

The  
**CIS Research Agenda:  
Overview of Relevant Research**

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## INTRODUCTION

This document provides an overview of research findings related to the *Research Agenda* developed by the National Cancer Institute's Cancer Information Service, in order to provide context for the research questions that have been articulated. In addition, the overview highlights gaps in the existing body of research that can potentially be addressed through the CIS Research Program. For each of the research questions, the document briefly summarizes the current state of knowledge. In some cases existing research directly addresses the research question; in other cases the available research has some relevance to, but does not directly address, the research question. Finally, for some research questions no relevant literature was identified. This overview is intended to assist the CIS network and research partners in identifying priority areas for collaborative research under the Research Program. Specifically, CIS encourages research that will address the gaps in knowledge relevant to the research questions.

The overview is based on recent research (generally since 1990), review articles, and research conducted in collaboration with the CIS or by NCI. Thus, it reflects a selective, rather than an exhaustive, review of the literature. In some cases, unpublished and preliminary findings are presented, for example from NCI's 2003 Health Information National Trends Survey (HINTS) and from CIS' Electronic Contact Record Forms (ECRF), which document users' contacts with CIS. Wherever possible, research findings that relate specifically to cancer information, communication, and education are presented. However, because the research related to health in general is more extensive, selected results from these studies are also included. As new research findings become available, this literature review will be updated.

Summary research findings are presented in four sections, according to the areas of focus stated in the *Research Agenda*: (1) testing innovative cancer communication and education interventions; (2) increasing access to and use of cancer-related information and education; (3) discovering effective models of disseminating successful cancer control interventions and study findings; and (4) understanding information seeking. For each section, the research questions are listed and the relevant literature summarized, beginning with a brief overview of the

research and followed by bulleted summaries of specific findings. Research involving CIS is indicated with an asterisk.

## TESTING INNOVATIVE CANCER COMMUNICATION AND EDUCATION INTERVENTIONS

Research questions concerning testing innovative cancer communication and education interventions are listed below. These specific questions, which focus on different elements of cancer communication and education interventions, fall under a single overarching research question, as follows: *What types of interventions are effective in aiding/improving cancer preventive and screening practices, cancer-related decision-making, clinical trials participation, and quality of life for cancer patients?*

**Question 1: Are new public health informatics approaches (e.g., computer-generated message tailoring, multi-media interventions, ehealth interventions) to delivering cancer-related information effective?**

### **Overview of Relevant Research:**

Recent literature discusses the potential risks and benefits associated with multimedia and electronic health interventions – frequently referred to as eHealth communication. Evaluations of the Comprehensive Health Enhancement Support System (CHESS) document the acceptability and effects of this computer-based interactive health intervention, including among underserved populations. The literature on online support groups, an increasingly popular form of eHealth communication, explores their advantages, disadvantages, and effects. A recent CIS survey assesses users’ receptivity to online “chat rooms” and other potential new eHealth services. Researchers believe that the revolution in informatics technology holds great promise for tailored health communications. However, the cost-effectiveness of tailored communications using informatics technology must be examined. Furthermore, the existing research does not provide a complete understanding of the most effective ways to implement tailoring strategies (e.g., appropriate tailoring for individuals at different points along the cancer continuum).

### **Specific Research Findings:**

- While there is enormous potential for eHealth communication, there are also important barriers. For most Americans, eHealth is limited to searching the Internet for health



information. Few have access to tailored information, multi-media education, or other interactive tools. Although the digital divide is narrowing, the “broadband divide” (gap between Internet users with broadband and dial-up access) will restrict many people from accessing the rich multimedia and interactive features of eHealth communication. Literacy, linguistics, cultural, and disability barriers are also important issues (Eng, 2001; Neuhauser & Kreps, 2003).

- The Science Panel on Interactive Communication and Health (Eng & Gustafson, 1999) convened by USDHHS identifies potential benefits and risks associated with interactive health communication technologies (including the Internet, CD-Rom and DVD technology, and dial-in services) as follows:

Potential benefits:

- Improved tailoring of health information.
- Broader choices for users; for example, users can selectively combine text, audio and visuals depending on their learning style.
- Greater access to health information and support on demand.
- Greater ability to promote interaction and social support among users and between consumers and health professionals.

Potential risks:

- Inaccurate or inappropriate health information and support could result in inappropriate treatment or cause delays in seeking health care.
- Damage to patient-provider relationship (e.g., patients lose trust in provider).
- Violations of privacy and confidentiality as personal information is used in tailoring interventions.
- Widening the technology and health gap as those without access to the Internet and other technologies fall behind in their ability to obtain information.

- CHESS uses PCs in the homes to provide breast cancer patients (and patients with other serious illnesses) with access to a broad range of information and support services. Specifically, CHESS provides (1) health information, including brief answers to frequently asked questions, a library of articles, a consumer guide, Web links, and a referral directory; (2) support services, including discussion groups, “ask an expert,” chat room, journaling, and personal stories; and (3) decision services, including self-assessment tools, health charts, and tools for decision making and action planning. Studies have identified a number of positive outcomes associated with use of CHESS, including satisfaction with health

information, increased information competence, increased social support, reduced negative emotions, and improved quality of life. These benefits have occurred across a variety of populations, with the greatest benefits for underserved populations (low-income, minority populations, inner city) (Gustafson et al., 1999; Gustafson et al., 2002; Gustafson et al., 2004; Kreps et al., 2003; Neuhauser & Kreps, 2003; Shaw et al., 2000).

- Studies of CHES find that low-income, minority, and elderly populations are at least as likely to accept and use CHES as younger, White, and more affluent populations. However, various population subgroups use CHES very differently. In particular, the underserved use the discussion groups less frequently, but use the health information services (e.g., library, frequently asked questions) and decision services (self-assessment tools and health tracking charts) more frequently (Gustafson et al., 2002; Gustafson et al., 2004).

➤ **How effective is computer-generated message tailoring?**

- A review by the Institute of Medicine of tailored health communication studies concludes that while the data are not unequivocal, most studies show positive effects in terms of changes in knowledge, beliefs, and health behaviors (Institute of Medicine, 2002). For example, computer-tailored materials have been found effective in promoting smoking cessation, dietary change, mammography, “passive” cancer detection (i.e., being alert to symptoms), and physical activity for certain populations. Tailoring in various studies has been based on perceived barriers, perceived susceptibility, beliefs, risk factors, stage of change, cues to action, and other psychosocial characteristics. In many cases, tailored communication is more effective when combined with other interventions (Borland, Balmford, & Hunt, 2003; Champion, Foster, & Menon, 1997; de Nooijer et al., 2002; Kreuter, Strecher, & Glassman, 1999; Institute of Medicine, 2001; Heimendinger et al., 2004; Manfredi et al., 1993; Neuhauser & Kreps, 2003; Skinner, Strecher, & Hospers, 1994; Skinner et al., 1999).
- Researchers believe that the revolution in informatics technology holds great promise for tailored communications. For example, computer-based “expert systems” can match information to a person’s needs; handheld computers make it possible to provide “on demand” information in “real time”; computer “coaches” can be available 24 hours a day; and computer-based delivery options can effectively simulate conversation by tailoring information in real time based on user responses. However, the cost-effectiveness of

tailored communications using informatics technology must be examined (Abrams, Mills, & Bulger, 1999; Houston & Ehrenberger, 2001; Kreuter, Strecher, & Glassman, 1999; Neuhauser & Kreps, 2003).

➤ **How effective are on-line health/cancer support groups?**

- Participation in health-related online support groups and communities has been steadily rising. According to the Pew Internet and American Life Project, 54% of Internet users have visited a website that provides information or support for people interested in a specific medical condition (Fox & Fallows, 2003).
- A number of studies have found that participants in online support groups perceive many advantages, including convenience (no need to travel, 24-hour availability), anonymity, selectivity in responding, capacity for immediate and time-delayed responses and reactions, unlimited number of participants (including health professionals), lack of geographic boundaries, and exposure to a wide range of opinions, expertise, and experience (Clines & Haynes, 2001; Eysenbach, 2003; Fox & Fallows, 2003; Houston & Ehrenberger, 2001; Klemm et al., 2003; Lieberman et al., 2003; Mabe, 2000; Shaw et al., 2000; Street, 2003).
- Cancer patients value connecting to others who can provide emotional support through online support groups. A study of women participating in an online breast cancer support group found that the anonymity allowed women to communicate in ways that would have been more difficult face-to-face. Women expressed that the group provided abundant emotional support, encouragement, and informational support (Shaw et al., 2000). Studies have found that breast cancer patients participating in online support groups experience reduced depression and stress, and less negative reaction to pain (Lieberman et al., 2003; Winzelberg et al., 2003).
- A survey of CIS callers conducted in 2001-2002 found that 19.7% of callers who were cancer patients were very interested in CIS-moderated chat rooms, and another 26.7% were somewhat interested. Family members/friends of cancer patients were less interested in CIS-moderated chat rooms (15.2% very interested and 23.1% somewhat interested). Patients expressed greater interest in other potential new eHealth services; 51.5% were very interested in using e-mail to communicate with a CIS information specialist, 63.5% were very interested in talking with an information specialist by phone while searching for

information on the Internet; and 70.6% were very interested in receiving information proactively from CIS by e-mail (Bright et al., 2005).\*

**Question 2: What types of interventions are effective in aiding/improving cancer screening and treatment decision-making? How does this vary among different cultures and subpopulations?**

**Overview of Relevant Research:**

A number of studies have evaluated the impact of interventions designed to promote informed decision-making related to cancer. Two recent reviews summarize the research evidence in this area: (1) as part of the *Guide to Community Preventive Services*, the Task Force on Community Preventive Services reviewed studies of population-based interventions that focus on decision-making related to cancer screening (Briss et al., 2004; Community Guide, 2005); and (2) the Agency for Healthcare Research and Quality reviewed studies focusing on cancer-related decision aids (AHRQ, 2002). Both reviews identify significant gaps in our understanding of how decision aids and other interventions impact cancer-related decision-making.

**Specific Research Findings:**

- According to the Task Force on Community Preventive Services, the potential benefits of interventions that promote informed cancer-related decision-making include increased patient involvement in the decision-making process; improvement in the quality of decisions; increased patient satisfaction with and adherence to the chosen course of action; improved health outcomes; increased patient access to accurate and balanced health information; enhanced ability of patients to assess the quality of available health information; and improved tailoring of health care to the individual's preferences and desires. The Task Force also defined potential drawbacks to such interventions, including the potential of presenting biased information and the difficulty patients may have in dealing with uncertainty (Briss et al., 2004).
- There has been a strong interest in developing decision aids for cancer patients and their health care providers. Decision aids, defined as "interventions designed to help people make specific and deliberative choices among options by providing (at a minimum) information on the options and outcomes relevant to a patient's health," are especially

\* Research conducted by or in cooperation with CIS.

important for cancer patients. Decision aids are valuable for several reasons: (1) limited patient understanding due to a variety of factors including issues in patient-provider communication, information overload, patient anxiety, and denial; (2) patients with cancer are especially vulnerable as they face the diagnosis of a potentially terminal illness; (3) research suggests that patient-provider communication can be problematic when dealing with ethnically diverse, poorly educated, or elderly patients who are often overrepresented in the cancer population; and (4) treatment decision-making in oncology is particularly challenging because of the number of different treatment options available, many of which have rather modest benefits and significant side effects (AHRQ, 2002; O’Conner et al, 1999, as cited in AHRQ, 2002, p. 10).

- In its review of the research, the Task Force on Community Preventive Services examined whether interventions designed to promote informed decision-making related to cancer screening (1) promoted understanding of cancer screening; (2) facilitated participation in decision-making at a level that is comfortable for individuals; and (3) encouraged individuals to make cancer-screening decisions that are consistent with their preferences and values. The review focused on interventions based in the community or healthcare systems and included, but was not limited to, interventions utilizing decision aids. The interventions used small media, counseling, small-group education, provider-oriented strategies, or a combination of these. The interventions generally improved individuals’ knowledge about the disease, accuracy of risk perceptions, and knowledge and beliefs about the pros and cons of screening and treatment options. However, few studies evaluated whether the interventions resulted in individuals participating in decision-making at a desirable level, or whether they led to decisions that were consistent with individuals’ values and preferences. In addition, too few studies were available to determine the effectiveness of interventions targeted to communities outside the healthcare system (Briss et al., 2004)
- The review conducted by the Agency for Healthcare Research and Quality (AHRQ) (2002) focused specifically on cancer-related decision aids in order to determine their impact on cancer prevention, screening, and treatment decisions. The review involved a wide range of decision aids (including brochures, audio and videotapes, interactive computer programs, decision boards, workbooks) designed to improve communication between health professionals and patients, help patients in making decisions about their health care, and incorporate patients’ values in health care decisions. The review found that decision aids increased patients’ knowledge about cancer and the pros and cons of different options;

increased patients' satisfaction with their decisions; decreased their decisional conflict and uncertainty; and did not increase patients' anxiety. In terms of the impact of decision aids on cancer-related decisions, the researchers conclude that:

- Decision aids are effective for cancer-related screening decisions, particularly for prostate specific antigen (PSA) screening, colorectal screening, and BRCA testing. In all studies, decision aids improved knowledge about screening and, in a number of cases, affected the intention to be screened.
  - Data regarding decision aids for cancer-related treatment decisions are very limited, and it is not possible to draw definitive conclusions about their effectiveness.
  - A number of different types of decision aids have been shown to be effective, at least in terms of increased knowledge, including brochures, audio and videotapes, and educational/counseling sessions. There is not sufficient evidence to indicate which types of decision aids might be most effective.
- In another review of decision aid studies (mostly cancer related), researchers found that decision aids have the greatest effect on the choices of patients who were undecided (e.g., about treatment options) at baseline. In contrast, decision aids are less likely to change the decision of the majority of individuals who have a stated preference at baseline. Generally, decision aids influenced patients to choose less intensive treatment options (e.g. breast-conserving surgery for breast cancer), likely as a result of better understanding about the potential risks of intensive treatment. When patients use decision aids, their choices are more likely to be based on better knowledge, more realistic expectations of outcomes, and personal values for outcomes. The researchers point out the lack of data on the long-term effects of decision aids, such as persistence with choices, distress, regret, and quality of life (O'Connor et al., 1999).
  - The CHESS interactive computer program includes a Decision Aid module designed to help users make cancer-related decisions. For breast cancer patients, the Decision Aid module focuses on surgical options, whether to take adjuvant chemotherapy or tamoxifen treatment, and whether to join a clinical trial. Users can read descriptions of different treatment options, excerpts from personal stories of women who have chosen different options, and criteria used by other women to make choices. An Action Plan module is designed to help women implement their decisions. While evaluations of CHESS have found a number of positive effects, program evaluations to date have not focused on how use of CHESS influences users' cancer-related decision-making. An early study of CHESS found that the Decision Aid and Action Plan modules were used less frequently than other components of

the program (although these modules were limited in scope at the time of the evaluation and many study participants had already made treatment decisions prior to the study) (AHRQ, 2002).\*

- Several studies examined the use of decision aids related to prostate specific antigen (PSA) screening for prostate cancer. Because of the uncertainty surrounding the value of PSA testing, patients need assistance to make individual decisions. Studies have found that decision aids increase knowledge about PSA screening and result in reduced screening rates (greater preference for “watchful waiting”). A recent study compared video versus Internet-based decision aids for men considering the PSA test. Men assigned to the Internet group could use the decision aid from home; men assigned to the video group viewed the video before a clinical visit. There were no differences between the two groups in terms of perceived convenience, effort, or satisfaction with the decision aids. However, men who used the video decision aid were more likely to review the materials and demonstrated greater knowledge about the PSA test compared to men who used the Internet version. In addition, men who used the video decision aid were also more likely to decline the PSA test (Frosch et al., 2003).

➤ **How does this vary across different populations?**

[No relevant literature identified]

**Question 3: Who are the most effective messengers and what are the most effective channels in delivering cancer-related information and interventions for different populations? What are the optimal combinations of messenger(s) and channel(s) for different populations?**

**Overview of Relevant Research:**

NCI's 2003 HINTS provides information about preferred channels and messengers for cancer information among different populations (see Q. 5 in Understanding Information Seeking). However, little is known about the effectiveness of different combinations of messengers and channels in terms of cancer-related decision making and behaviors. Literature review in this area is ongoing.

**Question 4: What are the most effective ways to deliver cancer-related information and education to individuals and communities with limited health literacy? How can health literacy be strengthened among these audiences? How can existing communication and education protocols and resources be effectively adapted for those with limited health literacy?**

**Overview of Relevant Research:**

A recent Institute of Medicine report documents the problem of low health literacy in the U.S. and issues recommendations to address the problem. Health literacy has been defined as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine, 2004, p.4). Health literacy problems are magnified as patients are asked to take more responsibility for their health in a health care system that is increasingly complex and technologically sophisticated.

**Specific Research Findings:**

- According to the 1992 National Adult Literacy Survey, about 90 million adults in the U.S. (47%) have limited literacy skills. While these adults can perform a variety of

\* Research conducted by or in cooperation with CIS.



straightforward tasks using printed materials, they are unlikely to be able to perform many of the more challenging tasks associated with health care (e.g., interpreting a medicine label correctly). Low health literacy is more prevalent among the poor, members of ethnic and cultural minorities, those with less than a high school education, those who live in southern and western regions of the U.S., and the elderly (Institute of Medicine, 2004).

- Using the 1992 National Adult Literacy Survey, researchers developed a Health Activities Literacy Scale (HALS) based on survey items that measure literacy related to health tasks (e.g., interpreting instructions on a medicine label). Some 19% of the U.S. population falls into the lowest literacy group (Level 1 and below), 27% in Level 2, 36% in Level 3, 17% in Level 4, and only 1% at the highest Level 5. The study found that health literacy is strongly related to education, race/ethnicity, wealth status, and health status. Healthy adults had higher average HALS scores than adults reporting health conditions (Rudd et al., 2004).
- The prevalence of inadequate or marginal health literacy is higher among the elderly, even after taking into account dementia, cognitive impairments, and diseases that affect sensory functions (Dubow, 2004). A study of Medicare enrollees found that 33.9% of English-speaking seniors and 53.9% of Spanish-speaking seniors had inadequate or marginal health literacy. Limited health literacy, coupled with the physical disabilities and chronic illnesses common in the elderly, adds to the barriers faced by elderly patients as they attempt to actively participate in their health care (Gazmararian et al, 1999).
- Numerous studies document that health materials, such as patient education brochures, discharge instructions, and consent forms far exceed the average reading ability of many adults in the U.S. This problem is magnified by the increasing multicultural and multilingual diversity of the U.S. population (AMA, 1999; Davis et al., 2002; Institute of Medicine, 2004; Rudd et al., 2000). An assessment of printed materials designed for African American audiences found that about 45% of breast cancer materials and 60% of prostate cancer materials were not culturally relevant (Guidry et al., 1998a)
- Literacy is related to multiple aspects of health, including health attitudes and knowledge, health status, and use of health services. For example, low literacy is associated with less knowledge about cancer control and greater misunderstanding about susceptibility to cancer, the benefits of early detection, and cancer prognosis. One study found that women with lower literacy skills were more likely to have negative attitudes related to mammograms compared to women with higher literacy skills. Literacy is also inversely

related to the influence of friends and family; as the literacy level of women decreases, the influence of friends/family in the decision to get a mammogram increases (AMA, 1999; Davis et al., 2002; Garbers & Chiasson, 2004; Institute of Medicine, 2004; Lee et al., 2004).

- Limited health literacy can take a psychological toll; one study found that those with limited health literacy had a sense of shame about their skill level (Parikh et al., 1996, as cited in Institute of Medicine, 2004). The sense of shame and stigma are major barriers to improving health literacy (Institute of Medicine, 2004).
- The American Medical Association's Ad Hoc Committee on Health Literacy reviewed studies involving simplified health education materials for low-literate populations (AMA, 1999). They conclude that while a few studies have shown that simpler written materials can improve health knowledge, there is no evidence that using such materials has a beneficial effect on patients' health outcomes. They suggest that even simplified materials may not be understood by individuals who have very limited literacy. The Institute of Medicine also reviewed interventions designed to improve health literacy and found mixed results in terms of impact on understanding, health behavior, and health outcomes (Institute of Medicine, 2004). The report identifies promising community-based approaches targeting special populations (e.g., Native Americans, Asians).
- Patients with low health literacy tend to be more responsive to information based on the health belief model, where priority is given to patient action, motivation, and self-empowerment. Videos have been shown to increase comprehension among low-literate patients compared with written materials. For example, one study found that a video and a pamphlet were more effective in promoting mammography than a pamphlet alone. Culturally sensitive videos have also been used effectively to promote cervical cancer and colon cancer screening among low-literate populations (Davis et al., 2000).
- Experts have developed guidelines for written materials targeting audiences with limited health literacy. These guidelines include using short sentences, the active voice, large print, and summarizing points, and grouping segments of information. Visual aids can reduce the amount of reading required and clarify written materials. Pretesting is essential to ensure that materials are understandable and appropriate (Dubow, 2004; Harris, 1998; Rudd et al., 2000).

**Question 5: How effective are different types of smoking cessation quitlines (e.g., proactive counseling vs. reactive counseling vs. information/referral)? Are different types of quitline services more appropriate for different subgroups? For proactive smoking cessation quitline services, what is the optimal packaging of sessions? How can attrition and dropout from proactive quitlines be improved? How do characteristics of tobacco users, environmental factors, and smoking cessation treatment factors affect outcomes?**

**Overview of Relevant Research:**

A significant science base demonstrates the effectiveness of telephone-based tobacco cessation services. While a number of studies demonstrate the effectiveness of proactive quitlines, there is less evidence supporting reactive quitlines. Based on the strength of the research evidence, both the Public Health Service and the Centers for Disease Control and Prevention (CDC) have endorsed proactive quitlines (CDC, 2004; Fiore et al., 2004; Hopkins et al., 2001), and in its *National Action Plan for Tobacco Cessation*, the Subcommittee on Cessation of the Interagency Committee on Smoking and Health recommended establishing a national quitline number to increase American's access to quitline services (Fiore et al., 2004). Based on these recommendations, a national access number (1-800-QUIT-NOW) was established in late 2004, with NCI as the portal for the service. While it is clear that multiple telephone counseling sessions are more effective than a single session, the optimal "packaging" of telephone services (e.g., number and timing of contacts, content and intensity of counseling) has not been established. Similarly, little is known about how characteristics of tobacco users, environmental factors, and various treatment factors affect outcomes. These research questions are intended to address such gaps in knowledge and are consistent with research questions articulated by the North American Quitline Consortium, a national partner of the CIS (Ossip-Klein, 2005).

**Specific Research Findings:**

- Quitline services have the potential to reach large numbers of tobacco users, including low-income, rural, elderly, uninsured and racial/ethnic minorities, who may not otherwise have easy access to smoking cessation services. It is estimated that quitlines reach 2-3% of tobacco users in their states each year. With promotion, outreach, and health system integration, quitlines have the potential to reach 7-10% of the tobacco-using population each year. In comparison, counseling programs reach less than 1% of smokers each year (CDC, 2003).

\* Research conducted by or in cooperation with CIS.

- Quitlines reduce common client barriers to smoking cessation services, such as transportation and childcare difficulties, costs, and limited availability. Quitlines offer confidentiality, multiple language capability, longer and more flexible hours, and free counseling. Quitlines help de-stigmatize cessation, provide critical social support, and can include referrals to health care providers and community resources (CDC, 2004; World Bank, 2004). As evidence of the greater accessibility of quitlines, surveys have found that smokers are several times more likely to use such a service than they are to use a face-to-face program (CDC, 2004; McAfee et al., 1998).
- There is strong evidence of the effectiveness of smoking cessation quitlines, particularly those using a proactive approach (i.e., the quitline counselor initiates contact with the tobacco user, often following an initial reactive counseling session) (CDC, 2004; Fiore et al., 2004; Hopkins et al., 2001; Lichtenstein et al., 1996; Stead et al., 2004). A large randomized controlled trial that served as the basis for the California Smokers' Helpline, the first publicly supported statewide quitline, found that telephone counseling increased the percentage of smokers making a quit attempt and decreased their rate of relapse, and found a strong dose-response relationship between the number of follow-up sessions and treatment effects (Zhu et al., 1996a). Further research has demonstrated the continued effectiveness of the California quitline after it scaled up to statewide operation (Zhu et al., 2002). A recent meta-analysis of quitline studies confirmed the effectiveness of proactive telephone counseling (Stead et al., 2004). According to this analysis, a call from a counselor increases the chances of quitting by approximately 50 percent, compared to a minimal intervention such as providing standard self-help materials. A number of the quitline studies have been conducted under "real world" conditions, increasing confidence that the efficacy found in small trials can be sustained as quitline services are implemented on a wider scale (CDC, 2004).
- Reactive quitlines, which respond to callers' immediate requests for assistance but do not provide outbound counseling calls, have not been studied as widely as proactive quitlines (CDC, 2004; Stead et al., 2004). CDC identified two studies that provide some support for a reactive approach (CDC, 2004). In one study, a well-promoted quitline that provided a single, yet substantial (50 minute) pre-quit counseling session was shown to increase callers' quit attempts and reduce the incidence of relapse when compared to an intervention that provided callers with only self-help materials (Zhu et al., 1996a). In another study, communities in which a quitline was promoted were shown to have significantly higher

quit attempt rates and cessation rates than similar communities without a promoted quitline (Ossip-Klein et al., 1991). It is unclear whether the effects were the results of the promotion alone or promotion in conjunction with the quitline itself. The CDC recommends that further studies are needed to assess the efficacy of reactive quitlines (CDC, 2004).

- Several states provide proactive quitline services based on referrals from health care providers. With this approach, providers obtain consent from patients to refer them to a quitline. Following the provider's referral, quitline counselors contact the tobacco user to offer services. Provider referral programs, including fax referrals, can significantly increase the numbers of smokers receiving quitline services (Bentz, 2005; Massachusetts DHHS, 2002).

➤ **Are different types of quitline services more appropriate for different subgroups?**

- While the research evidence indicates that smoking cessation quitlines are effective with various population subgroups, little is known about which approaches (e.g., proactive counseling vs. reactive counseling vs. information/referral; number and timing of contacts; content and intensity of counseling) are most effective for different groups.
- Quitlines are widely used by **minority** and **low-income** populations. About one-third of callers to the California quitline are ethnic minorities (Zhu et al., 2000). Data from the California quitline has shown that a culturally and linguistically targeted campaign, tagged with the quitline number, drew smokers of ethnic minority backgrounds at the same rate as the general market campaign drew Caucasian smokers (Zhu et al., 1995). The American Legacy Foundation's Great Start quitline for pregnant smokers received nearly 10,000 calls within 3 months, primarily from low-income smokers. Two-thirds of callers had no more than a high school education (CDC, 2003).
- Studies to establish the efficacy of proactive telephone counseling have included English and Spanish-speaking participants of **ethnically diverse backgrounds**. No significant differences in outcomes along ethnic or linguistic lines have been reported, suggesting that this type of counseling is effective for smokers from many ethnic and racial backgrounds (Stead et al., 2004). As yet, research has not established an evidence base for Asian-language quitlines (CDC, 2004).

- Studies to establish the efficacy of proactive telephone counseling have included participants of diverse socioeconomic backgrounds. No significant differences in outcomes along socioeconomic lines have been reported, suggesting that **low-SES** tobacco users can benefit from quitlines (CDC, 2004).
- Some quitlines have developed special protocols addressing the unique needs of **pregnant smokers**, and others specifically focus on this audience (e.g., The American Legacy Foundation's Great Start quitline) (Haviland et al., 2004). In a review of studies testing the effectiveness of quitline protocols for pregnant women, CDC concludes that the results are promising (CDC, 2004).
- The proportion of quitline callers who are **adolescents** is small (less than 2% younger than age 18 in 2001) (Zhu 2002, as cited in CDC, 2004). Little is known about the efficacy of quitlines for adolescents as they have not been included as participants in most of the major trials. There are a number of challenges to providing quitline services to adolescents, including the requirement in many states that parental consent be obtained before providing proactive services (CDC, 2004). Some researchers have suggested contacting adolescents via cellular phones to increase participation (Lipkus et al., 2004). CDC recommends that until the evidence base has been more firmly established, states should not aggressively promote quitline services for adolescents (CDC, 2004).
- There is evidence that telephone counseling can be effective for chewing tobacco cessation, as well as smoking cessation (Severson et al., 2000). Quitline media campaigns, even if they do not specifically target **tobacco chewers**, result in small but significant numbers of calls from "chewers." In response, most quitlines have developed special protocols for working with this audience (Zhu, 2002, as cited in CDC, 2004).
  - **For proactive smoking cessation quitline services, what is the optimal packaging of sessions?**
- Studies clearly demonstrate that multiple telephone counseling sessions are more effective than a single session in terms of smoking cessation rates. For example, one study found that quit rates increased from 5.5-7.5% with a single outreach call, to 9.9% with six calls (Zhu et al., 1996).

- The structure of proactive quitlines varies, with many providing some form of immediate “reactive” assistance when a smoker first calls, and then offering more comprehensive counseling through proactive follow-up calls. However, the number and timing of follow-up calls varies across quitlines and the optimal scheduling of calls has not been determined (CDC, 2004; Ossip-Klein & McIntosh, 2003). California’s quitline schedules follow-up sessions according to the probability of relapse, with the first call occurring within 24 hours of quitting and subsequent calls at 3 days, 1 week, 2 weeks, and 1 month. Thus, the sessions are front-loaded around the quit day and become less frequent as the probability of relapse decreases (CDC, 2004). This model has the advantage of preventing relapse before it happens or addressing it soon afterward (Zhu et al., 1996). In other states, the Free & Clear program provided by the Center for Health Promotion offers the first session shortly after the quit date and the other sessions distributed over a three- to four-month period, at the rate of one session per month. This model has the advantage of identifying callers who have relapsed and creating an opportunity to encourage them to quit again (Orleans et al., 1991).
- In an evaluation of the Oregon quitline, researchers found that providing nicotine replacement therapy (NRT) increased the number of contacts and total number of counseling minutes received for brief, moderate, and intensive counseling protocols (Hollis et al., 2005). Callers’ odds of being “quit” at 12 months post-counseling were somewhat greater with intensive counseling versus brief counseling, and greatest when NRT was offered. Another study found that participants interested in receiving NRT were significantly more likely to complete more calls. In a large-randomized trial evaluating three levels of counseling with and without an offer of NRT, callers receiving NRT completed more counseling calls than callers who did not (Zbikowski, 2005).

➤ **How can attrition and dropout from proactive quitlines be improved?**

[No relevant research identified; this research question was identified as a priority for the North American Quitline Consortium’s research agenda]

- **How do characteristics of tobacco users (e.g., motivation/readiness to quit, self-efficacy, use and quitting history, medical and psychological conditions), environmental factors (e.g., recruitment strategies/methods, media messages, social support, tobacco-related policies, community resources), and smoking cessation treatment factors (e.g., type of cessation service, intensity, timing/during of service, counselor characteristics/training/methods) affect outcomes?**

[No relevant research synthesis was identified. This question was identified as a priority at the USDHHS conference, Developing a Research Agenda to Improve the Impact of Tobacco Use Quitlines, February 23-24, 2005, Rockville, MD.]



## INCREASING ACCESS TO AND USE OF CANCER-RELATED INFORMATION AND EDUCATION

The specific research questions in this section fall under a single broad research question concerning access to and use of cancer-related information and education, as follows: *What strategies are effective in increasing access to and use of the latest, most accurate, and most appropriate cancer-related information and education to those in need, especially the underserved?*

**Question 1: To what extent is the public aware of national and local resources for cancer-related information? To what extent is the public aware of CIS and the services offered by CIS? What are their perceptions of CIS? How do perceptions vary across population subgroups and by phase along the cancer continuum?**

### **Overview of Relevant Research:**

NCI's 2003 Health Information National Trends Survey (HINTS), a nationally representative survey of 6,369 adults, provides current information about levels of awareness of CIS and other cancer-related organizations among various population groups. However, HINTS did not explore the public's perceptions of CIS and other cancer organizations, or their knowledge about the kinds of information and services organizations offer.

### **Specific Research Findings:**

- To assess levels of awareness of the CIS, a composite measure was developed using the HINTS data; respondents who said they had heard of either the CIS *or* the 1-800-4-CANCER information number are considered to be aware of CIS. According to this analysis, overall, 32.8% of U.S. adults are aware of CIS. There is greater awareness of the National Institutes of Health (60.0%) and the National Cancer Institute (76.7%) than of the CIS specifically. The survey also found markedly higher awareness (96.9%) of the American Cancer Society than of NIH, NCI, or CIS (Squiers et al., 2005).
- According to HINTS, levels of CIS awareness vary among population subgroups:
  - Females were significantly more likely than males to report having heard of the CIS (35.1% vs. 30.2% respectively).

- Adults 65 years of age and older (37.1%) were significantly more likely to have heard of the CIS than adults age 35-64 (34.1%) or adults 18-34 (28.3%).
  - Hispanics (50.7%) were more likely to say they had heard of the CIS compared to African Americans (45.2%), those identifying their race as “other” (35.4%), Whites (27.9%), and those identifying themselves as multiracial (27.2%).
  - Awareness of the CIS was inversely related to income and education. Respondents making less than \$25,000 a year were most likely to have heard about the CIS (46.8%) compared to those making \$25,000-49,999 (31.7%) and those making more than \$50,000 per year (23.7%). Respondents with less than a high school education were most likely to report having heard about the CIS (47.4%) compared to high school graduates (36.4%), respondents with 1-3 years of college education (30.1%), and college graduates (20.8%).
  - Respondents who reported having ever been told they had cancer were more likely to have heard about the CIS (41.3%) than respondents who had not (31.7%).
  - Awareness of CIS was similar among respondents with and without a family history of cancer (32.2% and 33.7%, respectively).
  - Respondents with and without a regular health care provider were equally likely (32% each) to have heard about the CIS (Squiers et al., 2005).
- HINTS findings suggest that awareness of CIS is linked with use (or potential future use) of the telephone service. Of respondents who had ever looked for cancer information, those who had heard of the CIS were more likely to report that they had looked for cancer information via a telephone information number (a 1-800 number) (52.0%) compared to those who had not heard of the CIS (48.0%). In addition, when respondents were asked where they would go first if they had a strong need for cancer information, a significantly greater proportion of respondents who had heard of the CIS said they would go to a telephone information number (77.0%, compared to 23.0% of respondents who had not heard of the CIS). In neither case do we know if respondents were referring to 1-800-4-Cancer specifically, but it is reasonable to assume that at least some proportion of respondents were (NCI, 2004).

**Question 2: To what extent are health care providers aware of CIS and the services offered by CIS? What are their perceptions of CIS? To what extent do providers use CIS themselves and refer patients to CIS? What are providers' perceived barriers to using CIS? What types of interventions are effective in increasing providers' awareness of, referrals to, and use of cancer education and information resources such as the CIS and smoking cessation quitlines?**

### **Overview of Relevant Research:**

Little is known about health care providers' awareness and use of CIS, whether for themselves or for their patients. A pilot study in New York (the Bridging the Digital Divide Project) was the only study identified that explores these issues. CIS user data provide information about the reasons providers contact CIS (i.e., topics about which they request information). A few studies provide insight into the reasons providers do not often use eHealth tools in the clinical setting or refer patients to health information on the Internet. Smoking cessation quitline programs in a number of states have developed strategies and programs to encourage health care providers to refer patients for telephone counseling.

### **Specific Research Findings:**

- Of health care providers who contacted CIS in 2003, more than one quarter (28.2%) requested publications. The other common "subjects of interaction" (main topics discussed) were clinical trials (18.6%), treatment information (12.5%), cancer site information (11.1%), and support services (10%). It is not possible to determine whether providers were requesting information for themselves or to pass on to their patients (CIS, 2004). \*
- CIS user data indicates that health care providers are likely to be "repeat users" – that is, they contact CIS multiple times. In 2003, 41.1% of health care providers who contacted CIS by telephone said they had contacted CIS previously. Overall, about 22% of callers were repeat users. These findings suggest that health providers rely on and are satisfied with the information received from CIS (CIS, 2004).
- Among cancer patients who called 1-800-4-CANCER or used CIS' *LiveHelp* service in 2003, 8.7% said they had learned about CIS from a health professional. Among relatives and friends of cancer patients who contacted CIS, 6.8% had learned about CIS from a health professional (CIS, 2004).\*

\* Research conducted by or in cooperation with CIS.

- A pilot study (Bridging the Digital Divide Project) developed by CIS of New York State involves an online cancer education curriculum for health care providers (and consumers) working in an underserved community (Harlem). A survey of participating health care providers found that familiarity with CIS varied depending on where the provider worked. About 46% of providers from a community hospital, 51% of providers from a comprehensive cancer center, and 60% of providers from other community-based organizations were familiar with CIS (Perocchia, et al., 2003).\*
  - Prior to the launch of the Bridging the Digital Divide Project study, focus groups were conducted with physicians, nurses, social workers, and other health care providers from community-based health care facilities. Providers cited difficulties in using information from the Internet to address their patients' health information needs. They stated that many patients with low-literacy skills would have difficulty understanding the information (Perocchia, et al., 2003).\*
  - While clinicians widely use the Internet, few routinely apply eHealth tools in the clinical setting. Surveys conducted between 1999 and 2001 find that about 15 percent of physicians' time online was spent obtaining general clinical information and about 8 percent for clinical work relating to their patients. Barriers to the adoption of eHealth tools include perceived drain on time, legal and liability issues, lack of reimbursement, and lack of applications that can be efficiently integrated into the clinician's workflow (Eng, 2001).
  - Physicians may not refer their patients to health Web sites because they do not have the time to select appropriate sites. For nurses, additional reasons include the shortage of nursing staff and the lack of technology necessary to provide access. Both nurses and physicians express concern about the quality of health information, product promotion, and biased points of view on health Web sites (Brooks, 2001; Ferguson, 2000; Pringle 2002; Silberg, Lundberg, & Musacchio, 1997, all as cited in Perocchia et al., 2005).\*
- **What types of interventions are effective in increasing providers' awareness of, referrals to, and use of cancer education and information resources such as the CIS and smoking cessation quitlines?**

\* Research conducted by or in cooperation with CIS.

- In the Bridging the Digital Divide project, providers were asked where they refer their patients for additional cancer information. Providers from a comprehensive cancer center were most likely to say they referred patients to the Internet (73%, compared to 43% of providers from a community hospital and 65% of providers from other community-based organizations). Providers from the comprehensive cancer center were also most likely to refer patients to a telephone information service (51%). In comparison, about 40% of providers from the community hospital and other community-based organizations referred patients to telephone information services. Following a training workshop focusing on online cancer resources, almost all of the providers said they would use the Internet to find cancer information and refer patients to the CIS (Perocchia, et al., 2003).\*
- Smoking cessation programs are experimenting with strategies designed to encourage providers to refer patients to quitlines. Programs publicize and promote quitline services to providers, provide training, and offer referral tools (e.g., brochures, information cards for patients) and systems (e.g., proactive fax referrals). For example:
  - The Arizona Smoker's Helpline works with the HealthCare Partnership Continuing Education and Training Unit to train providers on how to deliver brief cessation interventions and refer patients to the helpline. A pilot test of the program in one county and with the WIC program showed an 81% increase in enrollment in cessation services among county residents and a 226% increase among WIC participants (Massachusetts DHHS, 2002).
  - In Oregon, promotion of the quitline to providers has resulted in a high number of referrals from physicians (13.6% of all calls come from physician referrals). A fax referral program has also been successful. An evaluation found that 17% of quitline users who had been referred to the quitline through provider fax referrals were actively quitting at the time of follow up compared to 5% of other quitline users (Massachusetts DHHS, 2002).
  - State-level fax referral systems have been established in Wisconsin (Fax to Quit), Massachusetts (QuitWorks), Utah, and Arizona (Bentz, 2005; Massachusetts DHHS, 2002).
  - In Georgia, marketing to providers increased quitline referrals by 163%, and provider referrals represent 23% of total quitline calls (Bentz, 2005).
  - A study in Mississippi tested a referral strategy involving dentists. The researchers reported that the dentists' were receptive to the referral program and coordination with the quitline was easy (Gordon, 2005).

\* Research conducted by or in cooperation with CIS.

- In a review of Oregon fax-referral systems, Bentz (2005) concluded that implementation is well-accepted by providers and the cost for a provider referral is less than a typical media-driven referral.

**Question 3: How do individuals who receive information or education from the CIS or other cancer-related resources evaluate, assimilate, and use the information they receive? What factors influence how individuals evaluate, assimilate, and use the information? What are the outcomes of receiving information and education?**

#### **Overview of Relevant Research:**

CIS' 1996 and 2003 User Surveys provide information about how individuals who contact CIS use the information they receive (e.g., to talk with others) and about changes in knowledge, self-efficacy, and also some behavioral intentions and behaviors. Because the surveys were conducted a few weeks after users' contact with CIS, only short-term changes are captured; there is currently no way to assess whether changes are sustained. To date, analyses have not been conducted to examine differences according to stage along the cancer continuum or whether the user is a family member/friend or cancer patient. Because the surveys sampled only first-time users, differences in information use between first-time and repeat users cannot be determined.

#### **Specific Research Findings:**

- The CIS 2003 User Survey found that 28% of users had discussed the information received from CIS with a health care professional, and another 43% planned to do so. The following subgroups were more likely to have talked with a health professional about the information received from CIS:
  - Hispanics (40%), compared to whites (28%) and African Americans (25%);
  - Individuals diagnosed with cancer (37%), compared to those not diagnosed (20%); and
  - Younger adults (32% of those ages 41-50), compared to those ages 61 and older (25%) (CIS, 2004b). \*

\* Research conducted by or in cooperation with CIS.

- A 1996 national survey of CIS callers found that callers used the information they received to talk to others. Of callers who contacted CIS about someone else, over three-quarters reported that they discussed the information received with the person they had called about. About three-quarters of callers also shared the information with others, primarily with other family members. There were differences in rates of information sharing depending on the reasons why the caller contacted CIS; for example, callers were most likely to share information about prevention with the person that they called about, and least likely to share information about symptoms (CIS, 1996; Ward et al., 1998).\*
- Contact with CIS also increased user' knowledge and self-efficacy, according to the 2003 User Survey. About three-quarters of users said their cancer knowledge increased a lot (39%) or somewhat (34%) as a result of their contact with CIS. Persons with a personal relationship to cancer<sup>1</sup>, Hispanics, younger people, and those with some college were more likely to report that CIS had increased their knowledge somewhat or a lot. Sixty-seven percent of all users reported that they felt more confident in their ability to seek information following their contact with CIS. In addition, 60% of those diagnosed with cancer and contacting the Information Service for themselves reported feeling more confident in their ability to actively participate in their treatment decision. Forty-five percent of users who did not have a personal relationship with cancer reported feeling more confident in their ability to understand the causes and risks of cancer (CIS, 2004b). \*
- The User Survey found that information from CIS helped smokers make tobacco-related changes in their lives. Following their contact with CIS, 14% reported that they had quit smoking, 35% had cut back, and 45% indicated that they planned to quit or cut back. Among smokers who had already cut back, nearly all (96%) reported that they planned to quit. Of those, 40% had set a quit date (CIS, 2004b). \*

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<sup>1</sup> Refers to callers who were diagnosed with cancer themselves, or the person on whose behalf they contacted CIS was diagnosed with cancer

**Question 4: What are the barriers to accessing and using CIS and other cancer-related information and education resources? How do these barriers differ by population subgroups?**

**Overview of Relevant Research:**

A primary barrier to accessing CIS and other cancer-related information and education resources is lack of awareness. NCI's 2003 HINTS provides current data on levels of awareness of CIS, NCI, NIH, and the American Cancer Society (see Q. 1 in this section). However, the survey did not measure the public's perceptions or knowledge about CIS, such as knowledge about the types of information and services available or perceptions about whether CIS can meet their information needs. There is also a lack of information about perceived access to CIS and other information and education resources; individuals may be aware of a resource but not perceive it as accessible (e.g., not know how to access it, not feel confident in accessing it).

(Barriers related to cancer-information seeking are discussed in several other sections: barriers related to health literacy in Q. 4 in the Testing Innovative Communication and Education Interventions section; barriers to obtaining health information on the Internet in Q.5 in the Descriptive Studies section, and; individual-level barriers to information seeking in Q.7 in the Descriptive Studies section.)



**Question 5: To what extent do community-based interventions increase access to and use of cancer-related information and education resources, such as the CIS and smoking cessation quitlines, by minority and medically underserved populations?**

**Overview of Relevant Research:**

Through the Partnership Program, CIS works with partner organizations that have an established presence in communities, are trusted within their communities, and are dedicated to serving minority and medically underserved populations. The recent National Partner Survey provides up-to-date information about partner organizations' efforts to promote CIS. However, the extent to which partnerships may have increased access to and use of CIS services among minority and medically underserved populations has not been studied. HINTS provides current data on levels of CIS awareness among the population groups targeted through the Partnership Program (i.e., minority and underserved). The success of future Partnership Program promotional efforts can be assessed against these baseline measures.

**Specific Research Findings:**

- CIS' 2003 National Partner Survey found that about three-quarters of its partner organizations promoted CIS through person-to person mechanisms, specifically presentations (76%) and coalitions (71%). More than half have included information about CIS in their organization's newsletter or other organizational publications. Thirty-eight percent mentioned CIS on their organization's web site, in published articles (33%), or in public service announcements (32%). Twenty-seven percent had included information about CIS on an e-mail or listserv. Program Development partners were more likely than Education Program or Networking partners to promote CIS in various ways (CIS, 2003).
- According to the National Partner Survey, partner organizations that promote CIS are most likely to promote NCI publications and print materials (87%) and the 1-800-4-CANCER service (81%). Many also promote the Web site (69%) and the CIS Partnership Program itself (66%). Significantly fewer partner organizations (24%) promote CIS' *LiveHelp* service (CIS, 2003).

- Results from HINTS provide baseline measures of CIS awareness among the minority and medically underserved audiences targeted through the Partnership Program. Hispanics (50.7%) and African Americans (45.2%) were more likely to say they had heard of the CIS compared to those identifying themselves as “other” (35.4%), Whites (27.9%), and those identifying themselves as multiracial (27.2%). Awareness of the CIS was inversely related to income and education: Respondents making less than \$25,000 a year were most likely to have heard about the CIS (46.8%) compared to those making \$25,000-49,999 (31.7%) and those making more than \$50,000 per year (23.7%). Respondents with less than a high school education were most likely to report having heard about the CIS (47.4%) compared to high school graduates (36.4%), respondents with 1-3 years of college education (30.1%), and college graduates (20.8%) (Squiers, 2005. (Additional HINTS findings related to awareness of CIS are discussed under Q.1 in this section.)

**Question 6: To what extent do interventions implemented within health care systems increase access to and use of CIS and other cancer-related education and information resources and smoking cessation quitlines?**

**Overview of Relevant Research:**

To date, CIS has not implemented interventions within health systems in a widespread or systematic manner, although through the Partnership Program CIS collaborates with health state/local health departments, health professional organizations, and other health organizations. CIS is interested in exploring the effectiveness of interventions implemented within health systems, for example to increase providers’ awareness and use of CIS and to encourage them to refer their patients to CIS for cancer-related information. A number of state-level smoking cessation quitlines work in close collaboration with health systems (e.g., managed care organizations, other health plans, Medicaid, WIC). As discussed previously, quitline programs have trained providers in smoking cessation interventions, promoted the quitline, and established referral systems whereby providers can refer their smoking patients to the quitline. Provider referral programs, including proactive fax referrals, can significantly increase the numbers of smokers who call quitlines (Bentz, 2005; Gordon, 2005; Massachusetts DHHS, 2002)

(See related discussion in Q. 2 in this section and Q.5 in Testing Innovative Cancer Communication and Education Interventions section.)

**Question 7: To what extent do social marketing approaches increase access to and use of cancer information and education resources such as the CIS and smoking cessation quitlines?**

**Overview of Relevant Research:**

There is a large body of research related to the use of social marketing to promote health behaviors, including use of health information and education resources. Social marketing refers to the use of commercial marketing concepts and tools to influence behaviors and includes promotion as one element of the “marketing mix.” This overview focuses on how the mass media have been used to increase awareness and utilization of CIS and smoking cessation quitlines. CIS studies and evaluations conducted over many years demonstrate that the mass media can be used to increase awareness and use of CIS, including among populations that have traditionally underutilized CIS’ services. Recent CIS data suggest that the Internet and organizations/community groups are increasingly important channels for raising awareness of CIS. Mass media advertising also plays a key role in increasing awareness and utilization of smoking cessation quitlines, with call volume closely linked with the intensity of advertising campaigns. However, the relative effectiveness of different types of marketing or promotion strategies has not been well studied. To date, evaluations of CIS’ promotional efforts have generally focused on individual campaigns and the impact on call volume. Studies have not examined, in any systematic or comprehensive manner, how different social marketing approaches or campaign characteristics (e.g., different messages) influence outcomes. Furthermore, outcome measures have generally been limited to utilization; thus, little is known about how promotional campaigns influence knowledge, attitudes, self-efficacy, behavioral intention/behavior among individuals who contact CIS as a result of the campaign.

**Specific Research Findings:**

- In a 1993 review of how the mass media have been used to promote calls to CIS, researchers concluded that the mass media can produce a demonstrable effect on the number and types of calls to the CIS, as well as on the types of callers. Based on the body of research about media promotion of CIS, the authors concluded:

\* Research conducted by or in cooperation with CIS.

- Paid advertising can result in substantial increase in call volume. For example, in a smoking cessation campaign targeting mothers with young children, markets with paid advertising generated nearly 10 times as many calls to CIS as did the control markets.
  - Television promotion appears to increase calls more than promotion through other media.
  - An increase in calls depends on the intensity of the media exposure and the amount of resources committed to media placement.
  - News is the most significant force in increasing call volume (e.g., celebrity diagnosis with cancer, news about a scientific “breakthrough”).
  - Media promotions can increase calls among “hard to reach” populations (e.g., African Americans). For example, National Minority Cancer Awareness Week campaigns increased calls from African Americans and Prostate Cancer Awareness week campaigns increased calls from men (Arkin et al., 1993).\*
- Television may be a more important channel for promoting CIS for African Americans than Whites. An analysis of callers to CIS found that African Americans were more likely to report having learned about the service on TV. A campaign featuring Patti LaBelle in the 1991 National Minority Cancer Awareness Week led to a jump in calls from African Americans (in the California CIS office, the percentage of calls from African Americans increased from 9% to 26%) (Freimuth, 1993).\*
  - The Texas Adios al Fumar program designed to increase awareness and use of CIS smoking cessation services among Hispanics found that radio, newspaper, postcard, and television ads were effective in increasing calls to CIS. In the 18 months prior to the start of the program, there was less than one call a month from Hispanic smokers on average; in the 13 months following implementation of the program, call volume increased to 20 per month. An analysis of cost effectiveness (cost per caller), found that television ads were the most cost effective, followed by radio, postcard, and newspaper ads (Daza, 2003).\*
  - Another targeted smoking cessation campaign – Quit Today! – used paid television and radio advertising to increase use of CIS assistance by African American smokers. The volume of calls from African Americans, who have historically underutilized the CIS, increased markedly following the campaign. About 54% of the African American callers said they had learned about CIS on television, and 42% on radio (Boyd et al., 1998).\*

\* Research conducted by or in cooperation with CIS.

- Callers to CIS and users of CIS' *LiveHelp* service are most likely to have learned about CIS on the Internet (18.4%) and through organizations and community groups (17%), according to data collected in 2003. Fewer users had learned about CIS on TV or radio (7.1% and <1%, respectively) or through the print mass media (about 2% each for newspapers and magazines). These findings suggest that partnerships and the Internet are particularly effective methods for increasing awareness and use of CIS (CIS, 2004).\*

➤ **To what extent have social marketing approaches been used to promote smoking cessation quitlines?**

- Research has clearly demonstrated that broad community-based promotion increases quitline utilization. Quitlines can be promoted through multiple channels, including direct media promotion, tagging the quitline number to media antismoking campaigns, health care providers, health systems, work sites, and schools. Overall, advertising, particularly when tagged to antismoking media campaigns, increases call rates and may stimulate calls from those who do not otherwise seek help. Fluctuations in the level of advertising are associated with fluctuations in call volume. "Peaks" in call volume are the result of heavy media advertising and "valleys" correspond with lulls in the advertising campaign. The occasional dramatic spikes in demand following intensified campaigns suggest that the primary factor limiting utilization is funding for advertising (CDC, 2004; Ossip-Klein & McIntosh, 2003).
- During its first decade of operation, the California Smoker's Helpline saw steady growth in demand. The growth is attributed not only to increased advertising, but also to the branding of the quitline and to grassroots efforts to institutionalize the service in the minds of health care providers, pharmacists, educators and others who are in a position to refer tobacco users (CDC, 2004).
- Some countries are phasing in promotion of the quitline number on cigarettes packs. When the Netherlands began this approach in 2002, call volume increased markedly. The average number of calls per week increased from 200 to over 1200 immediately following the launch of the campaign (Ossip-Klein & McIntosh, 2003; Willemsen & van der Meer, 2005).
- Combining media advertising with nicotine replacement therapy (NRT) can greatly increase utilization of quitlines. Cummings (2005) reported that New York's quitline experimented

\* Research conducted by or in cooperation with CIS.

with offering free NRT and promoted this “give away” through the media. The quitline received more than 425,000 calls in the first three days following the promotion.

- McDonald (2005) reported that segmenting messages by stage of change may increase call volume, especially by those not motivated to quit.

## DISCOVERING EFFECTIVE MODELS FOR DISSEMINATING SUCCESSFUL CANCER CONTROL INTERVENTIONS AND STUDY FINDINGS

**Question 1: What are the most effective approaches or models for disseminating successful cancer communication and education interventions? What are the determinants of adaptation, evaluation, implementation, and maintenance of evidence-based cancer communication and education interventions within different service programs, communities, and health care systems?**

### **Overview of Relevant Research:**

The gap between research and practice in cancer control interventions is well documented. However, strategies for translating evidence-based interventions into practice have not been well studied. The Agency for Healthcare Research and Quality (AHRQ) recently conducted a review of the literature related to dissemination and diffusion of evidence-based cancer control interventions. The AHRQ report summarizes the state of knowledge and includes recommendations for accelerating the transfer of research into practice. While models and frameworks exist that could potentially be applied to the dissemination of cancer control interventions, they have not been widely used or evaluated. In order to close the gap between research and practice in cancer control interventions, the AHRQ and other researchers have made a number of recommendations for future dissemination research.

### **Specific Research Findings:**

- As part of the Translating Research into Practice (TRIP) program, the AHRQ examined the state of knowledge related to diffusion and dissemination of evidence-based cancer control interventions (AHRQ, 2003). The primary objective of the report was to determine what strategies have been evaluated to disseminate evidence-based cancer control interventions. The quality of studies was generally weak; few used randomized, controlled designs and many were simply descriptive studies. Another limitation was that few studies examined

policy-level cancer control interventions. Thus, there was insufficient evidence to comment on the effectiveness of policy-level interventions to promote the uptake of cancer control interventions. The review focused on dissemination of cancer control interventions in specific areas (e.g., smoking cessation, dietary change, mammography). Findings include the following:

- Smoking cessation: Train-the-trainer approaches improved knowledge and awareness of smoking cessation issues among providers, but there is no evidence that they impact on providers counseling patients to quit smoking or on patients' smoking cessation rates. The use of educational facilitators (academic detailing) to disseminate smoking specific information increases preventive services, but the impact on smoking cessation activities is uncertain.
  - Dietary change: The use of educational facilitators to promote the use of office systems by health care providers shows some promise, but because the studies were descriptive it is not possible to draw firm conclusions.
  - Mammography: There was insufficient evidence to conclude that any dissemination strategy targeting health care providers is effective in terms of increasing mammography.
  - Cervical cancer screening: Educational facilitators increased overall indicators of preventive care, however there was no statistically significant increase in cervical screening rates. There is no evidence for effective strategies to disseminate interventions to promote cervical cancer screening.
  - Cancer pain control: Dissemination of a treatment algorithm for pain management produced only short-term change in provider adherence. Cancer pain role-modeling programs were shown to improve process measures such as knowledge and education of other health care providers. However, no information is given on integrated pain assessment into clinical practice.
- The AHRQ review and another review of interventions designed to change health care providers' practices found that passive approaches to disseminating cancer control interventions, such as publication in peer-review journals or mailing clinical practice guidelines, are generally ineffective. More active approaches, such as the train-the-trainer model, media campaigns, educating opinion leaders, health care provider reminders (e.g., computerized prompts), and cycles of audit and feedback, are more effective in promoting change in knowledge, attitudes, and behaviors in certain circumstances. However, these approaches are also more costly. Multi-faceted interventions are also more likely to be successful (AHRQ, 2003; Grimshaw et al., 2001).



➤ **What are barriers to effective dissemination of evidence-based cancer control interventions?**

- The gap between research and practice for prevention and health promotion results from several interacting factors, including limited time and resources for practitioners, insufficient training, lack of feedback and incentives for use of evidence-based practices, and inadequate infrastructure and systems organizations to support translation. In addition, interventions that prove successful in efficacy trials frequently do not translate well into the “real world” of effectiveness trials. The characteristics that cause an intervention to be effective in efficacy research (e.g., intensive, complex, highly standardized) are often at odds with programs that succeed in population-based effectiveness settings (e.g., having broad appeal, being adaptable for both participants and intervention agents). Researchers have identified a number of barriers to dissemination of health interventions (Bradley et al., 2004; Glasgow et al., 2003, 2004; Feifer et al., 2004). Glasgow and colleagues (2004) grouped barriers into four broad categories:
  - (1) Characteristics of the intervention: high cost; intensive time demands; high level of staff expertise required; not packaged or “manualized”; not developed considering user needs; not designed to be self-sustaining; highly specific to a particular setting; not modularized or customizable.
  - (2) Characteristics of the research design: not relevant or representative sample of patients, settings, or clinicians; failure to evaluate costs; failure to assess implementation; failure to evaluate maintenance and sustainability.
  - (3) Characteristics of potential adoption settings: competing demands, program imposed from the outside; finances or organizations unstable; clients and setting have specific needs; resources/time are limited; organizational support is limited; prevailing practices work against innovation; perverse incentives or regulation oppose change.
  - (4) Interactions among types of barriers: program reach or participation is low; intervention is not flexible; intervention is not appropriate for the target population; staffing pattern does not match intervention requirements; inconsistent organization and intervention philosophies; inability to implement intervention adequately.
- Case studies of the diffusion and adoption of evidence-based health interventions (none were cancer control interventions) found that the success and speed of the dissemination/adoption process depended on: (1) the level of support from senior

management at the adopting organization; (2) the effectiveness of clinical leadership in the adopting organization; (3) the credibility and persuasiveness of data to support start-up, implementation, and ongoing evaluation; (4) the extent to which changes in organizational culture are required; and (5) the amount of coordination across disciplines or departments that is required. To overcome barriers, researchers recommend that an infrastructure for diffusion be established that includes resources to accomplish the following: recruit new sites that might adopt the program; market the new program; educate staff and administrators about the new program; answer questions when implementation problems occur; and provide expert advice about ways to sustain the program. They note that such an infrastructure is expensive, but critical (Bradley et al., 2004).

➤ **What models or frameworks can be applied to dissemination of evidence-based cancer communication and education interventions?**

- Researchers point to several potentially useful models or frameworks for the dissemination of cancer control interventions. They note that such models or frameworks have not been used consistently for disseminating cancer control interventions, much less evaluated (Glasgow et al., 2004).
  - Diffusion of Innovation Theory, which addresses the process of adopting innovative ideas. Diffusion is dependent on how well information is communicated, effective collaboration between intervention developers and those practitioners who will implement it, and appropriate environmental support.
  - Reach, Efficacy, Adoption, Implementation, Maintenance Framework (RE-AIM), which is designed to assess the potential of an intervention for dissemination and public health impact. According to this framework, interventions are good candidates for dissemination if they have the potential to reach a large audience; can be broadly adopted; and can be implemented by different types of staff without a heavy investment of resources.
  - Social Ecologic Framework, which focuses on combining interventions at multiple levels (e.g., individual, interpersonal, organizational, environmental).
- Greenhalgh and colleagues (2004) developed a conceptual model for considering the determinants of diffusion, dissemination, and implementation of innovations in health service delivery, based on a review of empirical research studies. Elements of the model include: (1) characteristics of the innovation (e.g., compatibility, trialability, observability);

(2) communication and influence (e.g., social networks, peer opinion, expert opinion, marketing); (3) outer context (e.g., socio-political climate, incentives and mandates); (4) system antecedents for innovation (e.g., structural characteristics of adopter organizations); (5) system readiness for innovation (e.g., innovation-system fit, dedicated time/resources); (6) characteristics of the adopter (e.g., values, goals, skills); (7) assimilation; and (8) implementation process.

➤ **What types of dissemination research are needed?**

- Researchers recommend that potential for dissemination must be a priority throughout the planning, implementation, evaluation, and reporting phases of intervention research. To close the gap between efficacy and effectiveness research (1) study participants should approximate those who will participate in the “real world”; (2) interventions should be designed to facilitate replication and dissemination using modalities and resources that are feasible in and exportable to the intended nonresearch settings; and (3) research settings and community partners in intervention research should be selected for representatives (Glasgow et al., 2004).
- The traditional randomized controlled trial is often not possible or desirable for dissemination studies. Researchers need to consider alternative designs that are more feasible to implement in real-world settings with community partners (AHRQ, 2003; Glasgow et al., 2004).
- Research is needed to identify the characteristics of settings, programs, and groups that support successful dissemination. Currently more is known about the barriers to successful dissemination and adoption than about factors that facilitate the process (Glasgow et al., 2004).
- In order to accelerate the transfer of research into practice, researchers recommend that priority be given to the following types of dissemination studies (Glasgow et al., 2003, 2004; Greenhalgh et al., 2004):
  - Interventions in multiple settings and especially in settings that are representative of those to which the program is intended to generalize;
  - Innovative investigations of ways to enhance reach, adoption, implementation, and maintenance;

- Cross-over designs, sequential program changes, replications, multiple baseline, and other designs that can address key issues in translation;
- Cost-effectiveness studies;
- Investigations of long-term effects and sustainability of initially successful interventions; and
- In order to facilitate comparisons across studies and meta-analyses, study findings should be presented in a detailed manner (e.g., documenting the unique aspects of programs and their contexts and settings) and use standardized definitions and measures of key variables and outcomes.

➤ **What are potentially useful vehicles for dissemination of CIS-based research?**

- The recently launched Cancer Control PLANET – a public-private effort of NCI, the American Cancer Society, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and the Substance Abuse and the Mental Health Services Administration – provides a vehicle for disseminating information about proven interventions in cancer control prevention to program planners and practitioners via the Internet. The website provides information about research-tested cancer programs, including information about audiences, suitable settings, the time and resources required to implement programs, and evaluation findings. Program materials can be downloaded or ordered. The goal of Cancer Control PLANET is “to provide access to resources that can facilitate the transfer of evidence-based research findings into practice” (Cancer Control PLANET, 2005).
- The *Guide to Community Preventive Services* is another potential vehicle for disseminating CIS-based research. NCI is part of the Task Force on Community Preventive Services, convened by the Department of Health and Human Services, developing the Guide. The Guide presents the results of systematic reviews of research in different areas of health promotion, identifying “what works, for whom, and how well.” In the area of cancer, the Task Force conducted systematic reviews of studies of population-based interventions focusing on: preventing skin cancer by reducing UV light exposure; increasing breast, cervical, and colorectal cancer screening; and promoting informed decisions about cancer screening. The Guide and associated training materials (e.g., power point presentations) and practical guidance (e.g., related to leadership, strategic planning, community assessment, grant writing, and evaluation) are available on-line and in print format.

Findings are also presented in supplements to the *American Journal of Preventive Medicine*. The Guide is a work in process and additional cancer-related systematic reviews will be included in the future (Community Guide, 2005).

## UNDERSTANDING INFORMATION SEEKING

**Question 1: Who are cancer information seekers? What are their demographic and psychosocial characteristics? Are there different types of cancer information seekers in terms of skill levels and approaches to information seeking? How do individuals who call/use CIS compare to other cancer information seekers? How do repeat callers/users differ from those contacting CIS for the first time?**

### **Overview of Relevant Research:**

A number of surveys provide information about the socio-demographic characteristics of health/cancer information seekers. HINTS focuses specifically on *cancer* information seeking (rather than on health information seeking generally), and thus provides up-to-date information about which population subgroups are more and less likely to seek cancer information. A few studies also provide insight into the psychosocial characteristics of health information seekers.

The literature does not specifically define health or cancer information seekers in terms of their information seeking skills. However, researchers have developed categories of health information seekers that describe differing approaches to information seeking, and also defined phases of information seeking. One study suggests that information seekers who contact the CIS differ from individuals who seek information from other sources. About one-quarter of individuals who contacted CIS in 2004 were repeat users – that is, they had contacted CIS previously. Little is known about how these repeat users may differ from those who contact CIS for the first time.

### **Specific Research Findings:**

- According to preliminary analysis of HINTS, about 44.9% of adults in the U.S. have *ever* looked for information about cancer. Marked differences are found in cancer information-seeking behavior by gender, age, and other characteristics, for example:
  - Females (53.1%) are more likely than males (36.1%) to seek cancer information;
  - Adults aged 35-64 are most likely to seek information (49.6%, compared to 43.1% of the 18-34 age group and 33.1% of the 65+ age group);
  - Whites (49%) are more likely than African Americans (40.8%) and Hispanics (26.5%) to seek information;

- Cancer information seeking increases with income (from 34.8% in the <\$25,000 group to 56.4% in the >=\$50,000 group) and education (26.3% in the less than high school group to 62.3% in the college graduate group); and
  - Adults with health coverage (47.3%) are more likely to seek cancer information than those without coverage (32.5%) (NCI, 2004).
- A 2001 survey of U.S. households found that 38% of adults had sought information related to a personal health concern in the previous year from a source other than their doctor. About one in five adults used multiple sources to obtain information. Education exerted the strongest influence on health information seeking behavior; about 55% of the most educated group (graduate degree) had sought health information compared to about 25% of the least educated group (less than high school). Women, younger respondents, and higher income respondents were most likely to seek health information. Also, adults with chronic health conditions were more likely to seek health information than healthy adults; 42% of those with one chronic health condition and 45% of those with multiple conditions had sought health information from a source other than their doctor in the past year, compared to 35% of adults with no chronic conditions (Tu & Hargraves, 2003).
- Females are more likely to seek health information than males, according to a number of studies (Johnson, 1997; Manfredi et al., 1993; Tu & Hargraves, 2003). For example, a survey of English and Spanish-speaking California residents found that 52% of women had sought health information for themselves or their families in the past year, compared to 39% of men (Pennbridge, Moya, & Rodrigues, 1999).
- A survey of callers to CIS found that younger and more educated callers were more likely than their older and less educated counterparts to seek information from multiple sources (Muha et al., 1998).\*
- A comparison of cancer patients and their families who sought information from CIS or other sources (information seekers) and non-information seekers found that information seekers were more likely to have felt stressed at diagnosis, to talk with others about their cancer, to have someone who helps them cope emotionally, to prefer greater information about and involvement in their treatment plans, and to be less confident that physicians always have current information. Information seekers were also more likely than non-seekers to be female, younger, and educated (Manfredi et al., 1993).\*

\* Research conducted by or in cooperation with CIS.

- There is mixed evidence about the effects of anxiety on information seeking. High anxiety due to a cancer diagnosis was found to be associated with less information seeking in one study, but with more information in another. A third study found that lack of information can lead to anxiety and coping problems (Czaja et al., 2003).
- Individuals with a high internal locus of control are more likely to seek health information; conversely, individuals who feel powerless are less likely to seek information (Harris, 1998; Johnson, 1997).
- A survey of English and Spanish-speaking California residents found that those with Internet access were more likely to have sought health information than those without Internet access (56% compared to 41%) (Pennbridge, Moya, & Rodrigues, 1999).
- NCI's 2003 HINTS also provides information about passive health information seeking –that is, the extent to which individuals pay attention to health or medical topics on the media (specifically, television, radio, newspapers, magazines, Internet) (NCI 2004). Preliminary analysis of survey data finds that respondents are most likely to pay attention to health information on television (31.9% pay a lot of attention), followed by newspapers (24%) and magazines (23.1%). Attention to health information on the media differs according to gender, education, and other characteristics, as follows:
  - Women are more likely than men to pay attention to health topics on all media. For example, 39.7% of women say they pay a lot of attention to health topics on television compared to about 23.6% of men.
  - More educated respondents pay more attention to health topics in newspapers, magazines, and on the Internet compared to less educated respondents. This difference is especially pronounced for the Internet; 20.1% of the highest education group (college graduates) pay a lot of attention to health topics on the Internet compared to 3.7% of the lowest education group (less than high school). However, rates of attention to health topics on radio and television are similar across educational groups.
  - African Americans are more likely than Whites or Hispanics to pay a lot of attention to health information on television and also in newspapers and magazines. For example, 46.5% of African Americans say they pay a lot of attention to health information on television compared to 35.8% of Hispanics and 29.4% of Whites. For the Internet, similar percentages of African Americans and Whites attend to health information (13.7% and 13.1%, respectively, pay a lot of



attention); Hispanics are less likely to pay attention to health information on the Internet (7.8%). For the radio, similar percentages of African Americans and Hispanics attend to health information (21.2% and 20.2%, respectively, pay a lot of attention), with Whites less likely to pay attention (13.3%).

- Marked differences in passive health information seeking are also found by age. The oldest respondents (65+ years) are more likely to pay attention to health information on television and in newspapers compared to the youngest respondents (18-34 years). For example, 35.1% of the 65+ age group pay a lot of attention to health information on television, compared to 26.4% of the 18-34 age group. The reverse is true for the Internet; less than 5% of older respondents pay a lot of attention to Internet health information compared to about 14% of the younger age groups.

➤ **Are there different types of cancer information seekers in terms of skill levels and approaches to information seeking?**

- The literature does not specifically define health or cancer information seekers in terms of their information seeking skills. However, researchers have developed categories of health information seekers that describe differing approaches to information seeking, and also defined phases of information seeking. Categories of health information seekers and phases of health information seeking developed by researchers include the following:
  - Johnson (1997) defines the following categories of information seeking:
    - 1) Casual – “accidental” or “aimless” information seeking (i.e., run across information).
    - 2) Purposive-placid – more purposive and rational; to answer question, “What can I do to prevent cancer?”; lack of urgency, not very motivated.
    - 3) Purposive-clustered – to answer question, “Do I have cancer?”
    - 4) Directed – follows a cancer diagnosis; to answer question, “How can I cope?”; very focused; lack of information a problem at this stage.
  - Donohew (as cited in Johnson, 1997) groups information seekers into the following categories:
    - 1) Loners – more likely to be depressed, aggressive; less prior knowledge.
    - 2) Formal seekers – broad-based information-seeking strategies, perceive information to be more available; lower anxiety.

- 3) Risky seekers – more prior knowledge; narrowly focused information-seeking strategies; give lower ratings of information than other groups.
  - 4) Informal seekers – less likely to perceive information as available.
- Morris (as cited in Johnson, 1997) defines four information seeking styles:
    - 1) Ambivalent learner – less healthy; receptive to information.
    - 2) Uncertain patients – not received much information from health care providers.
    - 3) Risk avoiders – youngest and best educated; seeking information to gain control; most likely to rely on authoritative, professional information sources.
    - 4) Assertively self-reliant – least receptive to information; least discriminating about information sources; do not perceive themselves to have an information deficit.
  - The “Conceptual Model of Patient use of Healthcare Information for Healthcare Decisions,” developed to explain health information seeking and use among women with breast cancer, defines six phases of patient information use (Longo et al., 2001):
    - 1) Patient is unaware of available information relevant to her healthcare decision-making.
    - 2) Patient is aware that information is available relevant to her healthcare decisions, but does not attempt to access information.
    - 3) Patient is aware that information is available but is unable to access it (e.g., aware of information on the Internet, but no computer access).
    - 4) Patient accesses the information but cannot make use of it (e.g., cannot understand it).
    - 5) Patient accesses the information but does not make own healthcare decisions.
    - 6) Patient uses the information to make healthcare decisions.

➤ **How do individuals who call/use CIS compare to other information seekers in terms of skill level and approaches to information seeking?**

- A study comparing cancer patients and their families who sought information from CIS (CIS information seekers) to those who sought information from other sources (other information seekers) found that CIS information seekers had higher information needs and were more

thorough in their information seeking. CIS information seekers were more likely to seek information from multiple sources and wanted information about a greater range of issues (Czaja, et al., 2003; Manfredi et al., 1993).\*

➤ **How do repeat callers/users differ from those contacting CIS for the first time?**

- In 2004, 25.3% of individuals who contacted CIS by telephone or *LiveHelp* were classified as repeat users, that is, they indicated that they had contacted CIS previously. Given CIS' current data collection protocol as approved by OMB, it is not possible to determine how many times repeat users had contacted CIS previously. The user data suggest that individuals accessing CIS via telephone are more likely to be repeat users compared to individuals using *LiveHelp* (25.9% and 10.1%, respectively); however, first-time/repeat users status could not be determined for many *LiveHelp* users (CIS, 2004). \*
- A 1996 national survey of CIS callers found that repeat callers frequently call multiple times. About 25% of callers said they had talk to an Information Specialist twice, 17.1% 3 to 5 times, 1.8% 6 to 9 times, and 4.3% 10 or more times (CIS, 1996).\*
- An analysis of calls to CIS in 2003 finds that, overall, patients (29%) were more likely to be repeat callers compared to family members/friends of cancer patients (24%). Patients in recurrence (35.8%) and post-treatment (34.9%) were most likely to be repeat users (compared to 29.3% of patients in treatment and 20.9% of those not in treatment). A high proportion of health professionals (41.1%) and callers from other organizations (34.5%) were repeat users (CIS, 2004). \*

\* Research conducted by or in cooperation with CIS.

**Question 2: When do individuals seek cancer information across the cancer continuum? For cancer patients, how soon after diagnosis do individuals seek information? What triggers information seeking? What triggers information seeking at different points along the cancer continuum? What triggers information seeking for different audiences?**

**Overview of Relevant Research:**

CIS user data provides some information about when cancer patients seek information from CIS, but not about when they seek information from other sources. Furthermore, the CIS user data tell us only whether patients are in treatment, post treatment, or in recurrence – relatively broad measures of “when.” Several of the studies reviewed focus on issues related to information seeking around the time of diagnosis, such as patients’ ability to absorb information at that time. While the literature does not identify specific triggers for cancer information seeking, researchers have articulated various reasons for cancer information seeking (e.g., to discuss with providers, to achieve a sense of control). Data collected by CIS on how users learned about CIS suggest that the triggers for contacting CIS differ for patients, family members/friends, survivors, and other audiences.

**Specific Research Findings:**

- Of the cancer patients who contacted CIS by telephone, email, *LiveHelp*, or through written correspondence in 2003 (N=38,557), the largest percentage (40.2%) were in treatment. About 20% of patients who contacted CIS were in the post-treatment phase and 10.1% in recurrence. More than one quarter (26.2%) of the patients who contacted CIS was not receiving treatment; this broad category includes patients who have not begun treatment and also patients not receiving treatment for various other reasons. (Treatment status could not be determined for 3.8% of patients who contacted CIS.) These findings suggest that information needs are particularly strong during the active treatment phase of the cancer continuum, and also during periods of no treatment. However, it is important to bear in mind that these findings relate only to cancer patients who seek information from the CIS, not to all cancer patients (CIS, 2004).\*
- A study of cancer patients and their families who had contacted CIS or sought information from other sources found that the most common time to seek cancer information was the

\* Research conducted by or in cooperation with CIS.

period immediately after diagnosis and before starting treatment. The next most common time was during treatment. Individuals who had just been diagnosed were also most likely to use multiple information sources (CIS, printed materials, family and friends), followed by patients in treatment, between treatments, and after treatment. These findings suggest the intensive nature of information seeking following a cancer diagnosis (Manfredi et al., 1993)\*

- A study of acutely ill cancer patients (newly diagnosed with acute myeloid leukemia) found these patients wanted only limited information. They were primarily interested in practical information related to their care (e.g., managing side effects), and were not interested in information such as survival and remission rates or details about chemotherapy. In particular, patients did not want information about prognosis and generally thought they were given too much information. Patients thought they “ought to” seek medical information, but few did so in the interval between diagnosis and the time of their second round of chemotherapy treatment (about 2 months after diagnosis) (Fries, Elverdam, & Schmidt, 2003).
- A number of studies document that many cancer patients are shocked and numb when first told of the cancer diagnosis, and cannot process much information. Patients may stop listening once they have heard the word “cancer” (Hogbin & Fallowfield, 1989; Fallowfield, 1993; Hack et al., 1994; all as cited in Van Der Molen, 2000; Leadbeater, 2001; Ley, 1988, as cited in Van der Molen, 1999). According to a small qualitative study, patients who trust their doctors may not absorb all of the information given at the time of diagnosis, yet they feel comfortable with the provider’s decisions (Van der Molen, 2000). Researchers conclude that, “too much information at this stage is counterproductive as much of it will not be retained” (Van der Molen, 2000, p. 49).
- Studies of men with prostate cancer have found that the information needs of patients and their partners vary depending on where they are along the cancer continuum. In the time immediately after diagnosis, information-processing abilities are low as men and their partners adjust to the diagnosis. Information provided in this period may not be digested. The shock and inertia are then replaced by a period of intensive information seeking. The spouse is often the primary information seeker during this phase. Once the treatment decision is made, the need for information is typically low. Information-seeking behavior may increase immediately before and after therapy as information about treatment and side effects become pertinent. Information needs continue after treatment as patients and their partners are unprepared for the symptoms they experience (Echlin & Rees, 2002).

\* Research conducted by or in cooperation with CIS.

- Informational needs of cancer patients and their families vary across three stages: (1) diagnostic phase; (2) exploration of treatment alternatives phase; and (3) decision, implementation, and evaluation phase. During the diagnostic phase, some family members are shocked and withdraw, needing time to process the diagnosis. Others move into a vigilant approach and want all available information (Ballard-Reisch & Letner, 2003).
- A study of women with breast cancer found that the topics about which they seek information differ depending on the time since diagnosis. At 8 months after diagnosis, women wanted specific breast cancer information and treatment information. At 16 months, women continued to want specific breast cancer information, but also information about medications (Satterlund, McCaul, & Sandgren, 2003).
- A study of early and late stage cancer patients and their partners found that information seeking was ranked second as a coping strategy for early stage patients (and third for their partners). For late-stage patients, information was ranked much lower as a coping strategy (eleventh by patients and twelfth by their partners) (Gotay, 1984, as cited in Freimuth, 1989).

➤ **What triggers information seeking?**

- Individuals seek health information for: (1) general purposes; (2) to make a specific health-related decision; (3) to collect residual information related to a health decision (e.g., to confirm or rationalize a decision); (4) to share with others; and (5) to better communicate with health care providers (Johnson, 1997).
- Individuals can be grouped according to their personal health values and priorities into nine “valuegraphic” groups, five of which are health information seekers. The reasons for seeking health information differ among these groups:
  - 1) Generic – Highly price conscious and want only basic health care services. This group seeks health information that will guide them in obtaining the best economic value.
  - 2) Ready User – Actively involved in their own health and place a high value on achieving above-average health. They seek information about the latest high-quality clinical treatment services.

- 3) Family Centered – High value on family members’ health (more than their own health). They seek information about preventive care and support services for their families.
- 4) Independently Healthy – Driven by value they place on achieving optimum level of personal health and performance. They seek information that will help them maximize their health potential, particularly related to exercise and sports.
- 5) Naturalist - Place a high value on achieving good health (nutrition, physical activity) and have a tendency to avoid traditional medical care. Their high level of information seeking is focused on alternative health.

These five valuegraphic groups are more likely to use the Internet and other sources to obtain health information compared to the remaining valuegraphic groups (referred to as the Clinic Cynic, Avoider, Traditionalist, and Loyalist groups) (Navarro & Wilkins, 2001).

- Individuals with a “monitoring” informational coping style (as opposed to a “blunting” style) seek information because it provides them with certainty and lets them work through their experiences (Elf & Wikblad, 2001; Rees & Bath, 2001). Among breast cancer patients with a monitoring informational coping style, important reasons for seeking information are to achieve a sense of control, participate in decision making, and increase feelings of confidence (Rees & Bath, 2001).
- Cancer patients often do not verbalize their information needs related to social, emotional, and psychological issues (e.g., self-identity, effects of cancer on relationships, financial strain). They are better able to express their needs for strictly medical information (Van der Molen, 2000). Women are more likely than men to express a need for emotional support (Boudioni et al., 2000).

➤ **What triggers information seeking at different points along the cancer continuum? What triggers information seeking for different audiences?**

- CIS routinely asks callers to 1-800-4-Cancer and *LiveHelp* users how they learned about CIS. While this data does not provide information about triggers per se, it is reasonable to assume that exposure to information about CIS may trigger cancer information seeking (e.g., an individual sees information about CIS on the Internet or in a brochure and is prompted to seek cancer information). The CIS data reveal marked differences in how different types of users (i.e., cancer patient, family member/friend of cancer patient, general public, health

professional) learned about CIS, suggesting that the triggers for cancer information seeking may also vary among these groups. Some of the key differences are as follows:

- Patients were most likely to have heard about CIS from printed sources of information (10.5% specify NCI publications and another 17.9% say other printed sources), followed by the Internet (13.9%) and organizations/community groups (13.2%).
  - Family members/friends of cancer patients are most likely to have learned about CIS on the Internet (27.3%), followed by a telephone book or directory assistance (14.2%).
  - The general public is most likely to have heard of CIS through organizations and community groups (23.3%), followed by TV (13.3%).
  - Finally, health professionals are much more likely to have heard about CIS on the Internet (30.6%) than from any other source; the next most frequently mentioned sources of information among health professionals were printed materials (12%) and organizations/ community groups (11.1%) (CIS, 2004).\*
- A qualitative study explored when and why cancer patients in the United Kingdom use the Internet to seek cancer information (Ziebland et al., 2004). Researchers categorized the reasons for information seeking at different points along the cancer continuum as follows:
    - Before visiting the doctor – to discover the possible meaning of symptoms.
    - During investigations – to seek reassurance that the doctor is performing the correct tests and to prepare for results.
    - After the diagnosis – To gather information about the cancer (including information that is difficult to ask about directly), to seek advice about how to tell children, to contact online support groups, to seek second opinions, to make sense of the stages of the disease, to interpret what health professionals have said, and to deal with isolation.
    - When choosing treatments – to obtain information about treatment options, side effects, experimental treatments, research, and alternative and complementary treatments.
    - Before treatment – to find out what to take to the hospital, what will happen, what treatment will be like, what to expect of recovery, and how to identify and prepare questions for the doctor.
    - Short-term follow-up – to learn about side effects, for reassurance about symptoms, advice about diet, complementary treatments, advice on health benefits and financial issues, and to check that the treatment was optimal.

\* Research conducted by or in cooperation with CIS.



- Long-term follow-up – To share experiences and advice, contact support groups and chat rooms, to raise awareness about the disease, and to make anonymous inquiries.

**Question 3: What types of cancer information do individuals seek? What are the information needs of different socio-demographic subgroups of cancer patients? What are the information needs of cancer patients at different stages along the cancer continuum? How do the information needs of repeat callers/users change from first contact with CIS to subsequent contacts?**

#### **Overview of Relevant Research:**

Based on a review of the literature, NCI researchers have developed a typology of cancer patients' information needs and determined the most frequently cited information needs in the literature. The literature review, together with an analysis of CIS user data, provides insight into how information needs vary among different socio-demographic subgroups of cancer patients. There is also evidence that information needs differ depending on the caller's stage along the cancer continuum. However, the available research does not distinguish information needs at each stage of the cancer continuum as defined by NCI – prevention, detection, diagnosis, treatment, and survivorship. CIS user data suggests that repeat users/callers have information needs that are distinct from the needs of those contacting CIS for the first time.

#### **Specific Research Findings:**

- NCI researchers have developed a typology of cancer patients' information needs, based on a review of relevant research. The typology defines 10 categories of information needs, as follows:
  - Cancer specific information (e.g., type of cancer, course of disease, physical effects of disease);
  - Treatment-related information (e.g., side effects, risks/benefits, available treatments, treatment options);
  - Prognosis information (e.g., chance of cure, survival rate, recurrence rate);
  - Rehabilitation information (e.g., self-care and home-care issues, nutrition, follow-up care).

- Surveillance and health information (e.g., maintaining physical health or physical activity, prevention and early detection, maintaining psychological health);
  - Coping information (e.g., emotional reactions, emotional support, counseling, support groups);
  - Interpersonal/social information (e.g., effect on family, friends, caregivers, effect on social life/leisure, risk of disease for family members);
  - Financial/legal information (e.g., cost of treatment, insurance coverage, advanced directives, wills);
  - Medical system information (e.g., interactions with providers, experience/qualifications of providers, quality of medical equipment); and
  - Body image/sexuality information (e.g., physical appearance).
- The literature review found that the most frequently cited category of information needs was treatment-related information (especially about side effects, risks/benefits, and available treatments/treatment options). This finding is not surprising given that much of the research reviewed focuses on patients in the treatment stage. The next most frequently cited categories of information needs were cancer-specific information (especially about the nature of the disease), rehabilitation information (especially related to self care and home care during recovery), and prognosis information (especially about chance of cure, life span or survival rate, and recurrence rate) (Finney Rutten et al., 2004).

➤ **What are the information needs of different socio-demographic subgroups of cancer patients?**

- A preliminary analysis of recent CIS caller data examines the information needs of individuals who contact the CIS and how information needs are influenced by socio-demographic characteristics (Squiers et al., 2005a). For all of the cancer patients that call CIS, the most frequent subject of interaction is specific treatment information (59.6% of calls), such as information about clinical trials, side effects of treatment, and complementary and alternative treatments. The next most common subjects of interaction are general cancer site information (32.4%), support services (15.2%), and referrals to medical services (14.8%). Fewer patients who call the CIS seek information about psychosocial issues, cancer screening and diagnosis, prevention/risk factors, or organizations (less than 10% each). A multivariate analysis examined the extent to which callers' socio-demographic characteristics independently predict subjects of interaction. Findings include the following:

- Female callers are less likely than males to seek specific treatment information. However, female callers are more likely to seek general cancer site information, information about support services, psychosocial issues, and cancer screening and diagnosis.
- Older callers are more likely to seek specific treatment information and less likely to seek information about support services, psychosocial issues, and prevention and risk factors.
- Hispanic callers are more likely than non-Hispanics to seek information about support services.
- Compared to Whites, African Americans, American Indians/Alaskan Natives and multiracial callers are more likely to seek information about support services.
- More educated respondents are less likely to seek information about support services.\*

➤ **What are the information needs of cancer patients at different stages along the cancer continuum?**

- A preliminary analysis of recent CIS caller data examines the information needs of callers at different stages along the cancer continuum – treatment, post treatment, and recurrence (an additional category of “no treatment” includes patients who have not yet started treatment or who are not receiving treatment for various reasons) (Squiers et al., 2005a). As noted above, for all of the cancer patients that call CIS, the most frequent subject of interaction is specific treatment information. However, patients who are in recurrence are more likely to request such information (77.7%) compared to patients who are in treatment (64.0%) or are post treatment (42.9%). Conversely, callers who are in treatment (19.1%) or post treatment (17.1%) are more likely to ask about support services (e.g., economic assistance, care delivery services) compared to callers who are in recurrence (7.9%). A multivariate analysis examined the extent to which patients’ stage in the cancer continuum predicts information needs, independent of socio-demographic characteristics. The results indicate that, in comparison to patients in treatment:
  - Patients in recurrence are more likely to seek specific treatment information, and patients not receiving treatment and patients in post-treatment are less likely to seek this type of information.
  - Patients not receiving treatment are more likely to seek general cancer site information.

\* Research conducted by or in cooperation with CIS.

- Patients not receiving treatment and patients in recurrence are less likely to seek information about support services.
  - Patients in recurrence and patients not receiving treatment are more likely to seek referral information.
  - Patients in post-treatment are more likely to seek information about psychosocial issues (e.g., support groups, coping).
  - Patients not receiving treatment and patients in post-treatment are more likely to seek information about cancer screening and diagnosis.
  - Patients in post treatment are more likely to seek information about prevention and risk factors, and patients in recurrence are less likely to seek this type of information.\*
- In a review of the literature related to cancer patients' health information needs and sources, NCI researchers identified distinct patterns of information needs for patients in the diagnosis/treatment and post-treatment phases of the cancer continuum:
    - For patients in the diagnosis and treatment phase, the most frequently cited information needs were for cancer-specific and treatment-related information. In terms of cancer-specific information, the most frequently cited information needs related to stage of disease and specific diagnosis information. In terms of treatment-related information, the most frequently cited information needs concerned available treatments/treatment options and treatment side effects.
    - For patients in the post-treatment phase, the most frequently cited information needs were for treatment-related and rehabilitation information. Patients in this phase continued to be interested in information about available treatments/ treatment options and treatment side-effects. In terms of rehabilitation issues, the most frequently cited information needs related to self-care issues/home care, follow-up care and treatment, and long-term side effects (Finney Rutten et al., 2004).
- **How do the information needs of repeat callers/user change from first contact with CIS to subsequent contacts?**
- A comparison of first-time and repeat CIS users in 2003 finds differences in their subjects of interaction. For example, first-time users were more likely to ask about referrals to medical services, support services, clinical trials, and screening and diagnosis. Repeat users were more likely to ask about cancer site and treatment information (CIS, 2004).\*

\* Research conducted by or in cooperation with CIS.

**Question 4: What are the information needs of family members and other caregivers of cancer patients? How do these needs change depending on the cancer patient's stage along the cancer continuum? How and with whom do family members and other caregivers share information? What additional resources would be useful in facilitating the communication process?**

**Overview of Relevant Research:**

Family members and others in a caregiver role have substantial information needs, distinct from the information needs of cancer patients. According to some research, caregivers' cancer information needs frequently go unmet. Supporting caregivers with cancer information is especially important in today's health care environment; the trend towards shorter hospital stays and reduced professional home health care means that patients are increasingly dependent on family members and social networks. While it is clear based on CIS' experience that family members and friends of cancer patients frequently share cancer information, the dynamics (e.g., when, why, how) and effects of such information sharing have not been well studied.

**Specific Research Findings:**

- Caregivers' information needs include information about physical patient care, lifestyle changes associated with the caregiving role, emotional coping, community resources, and support services. Researchers have found that caregivers are often dissatisfied with the information available to them (Hileman et al., 1992; Laizner et al., 1993; Longman et al., 1992; Mills & Davidson, 2002, all as cited in Bernard, 2004).
- The information and psychosocial needs of family and friends of cancer patients differ from the needs of the patient. The psychosocial stressors for these significant others may include emotional isolation, role reversal, and differences in communication styles between patient and family members. Coping tasks include providing emotional support to the patient, assisting with treatment decisions, and helping with day-to-day functions (Miller, 1983; Haber et al, 1995, both as cited in Darrow et al., 1998).\*

\* Research conducted by or in cooperation with CIS.

- Studies of men with prostate cancer and their partners found that partners were high information seekers, but that their information needs were often unmet (Echlin & Rees, 2002; Rees, Sheard, & Echlin, 2003).
- For family members and other caregivers, it is important to recognize bereavement as part of the disease trajectory. Little is known about the information needs of family members during the aftermath of the patient's death (Bernard, 2004).
- An analysis of calls to CIS in 2002/2003 examined the subjects of interaction for callers who were spouses/family members/friends of cancer patients. The most frequent subject of interaction was specific treatment information (54.9%), followed by general cancer site information (36.9%), referrals to medical services (18.4%), and support services (16.7%). Based on the CIS contact records, it is not possible to determine how subjects of interaction may vary depending on whether the caller is in a caregiver role or not, or on the cancer patient's stage along the cancer continuum (Finney Rutten & Squiers, 2004)\*
- A 1996 study of CIS callers found that most who stated they had called for coping information were spouses/partners (21%), friends/coworkers (11%), and other family members (19%), rather than patients (33%). Significant others generally evaluated the information they received and other aspects of the call more positively than patients. These findings suggest that patients and significant others are distinct groups in terms of their information needs (Darrow et al., 1998).\*

➤ **How do these needs change depending on the cancer patient's stage along the cancer continuum?**

- Family members' information needs vary according to the patient's stage of disease and the level of care family members are expected to provide. Researchers have defined the phases of the "cancer trajectory" in different ways. One categorization defines six stages: diagnosis, hospital, post hospital, adjuvant treatment, recurrence, and terminal (Sales, 1991, as cited in Bernard, 2004). During the initial, diagnostic phase, seeking information is a coping strategy, bringing control over a situation where families feel powerless. At this stage caregivers want facts about the disease, treatment, symptoms, the patient's progress, and probable outcomes. Family members of advanced cancer patients (especially those caring for patients at home) especially want information about physical caregiving skills and

\* Research conducted by or in cooperation with CIS.

support services (Houts et al., 1991; Lewandowski & Jones, 1988, as cited in Hardwick & Lawson, 1995; Sales, 1991 and Wright & Dyck, 1984, as cited in Bernard, 2004).

➤ **How and with whom do family members and other caregivers share information?**

- A 1996 national survey of CIS callers found that of those who called about someone else, over three-quarters reported that they discussed the CIS information with the person they had called about. About three-quarters of callers also shared information with others, primarily with other family members. There were differences in rates of information sharing depending on the reasons why the caller contacted CIS; for example, callers were most likely to share information about prevention with the person that they called about, and least likely to share information about symptoms (CIS, 1996; Ward et al., 1998).\*
- Some studies have found that cancer patients are not receptive to friends and family members sharing cancer information. Patients may reject or avoid such information. For example, a study of acutely ill cancer patients (newly diagnosed with acute myeloid leukemia) found that patients were not interested in what their information-seeking relatives had found out and they felt pressure from their relatives related to information-seeking (Fries, Elverdam, & Schmidt, 2003; Van der Molen, 2000).

➤ **What additional resources would be useful in facilitating the communication process?**

[No relevant literature identified.]

**Question 5: What are the preferred channels for seeking information for different populations across time and across the cancer continuum? Do cancer information seekers use different channels (or combinations of channels) for different types of cancer-related information? What messengers or sources of information are perceived as credible among different populations? How is the Internet used for seeking cancer-related information?**

**Overview of Relevant Research:**

According to HINTS and other surveys, health care providers are generally perceived as the most important and trusted source of health information. There is limited information on how channel preferences may vary along the cancer continuum and among population subgroups. Recent research documents the rapidly increasing reliance on the Internet for obtaining health and cancer information, and identifies barriers and concerns related to using the Internet for this purpose. Evaluations of NCI's Bridging Digital Divide Projects examine the success of these interventions in expanding access to and use of computer-based channels among low-income and underserved populations.

**Specific Research Findings:**

➤ **What are the preferred channels for seeking cancer information specifically?**

- The American public turns to health care providers as their first choice for cancer information. NCI's 2003 HINTS asked respondents where they would go first if they had "a strong need to get information about cancer." According to preliminary data analyses, 48.5% of the respondents said they would first go to a health care provider. After health care provider, the Internet was the most frequent response (33.3%). Family, library, and various print media were all mentioned by about 5% or less of respondents. However, among respondents who have looked for cancer information in the past, the rank order of *actual* information sources differs from the stated preferred sources. Respondents were most likely to say they had looked for information on the Internet (48%), followed by books (13.7%) and then health care providers (10.8%). Lower income and less educated respondents were *more* likely to say they had sought cancer information from health care providers compared to their higher income and more educated counterparts (e.g., 17.9% of



respondents with less than a high school education had sought cancer information from a provider compared to 6.7% of college graduates) (NCI, 2004).

- A study of cancer patients (primarily with breast and prostate cancer) in Texas found that patients were most likely to rate physicians as a helpful source of information (99% of patients said physicians were helpful), followed by nurses (89%), pamphlets (88%), and television (65%). White patients were more likely to rate books and reference materials as helpful, while African American patients were more likely to rate pamphlets, television, and radio as helpful. Educational level had a major influence on African Americans use of print materials (Guidry et al., 1998).
- A survey of callers to CIS found that most (59%) did not seek information related to the topic of the call from any other sources. Among those who did seek information from additional sources, the main sources were health care providers, libraries/bookstores, and cancer associations (Muha et al., 1998).\*
- A study of cancer patients and their families who had contacted CIS or sought information from other sources found that the most widely used sources of cancer information (excluding CIS and their physicians) were printed materials, relatives/friends, patient support groups, the American Cancer Society, other organizations, and hospitals/cancer centers. Patients who had sought information from CIS were more likely to have used multiple information sources (Manfredi et al., 1993).\*
- While CIS' telephone service is much more widely used than *LiveHelp*, satisfaction levels are similar for the two channels. The 2003 User Survey found that 60% of users who contacted CIS by telephone and 64% of those who used *LiveHelp* were very satisfied with the service overall. For both modes of contact, 38% said the service exceeded their expectations, about half said the Information Specialist was very knowledgeable, and over 80% said they trusted the information a lot (CIS, 2004b).\*

➤ **What are the preferred channels for seeking health information generally?**

- A 2001 survey of U.S. households found that 38% of adults had looked for or obtained information related to a personal health concern from a source other than their health care provider over the past year. The most frequently cited sources were books or magazines

\* Research conducted by or in cooperation with CIS.

(23%), friends or relatives (20%), the Internet (16%), and television or radio (11%) (Tu & Hargraves, 2003).

- A survey of English- and Spanish-speaking California residents found that physicians/health care providers were the most widely used sources of health information, regardless of gender, ethnicity/race, age, or income (85% of all respondents named health care providers). The next most frequently cited sources were family members/friends (34%), advice book (32%), and newspaper/magazine/journal article (21%). Fewer had used the Internet (19%) or a telephone helpline (10%) (Pennbridge, Moya, & Rodrigues, 1999).
- When asked where they would look if they needed reliable information about health or medical conditions, 59% of Americans said they would contact a medical professional, 31% said they would look online, and 8% said they would find information some other way. Among Internet users, almost half said they would try to find information online (Fox & Fallows, 2003).
- Perceived accessibility of the channel is key, and is more important than perceived quality. Research shows that peoples' threshold for perceived inaccessibility is very low. Channels that involve the least effort are selected first (Johnson, 1997).
- People follow habitual patterns in information seeking, tending to stick to "tried and true" sources rather than engaging in a comprehensive search for information. Information seekers are often unaware of different sources of information and how to use them (Johnson, 1997).

➤ **What are the preferred channels for different populations?**

- According to a preliminary analysis of HINTS, trust in the various sources of cancer information is influenced by income, education, age, and race/ethnicity. Specific findings include the following:
  - Higher income and more educated respondents express the greatest trust in both health care providers and the Internet as sources of cancer information. For example, 68.7% of the highest education group (college graduates) say they trust cancer information from health care providers a lot compared to 57.6% of the lowest education group (less than high school). Conversely, higher income and more educated respondents are less likely to trust television and radio as sources of cancer

- information. For example, 11.7% of the highest education group trust television cancer information a lot compared to 28.8% of the lowest education group. Higher income and education groups are also less likely to trust friends and family as sources of cancer information (13.7% trust family/friends a lot compared to 23.8% of the lowest education group).
- The oldest respondents (65+ years) express less trust in media sources of cancer information (i.e., Internet, newspapers, magazines, radio, and television) compared to younger respondents. This age difference is especially marked for the Internet, with just 8.3% of the oldest age group saying they trust this source a lot compared to 27.9% of the youngest age group (18-34 years). For interpersonal sources of cancer information (health care providers and family/friends), trust levels are similar across age groups.
  - With the exception of health care providers, Whites are less likely to trust all sources of cancer information – television, radio, newspapers, magazines, the Internet, and family/friends – compared to Hispanics and African Americans (although in some cases the differences are small). The most striking difference is for television; just 16.3% of Whites say they trust cancer information on television a lot compared to 29.5% of Hispanics and 33.2% of African Americans. Whites' express similar trust levels in health care providers (63.4% trust a lot) as African Americans (59%) and Hispanics (60.7%) (NCI, 2004).
- Based on a review of the literature about cancer patients' information needs and sources, NCI researchers identified the following patterns related to health information sources among subgroups of cancer patients:
    - The range of information from which individuals seek information appears to be broader in younger patients than in older patients.
    - Older patients demonstrate greater reliance on information provided by cancer specialists or physicians than younger patients.
    - There do not appear to be dramatic differences in information needs or sources based on racial/ethnic differences.
    - Information needs and sources are influenced by socioeconomic class; greater amounts of information are sought from more diverse sources among those from higher socioeconomic strata.
    - The informational needs and common sources of information used by rural patients do not differ dramatically from those of urban patients (Finney Rutten et al., 2004).

- Some studies find that race/ethnicity are linked with preferred sources of health/cancer information. For example, one study found that White cancer patients were more likely to use printed materials (books, reference materials) when seeking information about treatment options and side effects; African American patients were more likely to rely on pamphlets and TV (Guidry et al., 1998). A survey of cancer patients in Hawaii found that Whites tended to use health information containing scientific, objective, and updated knowledge (telephone cancer information services, medical journals, newsletters, and the Internet). Cancer patients of Japanese background were more likely to rely on television and alternative medicine providers. Cancer patients of other ethnic backgrounds were more likely to use interpersonal communication sources (other cancer patients, family, friends, co-workers). Ethnicity was more important than educational attainment in determining preferred sources of information (Kakai et al., 2003).
- In 2003, almost 95% of individuals who contacted CIS used the telephone service and just 5.3% used the *LiveHelp* online service. However, use of *LiveHelp* has grown steadily since the service was first introduced in 2001. Cancer patients and the general public are less likely to use *LiveHelp* (both 3.5%) compared to health professionals (5.7%), family members/friends of cancer patients (6.4%), and non-health professionals (10.7%). Interestingly, tobacco users seeking help to quit (18.8%) and relatives/friends of tobacco users (13.2%) are the audiences most likely to contact CIS through *LiveHelp* (18.8%) (CIS, 2004).\*

➤ **What are the preferred channels across the cancer continuum?**

- In a review of the literature related to cancer patients' information needs and sources, NCI researchers found that the dominant information sources used during the diagnosis and treatment phase of the cancer continuum were printed materials (especially brochures and library materials) and health professionals (especially physicians). For patients in the post-treatment phase of the cancer continuum, health professionals and interpersonal contacts were identified as the key information sources. During this post-treatment phase, physicians, nurses, and other health care professionals were cited as sources of information equally often (Finney Rutten et al., 2004).
- A study of women with breast cancer found that sources of information differed depending on time since diagnosis. At 8 months after diagnosis, the most frequently used source of

\* Research conducted by or in cooperation with CIS.

information was books (primarily “Dr Susan Love’s Breast Book”), followed by the Internet and videos. At 16 months after diagnosis, the Internet was the most important source of information, followed by books and the American Cancer Society (Satterlund, McCaul, & Sandgren, 2003).

➤ **Do cancer information seekers use different channels (or combinations of channels) for different types of cancer-related information?**

[No relevant literature identified]

➤ **What messengers or sources of cancer information are perceived as credible among different populations?**

- HINTS found that doctors and other health care providers are the most trusted source of cancer information. Survey respondents were asked to indicate the degree to which they trust cancer information from various sources (doctor or other health care professionals, family / friends, newspapers, magazines, the radio, the Internet, and television). Sixty-one percent of respondents indicated that they trust health care professionals “a lot,” and an additional 30.2% trust health care providers “some.” The next most trusted source of cancer information was the Internet, with 23.5% of saying they trust the Internet a lot and 40.1% some. Respondents had lower levels of trust in other information sources: TV (19.9% a lot, 50.6% some), friends and family (18.7% a lot, 48.4% some), magazines (15.7% a lot, 49.8% some), and newspapers (13% a lot, 49.9% some) (NCI, 2004).

➤ **How is the Internet used for seeking cancer-related information?**

- Preliminary analysis of NCI’s 2003 HINTS finds that among the 44.9% of respondents who have looked for cancer information, 48% they had looked on the Internet first. Other information sources were used much less frequently – for example, books were mentioned by 13.7% of respondents and health care providers by 10.8% of respondents (NCI, 2004).
- Among HINTS respondents who go online, 50.6% have sought health information for themselves on the Internet, and 45.7% have sought health information for someone else. Among respondents who have looked for health and medical information online, 41.8%

have specifically looked for cancer information. Most (80.5%) of these respondents found cancer information through an Internet search (NCI, 2004).

- HINTS respondents were asked where they would go if they had a “strong need” for cancer information. After doctors and other health care providers (48.5%), the Internet was the most frequent response (33.3%) (NCI, 2004).
- Internet access continues to grow across the board, but demographic gaps remain:
  - Younger Americans are much more likely to have Internet access than older Americans;
  - Well-to-do Americans are more likely to have Internet access than less well-off Americans;
  - The employed are more likely to have Internet access than the unemployed;
  - White Americans are more likely to have Internet access than African-Americans and Hispanics;
  - Well-educated Americans are more likely to have Internet access than those who only complete high school; and
  - Suburban and urban residents are more likely to have Internet access than rural residents (Horrigan et al., 2003).
- Looking for health or medical information online is one of the most popular uses of the Internet (Center for the Digital Future, 2004; Fox & Fallows, 2003). Fully 80% of adult Internet users have searched for health information online. The most popular topics are specific diseases or medical problems (63% of Internet users have sought information on these topics) and medical treatments and procedures (47% have sought information) (Fox & Fallows, 2003).
- Internet searches for health information are often triggered by a visit to a physician, a diagnosis, or a symptom (Cline & Haynes, 2001; Fox & Fallows, 2003).

➤ **Who seeks/does not seek health information on the Internet?**

- NCI’s 2003 HINTS finds differences in use of the Internet for cancer information among various socio-demographic groups. Respondents who had looked for cancer information in the past were asked, “Where did you look first?” Differences among subgroups include the following:

\* Research conducted by or in cooperation with CIS.

- Younger respondents were more likely to say they had looked for information on the Internet first (63.7% in the 18-34 age group, compared to 47.2% in the 35-64 age group and 16.2% in the 65+ age group);
  - Whites (50.5%) were more likely than African Americans (44.7%) and Hispanics (36%) to name the Internet as their first source for cancer information;
  - Internet use is also associated with income and education. About 30% of respondents with less than a high school education sought cancer information on the Internet, compared to 56.6% of college graduates. About one-third of respondents in the lowest income group had sought cancer information on the Internet, compared to 59.8% of respondents in the highest income group; and
  - Males (53.1%) were more likely than females (45.7%) to report looking for cancer information on the Internet first (NCI, 2004).
- Among Internet users, Whites and African Americans are more likely to seek health information on the Internet (for both groups, 57% ever sought health information) compared to Hispanics (51%) (Spooner & Rainie, 2001).
  - Of individuals who seek health information on the Internet, 60% are in good health and seek health information infrequently, 35% are “chronic stable,” and 5% are newly diagnosed (Fox & Fallows, 2003; Spooner & Rainie, 2001). Individuals in poor health search for health information more frequently than those in good health and are more likely to use health-related chat rooms (Fox & Fallows, 2003; Houston & Allison, 2002; Spooner & Rainie, 2001).
  - Women, better-educated, and higher-income Internet users are more likely to use the Internet to obtain health information. Women are also more likely to have sought information on a broader range of health topics (Fox & Fallows, 2003).
  - Internet users under age 65 are more likely than seniors to look for health information online, possibly because most seniors are newcomers to the Internet and less likely to do any kind of search (Fox & Fallows, 2003). Major barriers for seniors relate to economics, lack of access to computers and the Internet, and privacy concerns. However, research suggests that this “gray gap” can be minimized. The Internet has been used effectively in nursing homes (Cline & Haynes, 2001) and by elderly breast cancer patients (Gustafson et al., 1998, as cited in Gustafson et al., 2002).

- “Veteran” Internet users (who have been online 3 or more years) and broadband (vs. dial-up users) are more likely to seek health information on the Internet. As more Internet users become veterans, the numbers turning to the Internet for health information will likely grow (Center for the Digital Future, 2004; Fox & Fallows, 2003).
- The primary reasons that some Internet users do *not* search for health information are that they (1) don’t have any health concerns; (2) are satisfied with health information received elsewhere; (3) perceive that information on the Internet is not trustworthy; and (4) “wouldn’t know where to start” looking for health information on the Internet (Fox & Fallows, 2003).
- About 42-43% of breast cancer patients use the Internet to obtain medical information. Breast cancer patients who use the Internet to obtain health information are younger, more educated, higher income, more likely to be White, and less satisfied with the information provided by their provider compared to breast cancer patients who do not use the Internet. Neither length of time since diagnosis or breast cancer stage are correlated with Internet use (Fogel et al., 2002; Pereira et al., 2000; Satterlund, McCaul, & Sandgren, 2003).
- A study of cancer patients in the United Kingdom found that use of the Internet for cancer information varied according to the type of cancer (Ziebland et al., 2004). Patients with cancer of the testes were most likely to seek information on the Internet (22% had done so either directly or through friends or family), followed by patients with breast cancer (19%), and prostate cancer (17%). Patients with cancer of the cervix (10%) and bowel (8%) were least likely to see information on the Internet.

➤ **What are Internet users’ opinions and expectations related to seeking health information on the Internet?**

- Internet users like the idea that they can access medical information from home at any time of day and can do so anonymously and quickly. They also value the diversity of information available on the Internet and that information is free and up to date. (Center for the Digital Future, 2004; Fox & Fallows, 2003; Institute of Medicine, 2002).
- Two-thirds (67%) of all Americans expect to find reliable health care information online; among Internet users, the rate is 81%. Three-quarters of Internet health seekers say they find what they are looking for “always” or “most of the time.” Internet users are about as



likely to say they will go online next time they need reliable health care information as they are to say they will contact a medical professional (46% and 47%, respectively) (Horrigan & Rainie, 2002).

- The most trusted source of online health information is the personal doctor, followed by medical universities and the federal government, according to Porter Novelli's nationally representative survey of U.S. adults. About 43% of respondents considered federal government resources such as the FDA, CDC, or NIH to be among the most trustworthy sources of online health information (Dutta-Bergman, 2003).

➤ **How do individuals seek health information on the Internet?**

- Most Internet users employ search engines (e.g., Yahoo or AOL home page) or links from another web site to seek information on health topics (Center for the Digital Future, 2004; Fox & Rainie, 2002). About one in three bookmark health-related websites. Favorites are WebMD, the Mayo Clinic site, the National Institutes of Health, InteliHealth, and DrKoop.com (Fox & Rainie, 2002).
- About half of Internet users who have sought health/medical information online used a website recommended by a health care provider. Internet users also frequently used websites recommended by friends (50%) and family members (40%) (Center for the Digital Future, 2004).

➤ **What are the outcomes of health information seeking on the Internet?**

- Among adults who have sought health information on the Internet, 73% say the Internet has improved the health information and services they receive. Females and younger users are most likely to give this response (Fox & Fallows, 2003).
- The most common results of finding health/medical information on the Internet are (1) seeking further advice or information, (2) becoming more comfortable with advice from doctors, and (3) contacting a health professional (Center for the Digital Future, 2004).
- In a study of callers to the CIS, 55% said they had used the Internet to obtain health information. At six weeks follow-up, the percentage using the Internet had increased to

82%. Most of the Internet users said that, as a result of seeking information on the Internet, they felt empowered to make decisions about their health (92%) and that the information helped them talk with their doctor (91%) (Fleisher et al., 2002).\*

- Breast cancer patients who have used the Internet to find health information generally find the information to be useful and discuss it with their providers. However, about half are unsure of the trustworthiness of medical information on the Internet (Pereira et al., 2000).

➤ **What barriers do consumers face in seeking health information on the Internet?**

- The growing array of health sites makes the process of searching for health information online daunting (e.g., as of March 2001 Yahoo found 1747 English-language sites using “cancer” as a search term). Many consumers require guidance and tools for seeking health information on the Internet (Eng, 2001).
- The major barriers to using the Internet for health information seeking are lack of access to computers or the Internet, unfamiliarity with or fear of using the Internet, uncertainty about the quality of information, and concerns about privacy. People who do not speak English are also disadvantaged as English is the dominant online language. In addition, most health Web sites are designed for educated audiences; for English-language health-related Web sites the average reading level is collegiate, and for Spanish-language sites the average reading level is 10<sup>th</sup> grade (Berland et al., 2001; Birru et al., 2004; Bush et al., 2004; Cline & Haynes, 2001; Eng, 2001; Pennbridge, Moya & Rodrigues, 1999; Pereira et al., 2000).
- Systematic studies of health information on the Internet have identified a number of issues for users, including the following: Searches often result in inaccessible URLs; materials are not related to the subject searched; and sites contain minimal, erroneous, or conflicting information (Berland et al., 2001; Biermann et al., 1999, as cited in Davis et al., 2002; Edgar, Greenberg, & Remmer, 2002; Davis et al., 2002; Lawry, 2001). However, critiques of health information on the Internet can be misleading as they often focus on issues other than accuracy (Eysenbach et al., 2002; Eysenbach, 2003). Furthermore, studies have found lower inaccuracy rates for cancer information than for other types of Internet health information (inaccuracy rates for cancer sites are in the order of 5%). There is little evidence that health information found on the Internet is worse than information in other media (Eysenbach, 2003).

\* Research conducted by or in cooperation with CIS.

- Lack of knowledge of computers and how to navigate the Internet are often cited as barriers to health information seeking. Teaching cancer patients and their families how to use the Internet to find health information is empowering. In one study, patients who were taught to use the Internet continued to use the Internet to seek cancer information, felt better able to evaluate cancer information on the Internet, and felt better able to deal with cancer (Edgar, Greenberg, & Remmer, 2002). NCI's four demonstration Bridging Digital Divide Projects are aimed at teaching underserved populations to use the Internet for health information purposes. For example, in the CancerInfoNet Project in Harlem, low-income English and Spanish-speaking populations were taught basic Internet skills and familiarized with online cancer resources. Following the training participants felt more comfortable using online resources, more knowledgeable about cancer Web sites, and more confident in their ability to judge the reliability and appropriateness of Web sites (Kreps et al., 2003; Perocchia & Rapkin, 2001).\*

**Question 6: How can individuals' information seeking behaviors across time and the cancer continuum best be measured and documented? What types of systems or data collection devices/instruments could be best used to capture information-seeking behavior?**

#### **Overview of Relevant Research:**

No research was identified that specifically examines methods for tracking cancer information seeking behaviors. However, several recent studies evaluating innovative systems designed to capture health-related experiences in "real time" are of interest. The electronic diaries and other methods studied could potentially be applied to tracking health information seeking behaviors and thus answer questions of interest to CIS (e.g., What triggers information seeking? What steps do information seekers take first?).

#### **Specific Research Findings:**

- In order to avoid the biases and inaccuracies inherent in retrospective or recall data, researchers frequently use diaries to collect "real time" health experiences and behaviors. However, compliance with traditional paper diaries is low. Thus, there is increasing use of

\* Research conducted by or in cooperation with CIS.

electronic diaries using palmtop computers to obtain real-time (or momentary) data. Studies have found that compliance with electronic diaries is higher than with paper diaries. For example, in a study of chronic pain patients in which subjects were asked to record pain levels at prescribed times, compliance with the electronic diary was 94%. For the paper diaries, 75-80% of the dates and times were falsified. The electronic diary used included various features to encourage compliance, including prompts to record data and feedback on compliance (Stone et al., 2003).

- Studies find that electronic diaries are readily accepted and even preferred over paper diaries. Patients' age, gender, and comfort/familiarity with technology are not associated with preference for paper versus electronic diary. Researchers recommend that electronic systems include "livability" features so that subjects can incorporate data collection into their daily lives (e.g., allowing patient to suspend beeping). Subjects' compliance also increases when they know that their adherence with the data collection protocol is being monitored (Hufford, 2003; Hufford & Shiffman, 2003).

**Question 7: Who are *non*-seekers? What are their socio-demographic and psychosocial characteristics? What are the perceived barriers to cancer information seeking? What can move someone from being a non-seeker to a seeker, and is this desirable? For individuals who are non-seekers, are there "surrogate seekers" who aid in their care and health-related decision-making? How can cancer information and resources and services be adapted to meet the needs of surrogate seekers and non-seekers?**

#### **Overview of Relevant Research:**

Several studies identify characteristics of individuals who do not seek health information and barriers to information seeking (e.g., denial, avoidance of threatening information, and religious beliefs). However, no literature was identified that explores whether, when, how, and why individuals move from being non-seekers to seekers of cancer information. HINTS provides data about "surrogate" health and cancer information seeking (that is, obtaining information for others). Studies of cancer patients suggest that surrogate information seekers play an important role in obtaining cancer information for non-seekers. (For additional information about the

\* Research conducted by or in cooperation with CIS.

socio-demographic characteristics of health/cancer information seekers and non-seekers, see Q. 1 in this section; for additional information about the information needs of caregivers, see Q. 4 in this section.)

### **Specific Research Findings:**

- Researchers have identified a number of characteristics of non-information seekers (Johnson, 1997):
  - They are fearful and have a sense of powerlessness;
  - They are less likely to enlist the support of others;
  - They do not feel a need for information beyond that provided by health care providers; and
  - They are less stressed when first diagnosed.
- Several studies have found that older patients are less likely to seek health information than younger adults. However, a more detailed analysis reveals that older adults are less likely to seek information from the medical establishment (physicians and other health care providers), but they are just as likely as younger adults to seek health information from other sources (e.g., media, friends) (Turk-Charles et al., 1997).
- A study of acutely ill patients (newly diagnosed with acute myeloid leukemia) finds that these patients engage in only limited information seeking. These patients obtained information mostly by talking to nurses and fellow patients, and few used printed information distributed to patients. The most common reasons for not seeking medical information were fear of losing hope and lack of energy. Elderly patients and those who were the most ill were least likely to seek information (Fries, Elverdam, & Schmidt, 2003).
- Compared to cancer patients who seek information from the CIS and other sources, non-information seekers are older, more likely to be male, and are less educated. They also have less social support, less familiarity with the medical system, and less self-reported anxiety about their cancer diagnosis. Compared to patients who seek information, this group has less desired to be involved in medical decision making and is less likely to seek a second opinion. These non-information seekers' beliefs and behaviors are stereotypical of a traditional passive patient role (Czaja et al., 2003; Manfredi et al., 1993). \*

\* Research conducted by or in cooperation with CIS.

➤ **What are the perceived barriers to cancer information seeking?**

- A qualitative study of recently diagnosed cancer patients found that reasons for non-information seeking include: (1) faith in the information provided by health care providers – thus, they did not feel a need to obtain additional information or did not want to be perceived as a “bad patient”; and (2) hopefulness or a desire to maintain hope, which resulted in avoiding negative information. Information seeking through a “proxy” can be helpful in allowing patients to maintain hope (Leydon et al., 2000).
- Cancer patients may not seek information because of denial (e.g., about their diagnosis, necessary treatment, or prognosis). Most individuals diagnosed with cancer go through processes of denial, at least initially (Johnson, 1997).
- Non-information seeking is associated with a “blunting” informational coping style; these individuals avoid threatening information. In contrast, individuals with a “monitoring” informational coping style seek information because it provides them with certainty and lets them work through their experiences (Elf & Wikblad, 2001). Among partners of men with prostate cancer, those with a blunting coping style (compared to those with a monitoring style) perceived less need for information related to prostate cancer and their partner’s treatment. For example, they felt less need for information about treatment, symptoms, prognosis, side effects, and how to help their partner (Rees, Sheard, & Echlin, 2003).
- African Americans have traditionally been less active health information seekers than Whites. A focus group study of African American cancer patients identified the following barriers to seeking cancer information (Matthews et al., 2002):
  - 1) Fear – often due to misinformation about cancer (e.g., perception of cancer as a “death sentence”).
  - 2) Family history of cancer – individuals with a family history of cancer had higher levels of fear, suspicion about treatment, and pessimism about their prognosis, all of which deterred information seeking.
  - 3) Embarrassment – taboos about cancer that inhibit revealing a diagnosis.
  - 4) Religious beliefs – faith that “God will take care.”
  - 5) Mistrust of medical system and providers – a legacy of the Tuskegee experiment.

(Note: Barriers to seeking health information on the Internet are discussed separately, see Q. 5 in this section.)

- **What can move someone from being a non-seeker to a seeker, and is this desirable?**

[No relevant research identified]

- **For individuals who are non-seekers, are there “surrogate seekers” who aid in their care and health-related decision-making?**
- According to a preliminary analysis of NCI’s 2003 HINTS, 16.8% of all adults report that someone other than a doctor or health care provider has looked for cancer information for them. Responses to this question vary by gender, age, and other socio-demographic characteristics:
  - Females (19%) are more likely than males (14.4%) to say someone has looked for cancer information for them;
  - Respondents aged 35-64 are most likely to say someone has looked for cancer information for them (19.2%, compared to 14.2% of the 18-34 age group and 13.9% of the 65+ age group);
  - Hispanics (12.4%) are less likely than Whites (17.4%) or African Americans (18.1%) to say someone has looked for information for them; and
  - Higher income (from 13.4% in the <\$25,000 group to 20.2% in the >=\$50,000 group) and more educated respondents (11.9% in the less than high school group to 20.6% of college graduates) are more likely to say someone has looked for information for them (NCI, 2004).
- Among HINTS respondents who said that someone other than a doctor or health care providers has looked for cancer information for them, 20.2% specified that a spouse looked for information, 52% said another family member, and 19.7% said a friend. Males rely on their spouses to seek cancer information far more than females; 36.9% of males reported that their spouse has looked for information, compared to 8.6% of females. Conversely, females are more likely to report that other family members (60%, compared to 41.1% for men) and friends (22.5%, compared to 15.9% for men) have looked for cancer information for them (NCI, 2004).

- Females are more likely than males to look for health information for others online. Among HINTS respondents who go online, 52.2% of females have looked for health information for someone else, compared to 39.4% of men (NCI, 2004).
- A study of acutely ill cancer patients (recently diagnosed with acute myeloid leukemia) found that relatives were more active than patients in seeking medical information. However, many of the patients were not interested in the information found by their relatives. Some patients felt pressure from their relatives related to information seeking (Fries, Elverdam, & Schmidt, 2003).
- A study of women undergoing breast biopsy found that women were less ready to receive detailed information than were their partners. Before the biopsy, women practiced “information management,” putting limits on the amount and depth of information they would accept. They focused on immediate issues (e.g., biopsy procedures), whereas their partners were interested in a wider range of information (Shaw, Wilson, & O’Brien, 1994, as cited in Harris, 1998).
- In studies of men with prostate cancer and their partners, it is clear that partners play an important role in information seeking. At the time of diagnosis, men were “emotionally numb” and unable to formulate questions or retain information. Partners frequently initiated the search for information and raised cancer-related issues for discussion. They wanted to know about their partner’s condition, treatment, treatment side effects, probable outcome, and other aspects of their partner’s disease (Echlin & Rees, 2002; Rees, Sheard, & Echlin, 2003).
- The Internet is frequently used to find health information for others. Of Internet users who have sought health information, 57% said the last time they searched for health information they were looking for someone else. These surrogate information seekers are heavily represented by parents, women, healthy people, and the middle-aged. Some of these health seekers are looking for caregiving guidance; others are fact finders on behalf of the ill (Fox & Fallows, 2003).
- A survey of CIS callers found that friends/family actively used the Internet to seek cancer information. Among callers who have computers, more than 80% of family/friends had sought cancer information on the Internet. Among patients and the general public, the



percentages using the Internet to obtain health information were lower (about 72% and 67%, respectively) (Bright et al., 2005).\*

- **How can cancer information and resources and services be adapted to meet the needs of surrogate seekers and non-seekers?**

[No relevant research identified.]

## MODELS OF HEALTH INFORMATION SEEKING

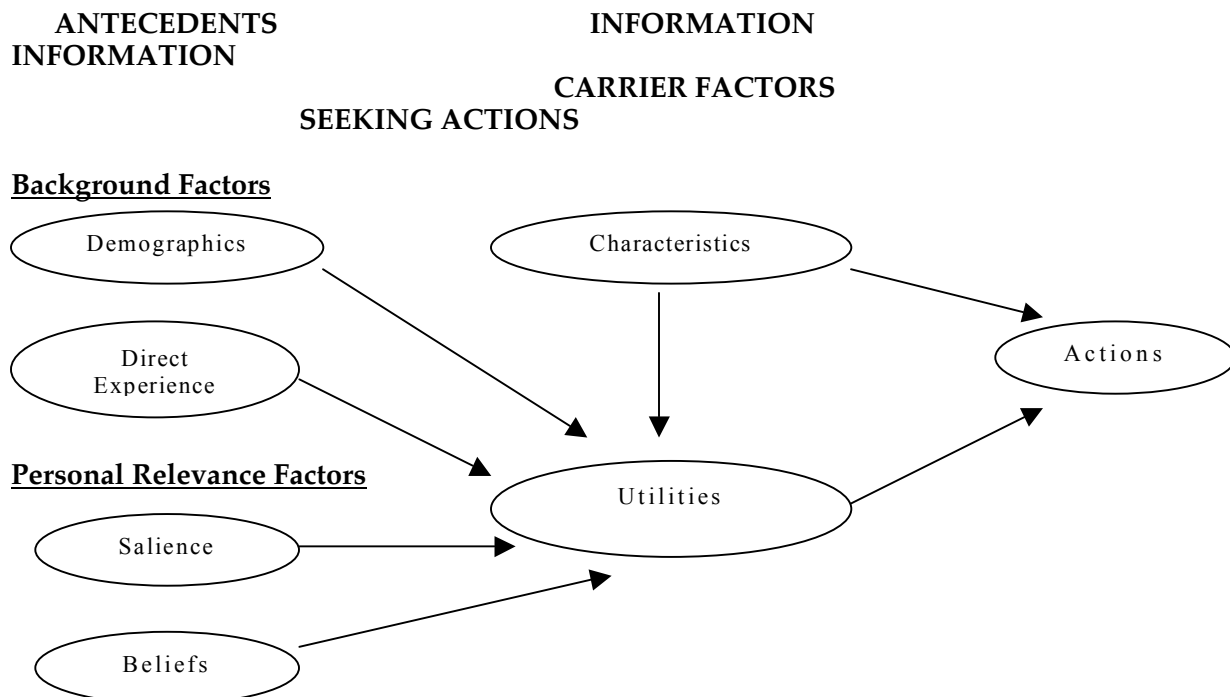
Following are brief descriptions of three models related to health information seeking:

1. Johnson (1997) developed the Comprehensive Model of Information Seeking (CMIS), designed to explain the communication channel usage of health information seekers.

The model includes:

1. Antecedents – these factors determine the underlying imperatives to seek information. The model focuses on demographics, personal experience (e.g., whether someone in their social network has experience with cancer), salience (i.e., personal significance of cancer information), and beliefs (e.g., related to efficacy of methods of prevention and treatment).
2. Information carrier (channel) – carrier characteristics include editorial tone, style, attractiveness, and understandability. The “utility” of the carrier refers to whether the information directly relates to the needs of the individual (e.g., whether it is perceived as relevant and important).
3. Information seeking actions.

### COMPREHENSIVE MODEL OF INFORMATION SEEKING (CMIS) HEALTH BELIEF MODEL

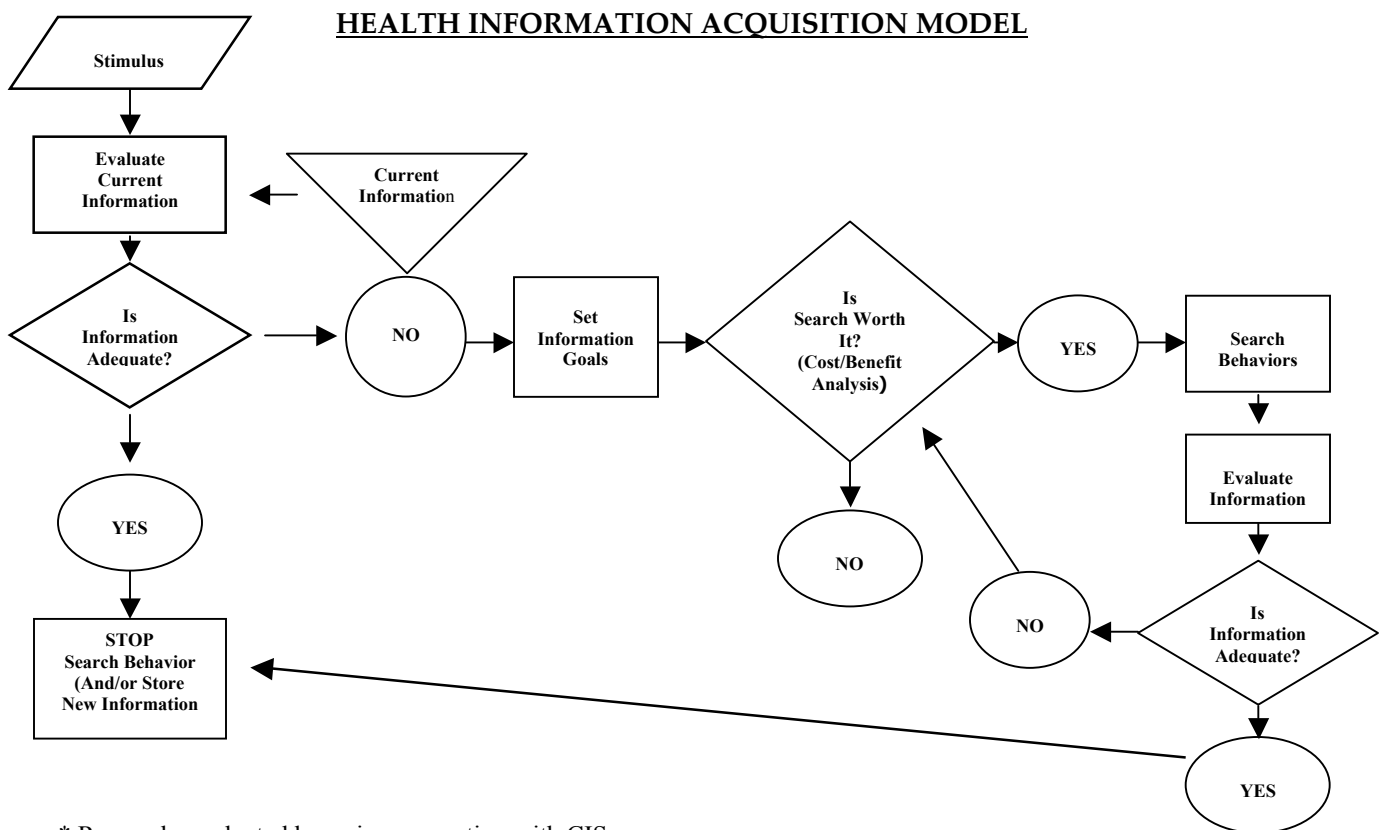


\* Research conducted by or in cooperation with CIS.

2. Freimuth (1989) developed the Health Information Acquisition Model, which emphasizes active information seeking, but also includes information acquired passively (e.g., from television PSAs). The model specifies six steps:

1. Stimulus – may be internal (e.g., symptom) or external (e.g., exposure to a PSA).
2. Information goals – may decide how soon they need information and where they will seek information.
3. Cost/benefit analysis of searching – costs may include financial and time expenditures, frustration, confusion, or emotional distress; benefits may include reduction of uncertainty or anxiety, and increased sense of control.
4. Search behaviors – characterized by extent, scope, depth, and method of search.
5. Evaluation of information – after each search activity, the searcher evaluates the information gained and determines the cost/benefit ratio.
6. Decision point on adequacy of information – as each piece of information is acquired, the health information seekers must decide whether to continue or terminate the search.

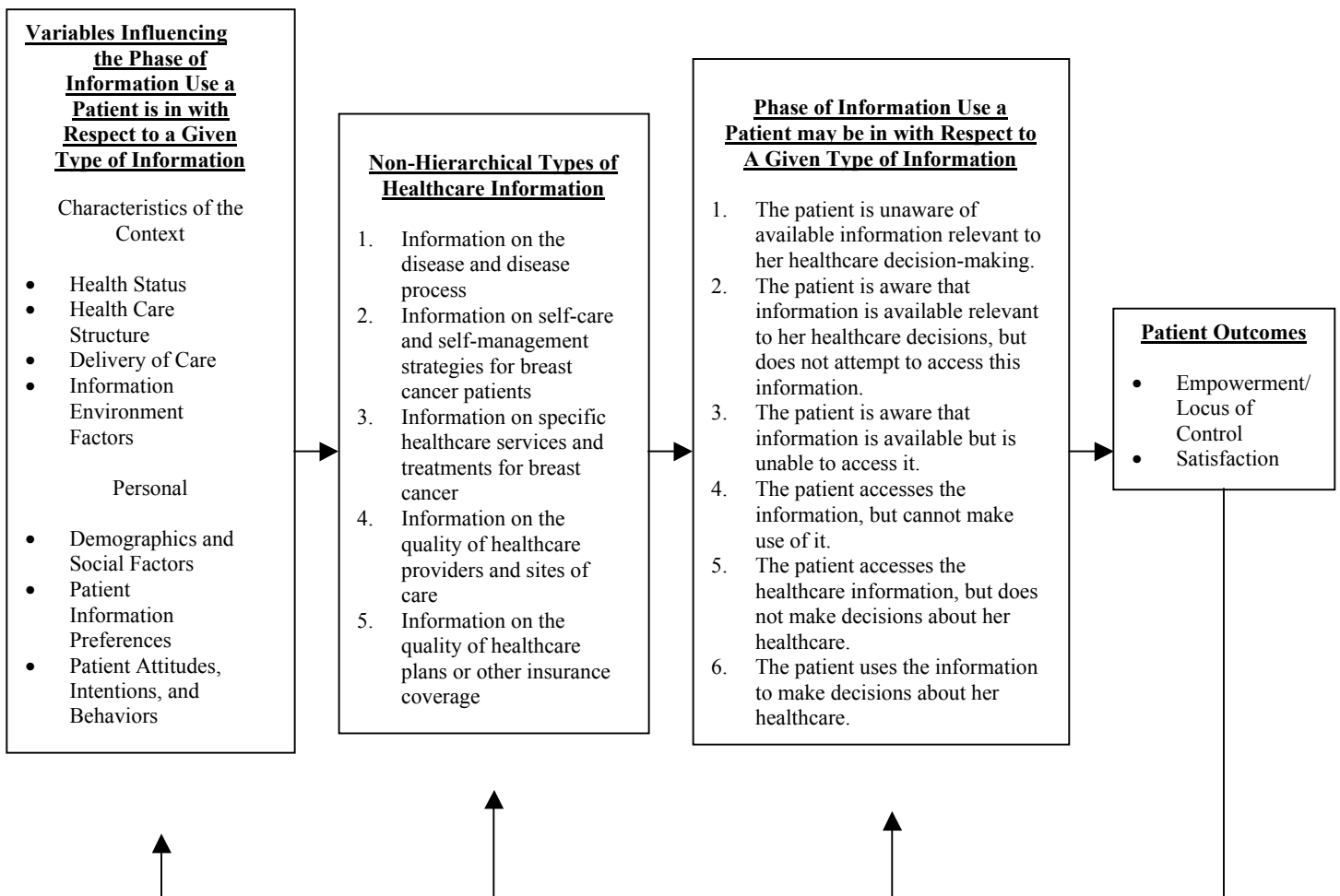
Johnson (1997) comments that this model is essentially a flow chart which describes a sequence of actions. The model does not spell out determinants of information seeking behavior.



\* Research conducted by or in cooperation with CIS.

3. The Conceptual Model of Patient Use of Healthcare Information for Healthcare Decisions was developed by Longo et al. (2001) specifically to explain seeking and use of health information among women with breast cancer. The model shows the interrelationship among various personal and situational factors that comprise the patient's information environment and different phases of the patient's use of information.

**CONCEPTUAL MODEL OF PATIENT USE OF HEALTHCARE INFORMATION FOR  
HEALTHCARE DECISIONS**



\* Research conducted by or in cooperation with CIS.

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