among cancer-related communication, knowledge, attitudes, and behavior.
Experts’ Recommendations

In planning the development of HINTS, NCI staff solicited written and oral comments from a group of experts with extensive experience in survey research, cancer, behavioral sciences, and communications research. The group met formally in Bethesda, Maryland, in April 2000. Potential underlying theoretical models, survey variables, and operational issues were discussed at this meeting. Attendees made the following recommendations for HINTS:

- The sample should consist of adults in the general population (i.e., not restricted to cancer survivors) and be nationally representative.
- The survey should be administered following best practices in survey measurement as recommended by the American Association for Public Opinion Research (AAPOR) to minimize errors from coverage, sampling, nonresponse, and measurement.
- HINTS should not include questions on cancer treatment options, misinformation, or specific cancer-related messages. While these are important topics, they are too much to cover in one survey. Special modules could be devoted to survivorship or treatment topics: priorities that have been included in subsequent budgets though have not yet been funded.
- General knowledge questions about cancer should be minimized, as other surveys have obtained this information.
- Questions relating to specific types of cancer should be limited to breast, cervical, colorectal, lung, prostate, and skin cancers, the most prevalent cancers, and those for which prevention or early detection strategies are available. The consultants considered it important that site-specific questions could be linked to related questions about risk factors, evidence-based prevention, and early detection practices. Knowledge questions alone would not be sufficient.
- Communication topics should be included to explore the public’s general health information needs, and should devote items to exploring issues related to cancer information seeking among the subset of the sample who have been looking for information related to cancer either for themselves or others. It should be possible to assess health information needs separately for different subgroups of the population, including those underserved by digital communication technologies.
- The survey should include questions on risk perceptions. These items should reflect state-of-the-science in measurement.
- The survey should include questions on issues relevant to the practical needs of NCI and other federal program efforts, for example, awareness of 1-800-4CANCER or the Health People 2010 initiative (U.S. Department of Health and Human Services [USDHS], 2000), but not focus largely or exclusively on the evaluation of specific programs.
- Data should be made available quickly and disseminated widely. The NCI website would be a useful source of information about HINTS, and the community should be encouraged to use these data.

Questionnaire Development

An internal HINTS advisory committee met to develop the principles and framework for the selection of topics and questions for the survey instrument. The committee agreed that HINTS should serve as a tool for both research and practical applications, with a general aim that approximately half of the questions be allocated for answering individual research hypotheses, and half be used for surveillance and other applied purposes. Although HINTS would obtain data on a variety of topics, the dominant emphasis would
be collecting cancer-relevant information, with an emphasis on cancer prevention and early detection of specific types of cancer, especially cancers for which there are evidence-based prevention and early detection strategies. The committee developed criteria for inclusion of measures on the survey instrument in three broad areas: scientific validity, utility, and implementation (Table 1).

Scientific validity criteria emphasized including items that have been demonstrated to measure population-based constructs in reliable ways, and for which external evidence has been collected to demonstrate suitability of the measure in assessing the construct in question. The utility criteria refer to the need for HINTS data to be both useful and utilized within the research and practice communities, and to serve a purpose in helping population scientists reduce the nation’s burden from cancer according to NCI goals. The implementation criteria cover operational issues, such as cognitively testing questions and an interview length of no more than 30 minutes.

**TABLE 1 Criteria for Inclusion of Measures in the HINTS Telephone Interview Instrument**

**Scientific Validity Criteria**
- Question(s) are a well-established measure for assessing cancer-related information or knowledge
- Self-reported data can provide valid estimates for the adult population (persons aged ≥ 18 years)
- Sample size is adequate

**Utility Criteria**
- Data will help guide the National Cancer Institute’s research agenda in health communication and health promotion
- Data will help guide the National Cancer Institute’s program efforts in health communication and health promotion
- Data would help monitor Healthy People 2010 health communication objectives
- Measures are identical or similar to those used in other national surveys
- Trends in prevalence estimates are changing
- An identified individual or group of individuals at NCI has a specific written plan for analyzing, disseminating, and publishing findings
- An identified individual or group of individuals at another federal agency, voluntary health organization, or research institution has a specific written plan for analyzing, disseminating, and publishing findings

**Implementation Criteria**
- The survey will be administered by telephone and conducted every 2 years
- The maximum length of the interview is 20–30 minutes, with half of the instrument reserved for a core set of surveillance questions to be repeated every 2 years
- There is equitable distribution of questions among topics
- There is a parsimonious number of questions for individual topics
- The instrument will have the capacity to be used for conducting experimental research to examine the effects of question wording
- Questions are appropriately worded based on technical review, cognitive testing, and field testing
- There will be minimal changes to questions used for surveillance purposes
Conceptual Development and Research Questions

The HINTS advisory committee solicited extensive input on potential theoretical orientations and research questions to be addressed from representatives within NCI; other federal agencies; the American Cancer Society and other nongovernmental organizations; and the academic and public health practice communities.

Feedback from these sources presented a resounding message: HINTS should be built upon extant models of health communication and behavior change, while taking into account the emerging qualities of a rapidly changing communication environment. This meant that, from a communication perspective, the HINTS instrument should include traditional communication constructs necessary to assess the broad influence of awareness campaigns. At the same time, the instrument should be broad enough to monitor the adoption of new and emerging communication media, especially those associated with emerging forms of interactive electronic media referred to generally under the rubric of “eHealth” (Eng, 2001).

Analyses of HINTS data could conceivably help answer hundreds of specific research questions. Rather than trying to create a lengthy list, a small set of research questions was developed to provide examples of the type of data that HINTS could provide. They included the following:

- Considering the full range of communication channels, what are the major sources of cancer information, and how do the channels differ by respondent characteristics?
- To what extent is access or lack of access to different sources of health information associated with cancer-related knowledge?
- What is the role of new media, such as the Internet, as a source of cancer information?
- How trustworthy are the sources of cancer and other health information perceived to be, and how satisfied are respondents with information access and content?
- What is the level of knowledge about cancer incidence, etiology, prevention, detection, and treatability, and what are the psychological and structural determinants of this knowledge?
- How are knowledge and behaviors related to sources of information and their use?
- How do people want to get information about cancer-related issues?

Instrument Development

The HINTS conceptual framework, depicted in Figure 1, was used as a guide to the selection and development of survey items. The communication side of the framework was built on the observations of Phillip Napoli (Napoli, 2001), who suggested that consumer use of medical information from electronic and paper media is best understood from an approach that would account both for the processes involved in passive mass media type exposure along with the more active processes associated with health information seeking. Thus, the model depicts two general stages in consumer-oriented health communication: (a) an awareness stage in which persuasive media actors push messages into awareness and contemplation, and (b) an information-seeking stage in which information consumers pull information from in-person and mediated sources. Questions were included to reflect attributes of these stages, with modules included to measure general exposure and attention paid to media from stage 1 of the framework, to modules measuring information-seeking behaviors in stage 2. Particular attention was given to Internet users, with a series of focused questions included to document on-line, health-related activities (from Rice & Katz, 2001).
FIGURE 1 HINTS framework. The HINTS framework relates psychosocial characteristics to the dynamic process of becoming aware of, and then seeking new information on, public health messages.
The biopsychosocial side of the framework was assessed by asking questions related to respondents' personal characteristics, including whether they reported ever having been diagnosed with cancer; their knowledge of cancer-related risks and prevention behaviors; their attitudes toward cancer-related risks and prevention behaviors; and self-reports of diet, exercise, and engagement in early detection practices. The HINTS advisory committee recognized that the models of behavior change underlying the framework needed to be dynamic enough to account for the impact of information along a continuum of influence, from early risk awareness to support for cognitively active information seeking (see, for example, Prochaska, DiClemente, & Norcross, 1992; Weinstein, 1988). Items were included to measure cognitive and behavioral responses across a continuum of influence (Kreps, 2003), with a special emphasis on risk perception (JNCI, 1999) and psychosocial responses to early detection and screening (Croyle, 1995).

**Review of Existing Surveys**

In June 2001, the contract for developing the HINTS questionnaire and administering the survey was awarded to Westat; finalizing the survey instrument became an immediate priority. Initial activities centered on reviewing other survey instruments with potentially useful items for inclusion in HINTS. Many surveys of the general population and specific population groups (e.g., cancer survivors) were reviewed, including surveys on communication, information seeking, health behaviors, health knowledge, health attitudes, and health beliefs.

The Pew Charitable Trusts (Fox & Fallows, 2003; Fox & Rainie, 2002), Kaiser Family Foundation (Kaiser Family Foundation, 2000), the University of California at Los Angeles (UCLA; Cole, 2000), and the Georgia Institute of Technology (2001) have conducted excellent surveys on communication, but none obtained comprehensive data on health attitudes, beliefs, and behaviors. National surveys routinely are conducted by Nielsen (www.netratings.com) and Harris Interactive (www.harrisinteractive.com) to collect data on mass media and Internet use, for example, average number of hours of television viewing per day or time spent on-line, but they do not collect health data.

National and state-based surveys, such as the National Health Interview Survey (NHIS); National Center for Health Statistics [NCHS], 2000) and the Behavioral Risk Factor Surveillance System (BRFSS; Powell-Griner, Anderson, & Murphy 1997), collect data on health risk behaviors and receipt of clinical preventive services, such as mammography, but have few questions on communication or on health knowledge, attitudes, and beliefs. Ad-hoc population-based surveys on cancer-related knowledge, attitudes, and behaviors occasionally are conducted by the American Cancer Society (ABC News, 2001), but do not obtain many communication-related measures. The General Social Survey (GSS) routinely collects detailed national data on knowledge, attitudes, and beliefs (National Opinion Research Center, 2002), but these data are not health or cancer specific, nor are communication measures usually included.

We also identified several individual research studies that obtained detailed data on topics such as cancer-related knowledge or preferred information sources (e.g., Bowen, Hickman, & Powers, 1997; Breslow, Sorkin, Frey, & Kessler, 1997; Freimuth, 1989; Johnson, 1997; Kim, Yu, Chen, Kim, & Brintnall, 1998; Lipkus, Iden, Terrenoire, & Feaganese, 1999; McDonald, Thorne, Pearson, & Adams-Campbell, 1999). These usually were restricted to defined populations, such as individuals with one type of cancer in a geographically limited area of people at risk for a particular type of cancer or surveys primarily intended to assess the effect of an intervention, and did not obtain the breadth of topic areas envisioned for HINTS. Therefore, although existing surveys did provide some
of the selected content, it was necessary for the HINTS advisory committee and Westat staff to collaborate in developing a number of new survey questions that required further pretesting and evaluation.

**Pretesting and Expert Review**

In September 2001, a draft survey instrument underwent cognitive testing at Westat’s survey laboratory, with nine adult participants from a broad range of demographic categories. The main focus of these one-hour individual interviews was on proposed items assessing cancer knowledge, beliefs, and attitudes, as well as exposure to, and perceptions about, cancer and health-related communication. In general, most of the questions performed well in terms of participants’ expressed understanding, between-subjects reliability, and perceived clarity (see Sudman, Bradburn, & Schwarz, 1996), with only a few items needing to be eliminated or substantially modified.

In November 2001 a revised draft of the instrument was circulated for comment to 10 subject matter experts from outside of the NCI. After further revisions, the survey instrument was submitted to the National Institute of Health’s Office of Human Subjects Research; HINTS was considered exempt from institutional review board (IRB) oversight because it was a survey of the general population that included no vulnerable populations, it would obtain no individual respondents’ identifiers, and the information to be collected was not considered sensitive.

The instrument was sent to the Federal Office of Management and Budget (OMB) for consideration and was approved by OMB in July 2002 with minor changes. Field testing of the instrument was conducted in August and September 2002 among 172 adults nationally, and further changes were made to a small number of questions. The average length of the instrument was 37 minutes; 30 questions were dropped to ensure that the average length of interviews would not exceed 30 minutes.

**Structure of the Survey Instrument for the First Administration of HINTS**

The survey was structured to take respondents through a progression of questions as efficiently as possible, beginning with basic questions regarding use of communication media and then followed by more specific questions on cancer-related knowledge and behaviors. The survey began with an introductory statement and a set of standard screening questions to identify respondents eligible for the survey (those 18 or older who lived in the household). After a sampled person was identified, interviewers asked respondents to report on their use of, and preference for, various types of communication media. Skip logic was used to ask follow-up questions of those respondents who had reporting using the Internet as a communication channel and those who reported searching for specific information related to cancer regardless of channel.

The HINTS advisory committee recognized that there are potentially a large number of cancer knowledge and screening questions that could be asked in the survey. We used different strategies to address this challenge. The instrument included a general cancer knowledge module to assess respondents’ overall sense of the risk for cancer and their knowledge about recommendations regarding the prevention and treatment of cancer. In this section, respondents were randomly assigned to one of the two sets of questions. Cancer, however, is a broad term relating to a whole host of risk factors and diseases spread throughout an individual’s life span and across body systems. For this reason, the survey divided respondents into one of several parallel question paths, depending on age and gender. Only persons who were either already in the recommended age range for a specific
### TABLE 2  Topic Areas Included in HINTS Survey Instrument

<table>
<thead>
<tr>
<th>Category and Topic Area</th>
<th>Number of Questions$^1$</th>
<th>Age Range for Respondents (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Communication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider–patient interaction</td>
<td>5</td>
<td>≥18 (all questions)</td>
</tr>
<tr>
<td>Media exposure</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Information seeking</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Channel credibility and reliance</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Internet usage</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Other topics</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total number of questions in category:</strong></td>
<td>35</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer History/General Cancer Knowledge</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer history</td>
<td>4</td>
<td>≥18</td>
</tr>
<tr>
<td>General cancer knowledge:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative prevalence</td>
<td>1</td>
<td>≥18</td>
</tr>
<tr>
<td>Preventability</td>
<td>3</td>
<td>≥18</td>
</tr>
<tr>
<td>Personal risk</td>
<td>2</td>
<td>≥18</td>
</tr>
<tr>
<td>Desire to change/barriers to change</td>
<td>6</td>
<td>≥18</td>
</tr>
<tr>
<td><strong>Total number of questions in category:</strong></td>
<td>16</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer-Specific Personal Risk and Screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon cancer:</td>
<td>3</td>
<td>≥18</td>
</tr>
<tr>
<td>Personal risk</td>
<td>25</td>
<td>≥45</td>
</tr>
<tr>
<td>Screening knowledge and behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer:</td>
<td>3</td>
<td>≥18 (women)</td>
</tr>
<tr>
<td>Personal risk</td>
<td>10</td>
<td>≥45 (women)</td>
</tr>
<tr>
<td>Screening knowledge and behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cervical cancer:</td>
<td>5</td>
<td>≥18 (women)</td>
</tr>
<tr>
<td>Prostate cancer:</td>
<td>3</td>
<td>≥18 (men)</td>
</tr>
<tr>
<td>Personal risk</td>
<td>3</td>
<td>≥35 (men)</td>
</tr>
<tr>
<td>Screening knowledge and behaviors</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Total number of questions in category:</strong></td>
<td>54</td>
<td></td>
</tr>
<tr>
<td><strong>Primary Cancer Risk Behaviors</strong></td>
<td></td>
<td>≥18 (all questions)</td>
</tr>
<tr>
<td>Tobacco use:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking status, amount, and type</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Quitting/beliefs about health risks</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Harm-reduction products</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Personal risk</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Detection/curability</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Fruits and vegetables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Frequency and amount</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Behavior</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Obesity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Height and weight</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
cancer screening test or who were within 10 years of being in the recommended age range were asked cancer-specific screening questions (e.g., only women 35 years or older were asked specific questions about mammography). Use of carefully balanced skip logic using computer-assisted telephone interview (CATI) technology allowed HINTS to collect specialized data on different types of cancers without overburdening individual respondents.

The survey converged again after the cancer section, with a set of common questions related to primary cancer-related behaviors (tobacco use, fruit and vegetable consumption, exercise, obesity), health status, and sociodemographics. The sociodemographics section included standardized measures of health status, race, education, income, and psychological distress to be comparable with items in other federal surveys (Pleis, Benson, & Schiller, 2003).

More detailed information about specific topic areas included in the final survey instrument for the first administration of HINTS is provided in Table 2. The total number of questions was 148, but because of eligibility restrictions and skip patterns, no individual respondent was asked all questions. (Data and other information about HINTS, including a copy of the survey instrument and instructions for how to access the HINTS data file, are available at http://cancercontrol.cancer.gov/hints/.)

Questions on cancer-specific personal risk and screening accounted for 34% of the entire instrument, followed by health communication (22%), primary cancer-related risk behaviors (18%), cancer history/general cancer knowledge (10%), household screener (9%), and health status/demographics (7%). Some changes in topics, as well as the mix of questions, are planned for the second administration of the survey (HINTS II), which will be administered early in 2005.

### Sample Design and Survey Operations

**Sample Design**

A list-assisted random-digit-dial (RDD) sample was used for HINTS. The list-assisted method uses a random sample of telephone numbers from all working “banks” (i.e., groupings of telephone numbers based on the first five digits available for customer assignment) of telephone numbers within the United States obtained from a vendor that supplies telephone numbers for sample surveys. Only banks with one or more working numbers (1+ banks) were sampled, and prescreening was used to eliminate as many...
business, fax, and cell phone numbers as possible from the sample of telephone numbers. One adult was selected at random within each household; for households with three or more eligible adults, the most recent birthday method was used to select the respondent.

An important aim of the sampling plan was to achieve adequate minority representation, and special efforts were made to oversample African Americans and Hispanics. Consideration was given to oversampling other minority populations (e.g., American Indians, Asians), but cost considerations precluded doing so. The goal of oversampling was to achieve 95% confidence intervals for key Black and Hispanic estimates that would be no greater than \( \pm 3 \) percentage points, which would require including approximately 1,500 Blacks and 1,500 Hispanics in the final sample. To achieve this goal at minimum cost, telephone exchanges were geographically stratified, based on the estimated percentage of Black and Hispanic residents within defined areas. Telephone exchanges that were estimated to have more than 15% of Black or Hispanic residents were oversampled at a 1.8 times higher rate than expected under proportional allocation to increase the number of respondents in these population groups.

**Efforts to Maximize Response Rates**

Because of drastic declines in response rates to telephone and other surveys in recent years (Singer, Van Hoewyck, & Maher, 2000), several methods were used to help reduce nonresponse rates. Household telephone numbers selected for HINTS were matched to mailing addresses using electronically available reverse telephone directories. The matching process was successful for 43% of telephone numbers. Introductory letters on NCI letterhead were sent to these households approximately 2 weeks prior to calling, which explained the purpose of the survey, gave assurances of confidentiality, and provided answers to frequently asked questions. Financial incentives of $2 were initially sent to a selected number of potential respondents to encourage participation.

Interviewers were trained extensively on how to gain the cooperation of potential respondents within the first minute of initial contact and how to make the transition successfully from the household enumeration to the full interview phase of interviews. Interviewer training took place over the course of a week and balanced classroom training using manuals of instruction developed for the project, with simulated practice scenarios, question-by-question answers and review, and on-the-job supervision by managing telephone specialists. For those respondents who refused to complete the survey, a gentle but persuasive letter was sent to households by express mail (known as a “refusal conversion” letter) stressing the importance of the survey for research on cancer prevention and urging the respondent to complete the survey when called a second time. A financial incentive of $2 was included with a sample of refusal conversion letters to encourage respondents to cooperate with interviewers. Finally, a selected group of the most effective interviewers attempted to recontact persons who refused in an attempt to persuade them gently to participate in the survey (refusal conversion).

**Data Collection, Response Rates, and Characteristics of the First HINTS Administration**

All data were collected by trained interviewers using the Blaise® CATI system, which automated the processes of interviewing, sampling, and data collection for quality control purposes. Blaise is a nonproprietary telephone interviewing system developed by Statistics Netherlands. Westat used its own proprietary survey scheduling system, which interfaced with Blaise, to assign telephone numbers and keep track of call status. After the English
language version of the instrument was finalized, Westat developed a Spanish language questionnaire. The Spanish instrument was developed by a team of bilingual translators who translated from English into Spanish first, back-translated from Spanish to English as a quality control check, and then was reviewed by a bilingual survey specialist for content equivalency. Bilingual interviewers were used to interview Spanish speakers in the sample.

Data collection for the full survey began in October 2002 and continued through April 2003. To obtain interviews, up to nine callback attempts initially were made to telephone numbers over a one-week period; in an effort to increase response rates, up to 30 total call attempts were made over the study period. The first time interviewers reached an answering machine, they left detailed messages describing the purpose of the study and their intent to call back. Ongoing review and editing of data was conducted throughout the data collection phase, for example, range checks for entered data values for questions, to improve data quality.

In total, 52,212 telephone numbers were drawn at random from exchanges throughout the United States. The sample was submitted to an independent directory service to determine ahead of time which numbers were listed as business or nonworking. Some 19,689 numbers (38%) were removed from the sample once they were determined ahead of time to be nonworking or associated with businesses, cell phones, institutions, or fax machines. The remaining 32,523 numbers were released to the Telephone Research Center in replicate samples across two waves. From that group, another 9,280 numbers eventually were removed from the sample as also being nonworking or nonresidential, and 3,734 numbers were coded as “undetermined” (i.e., the telephone rang with no answer, making it impossible to determine whether the number was residential or business).

In all, the telephone interviewers were able to reach 19,509 households. Participant recruitment into the survey proceeded in two phases: a screening phase and the extended interview phase. In the screening phase, the person answering the initial telephone call was considered the “household reporter,” or the person who knew enough about the other members of the household that he or she could help the interviewer select a single person (called the “sampled person” or SP) from the household for the interview. Often, the interviewer would be able to talk to the SP right away: The household reporter might have been selected for the survey or the SP was in the house and available. If the SP was not available to complete the interview, a follow-up telephone call would have to be arranged. In the HINTS administration, the final response rate for the household-level screening interview—that is, the rate at which household reporters voluntarily completed the initial screening interview—was 55%, calculated according to the guide of “Standard Definitions” published by the American Association for Public Opinion Research (AAPOR, 2001). The final response rate for the extended interview—that is, the rate at which SPs voluntarily completed the full HINTS interview—was 62.8%. HINTS response rates, although not as high as hoped, were typical of other recent telephone surveys of adults in the general population (see, for example, the comparative review by Krosnick and Chang, 2003).

Base weights were generated for each sampled identification number in the final data release based on the sampling strategy for the survey. A set of 50 replicate weights was generated according to procedures for jackknife variance estimation. The replicate weights can be used in statistical programs such as WesVar® (produced by Westat) or SUDAAN® (produced by Research Triangle Institute) to adjust for nonresponse. The final set of replicate weights included calibrations against comparable population data for gender, age, race, and education publicly available from the Current Population Survey (CPS). The complete set of weighting variables will be made available for public use along with responses to the extended interview. Papers using weighted data to make population estimates based on the HINTS data will be announced as they are made available at the NCI website.
Dissemination Planning

Disseminating HINTS findings to key audiences is essential so that use of the data will be maximized. The HINTS advisory committee directed the development of the dissemination plan based on explicit goals and objectives. The four dissemination objectives were the following: (1) to encourage scientists to conduct research using HINTS; (2) to promote use of findings from HINTS to inform and guide further research in cancer communication, behavioral science, public health, and informatics; (3) to promote use of HINTS to inform health policy decisions related to cancer prevention at the local, state, and federal level; and (4) to promote the translation of HINTS findings for cancer communication programs, including through NCI’s Office of Communications.

After deciding on dissemination goals and objectives, key audiences and communication channels for HINTS were identified. Audiences for dissemination efforts were broadly categorized into two groups—data users and results users—based upon their distinct information needs. Examples of data users include communication, behavioral, and other researchers who would use “raw” HINTS data to conduct independent analyses. Examples of results users include public health or communication practitioners, advocacy organizations, health editors, and policymakers interested in using HINTS to help inform program and policy decisions. Within each of these two groups, gatekeepers and opinion leaders were identified in order to effectively channel the information.

To support dissemination to and by data users, the NCI is making the HINTS data set available to the public roughly 6 months after the raw data are delivered to the government. The 6-month period allows the government to review the data for quality purposes, to develop taxonomies and codes that can be used in concert with other federal data sets, and to conduct initial analyses for internal purposes. The complete data set for the first administration of HINTS data along with accompanying codebooks was made available in SAS format (SAS Institute, Cary, NC) for download on the NCI website in February 2004. Users are requested to register in order to build an identifiable community of scientists and researchers. Plans are underway to host periodic user conferences and to promote specialized collections of HINTS-based research as a way of facilitating collective dissemination of results back to the broader scientific community.

To support dissemination to result users, the NCI is experimenting with different formats for displaying estimated population frequencies. One development effort, currently underway, is to create an “electronic codebook” of the data to be posted on the HINTS website. When completed, the web-accessible codebook will present users with contiguous descriptions of the format, text, history, skip logic, and population estimates for each question in the survey. Another development effort that is underway is to create a bound version of the weighted frequency data for each administration, along with a description of the instrument’s construction and conceptual history. NCI will take advantage of its User-Centered Informatics Research Laboratory to improve the effectiveness of each format through formative user testing. The NCI will seek feedback from both of its audience communities both formally and informally through user surveys, invited comments, and conference proceedings.

Future Versions of Hints

As envisioned by its creators, HINTS is intended to be an ongoing vehicle for providing data periodically to researchers and policymakers on the nation’s progress in conveying cancer-related health information to the U.S. adult population. Because of the importance
of its surveillance function, efforts will be made to protect the methodological integrity of repeated items across all future administrations. Psychometric analyses will be conducted routinely to document reliability and validity across cycles. Ongoing comparisons will be made with other national surveys, such as the NHIS and BRFSS, to evaluate the integrity of common “marker” items among the national data systems.

In addition to its role as a surveillance vehicle, future versions of HINTS will be used to carry out focused research on specific cancer communication topics as needed. HINTS designers have estimated that about half the survey instrument will be dedicated to collecting surveillance data, while the other half can be used to advance a basic science agenda. Special research topics that are currently under analysis or development include the following: (a) a study into affective and motivational determinants of early detection, (b) the influence of perceived risk on the adoption of healthy behaviors, and (c) attributes of the lay public’s mental model of cancer as a disease process.

As a communication-oriented survey, HINTS also affords researchers the opportunity to understand and refine its use of communication technology in the role of data collection. Survey administrators embedded a methodological experiment into Wave 1 of the 2002–2003 administration of the survey. Results from the experiment (Rizzo, Park, Hesse, & Willis, 2003) will be used to improve the probability of increasing response rates in future administrations. Of course, response rates are only a problem if nonrespondents are systematically different from respondents (Groves, 1989). A more comprehensive approach is to improve total survey performance by minimizing error and cost across all dimensions of coverage, sampling, response rate, and measurement (Dillman, 2000; Dillman, Phelps, Tortora, Swift, Kohrell, & Berck, 2002). Under the rubric of total survey performance, future administrations of the survey will include embedded experiments to assess the feasibility of employing new Internet-based and hybrid approaches to data collection (Couper, 2000; Krosnick, & Chang, 2003).

In fact, the range of future research possibilities using the HINTS vehicle is as broad as the “extraordinary opportunity” (NCI, 1999, 2000, 2001) that is the hallmark of the current era of health communication research.

Conclusion

HINTS provides a unique set of measures from across the areas of communication, knowledge, beliefs, attitudes, and behaviors related to cancer. Regular, biennial administration of the survey will permit assessment of important trends in the use of health information and new communication technologies over time. The survey offers a distinct opportunity to understand the interrelationships across measures in each of these domains and has great potential for practitioners and researchers in many disciplines and practice settings. Given the growing prominence and importance of health communication, coupled with changing profiles of channel usage over time, it is likely that HINTS data also will be useful for many other health application areas besides cancer.

Finally, NCI anticipates that HINTS will be an important source of data for comparison purposes with other surveys. Little is known about cancer communication practices, information preferences, or knowledge at the state or local level; additionally, such information is rarely available for populations directly affected by cancer, such as persons newly diagnosed with different types of cancer, survivors, on-line support communities, or family members. Surveys of representative local populations are needed to further understand their knowledge, communication, and information experiences and needs, as well as communication barriers.
References


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