

The Cancer Information Service
Research Agenda

Prepared by:

Linda Squiers, Ph.D.
Office of Cancer Information Service
Office of Communications

in collaboration with:

Katherine Treiman, Ph.D.
Consultant

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INTRODUCTION

The purpose of this document is to share with key stakeholders a research agenda that identifies broad research areas and questions of interest to the National Cancer Institute's (NCI) Cancer Information Service (CIS) in order to ensure that the CIS Research Program will:

1. contribute to the field of cancer communication;
2. be in alignment with NCI priorities; and
3. participate in research where findings can be directly translated and applied to service delivery.

Setting a research agenda will help guide the CIS network and its research partners in prioritizing and capitalizing on research opportunities in order to help the CIS understand, apply, and disseminate effective communication approaches to educate the public about cancer and contribute to the nation's cancer control efforts.

This document first describes the CIS program, the services offered by the Information Service, and the history and philosophy of the Partnership Program. Next, a broad history of the CIS' participation in cancer communication research is shared, laying the foundation for the new CIS Research Program. The process for setting the research agenda is explained. Finally, the four research areas of interest to the CIS are described and specific research questions are provided. This research agenda is accompanied by a literature overview that provides the context for the research questions. The CIS encourages research that will address the gaps in knowledge relevant to the research questions.

THE CANCER INFORMATION SERVICE PROGRAM

Through the National Cancer Act (National Cancer Act, 1971; National Cancer Act, Amendments, 1974), the U.S. Congress mandated that the NCI provide accurate and up-to-date information about cancer to all segments of the U.S. population. On July 1, 1975, the NCI established the Cancer Information Service and the first telephone call was received in 1976. Over the years, the Information Service was augmented by two additional program components: a Partnership Program and a Research Initiative. All program components are operated through five-year government contracts and are awarded through a competitive process. Contracts are awarded to Cancer Centers and academic institutions and together, they comprise a national information and education network.

The Cancer Information Service

For nearly 30 years, the National Cancer Institute's Cancer Information Service has been providing the latest and most accurate cancer information to patients, their families, health professionals, and the public. Since its founding, the CIS has answered over 10 million calls (2004). Currently, the Cancer Information Service offers a toll-free telephone number (1-800-4-CANCER) and an instant messaging service (LiveHelp) on the NCI's Web site (www.cancer.gov). Appendix A presents a listing of the services (Research Coordination, Partnership, or Contact Center) offered by each CIS contractor.

Smoking Cessation Assistance

The CIS also provides assistance to smokers through NCI's Smoking Quitline at 1-877-44U-QUIT and through an instant messaging service (LiveHelp) on the NCI's Web site (www.cancer.gov). Beginning in summer 2005, the CIS will offer proactive smoking cessation services to callers ready to set a quit date. In addition, the CIS is part of the National Network of Tobacco Cessation Quitlines. The National Network provides a single, easy-to-remember number, 1-800-QUIT-NOW, for access to available quitline services provided by the states. Calls to the national access number are routed to state-based quitlines based on the area code from which the call originates. Calls to the toll-free access number from states not currently providing quitline services are routed to the NCI's Smoking Quitline.

The Cancer Information Service Partnership Program

The CIS Outreach Program was initiated in 1991 and designed to work at the community level to bring cancer information to the public, with an emphasis on reaching minority and medically underserved populations, by working with organizations that have access to these populations. Each of the 19 regional offices that existed in 1991 had one Outreach Coordinator. The Outreach Program became the Partnership Program in 1993. The program shifted from a service model to a partnership model based on reciprocity and results-based cancer control projects. In 2005, each of the 15 regional offices has a manager and off-site staff at cancer centers or universities in the region. There are close to 70 regional Partnership Program contract staff (see Appendix B for map).

Through the Partnership Program, CIS reaches people throughout the United States and its territories. The CIS works with partners that have an established presence in the region, are trusted within their communities, and are dedicated to serving minority and medically underserved populations. The CIS has established partnerships with nonprofit, private, and

other government organizations at the national, regional, and state levels. Partners help deliver messages and materials about cancer to people who may have difficulty obtaining health information because of educational, financial, cultural, or language barriers. The Partnership Program provides technical assistance to partners including the following: strategic planning; training; coalition building; reviewing educational materials and messages; planning, development, and implementation of evidence-informed or evidence-based cancer-related programs (e.g., clinical trials initiatives); and evaluation of activities and programs.

Regional Partnership Programs are managed using nationally developed tools, including a gaps analysis, partnership development guidelines, a partner assessment tool, and a partnership portfolio database.

A HISTORY OF THE CANCER INFORMATION SERVICE IN RESEARCH

To understand, apply, and disseminate effective communication approaches that maximize access to and appropriate use of cancer information by all who need it, the CIS has been formally involved in health communications research for twenty years. In the early 1980s, the CIS developed three tools that laid the foundation for future research efforts. A Call Record Form was developed to document the demographic characteristics of callers, the cancer topics they called to discuss, and the action taken by the Information Specialist who took the call. In addition, the CIS developed a National Test Call Program that rated the performance of Information Specialists on specific quality criteria. Finally, a National User Survey provided information about caller satisfaction and perceptions of knowledge acquisition as a result of interacting with an Information Specialist. These tools allowed many descriptive research studies to be conducted.

In 1993, NCI provided funding to Dr. Al Marcus (AMC Cancer Center, Denver) to establish the Cancer Information Service Research Consortium (CISRC) comprising academic researchers, staff from regional CIS offices, and staff from the NCI Project Office. This grant allowed the CIS to formalize and strengthen the role of the CIS in cancer communication and behavioral research. The CISRC developed the research infrastructure required to support large-scale trials of health communication interventions. This first CISRC grant resulted in the publication of a supplemental issue of the *Journal of Health Communication* (1998) titled “The Impact and Value of the Cancer Information Service: A Model for Health Communication.” In 1998, *Preventive Medicine* also published a supplement that described the detailed methods used to develop, implement, and manage this consortium. The Consortium implemented three

randomized controlled studies that tested specific interventions, such as the usefulness of proactive dissemination of health information to CIS callers, the viability of proactively calling low-income women about screening mammography, the ability of a mass media campaign to increase call volume from African Americans, and the relative impact on behavior of targeted or generic messages and materials. The second CISRC grant, awarded in 1997, tested the utilization of tailored messaging to promote the 5 A Day program, colorectal screening, and smoking cessation. Findings from these studies will be published by the *Journal of Health Communication* in late 2005. The CISRC enabled the CIS to develop the infrastructure to conduct and support randomized trials within the Information Service.

During the time these studies were underway, the CIS also participated in many other studies that helped to refine its capacity to participate in cancer communication research. From 1994-2004, investigator-initiated studies conducted in cooperation with the CIS focused on a wide range of cancer-related topics such as clinical trials education, risk counseling, increasing cancer screening and cancer prevention practices through tailored messaging, and testing the effects of decision support technologies such as the Comprehensive Health Enhancement Support System (CHESS) (Gustafson et al., University of Wisconsin). A collection of research projects called "The Digital Divide Pilot Projects," funded by NCI, focused on developing research partnerships between the CIS and cancer control organizations to test strategies aimed at increasing cancer communication in underserved communities. While many studies in which the CIS has participated have been pilot studies designed to examine the feasibility of particular interventions, some were full-fledged trials examining the effectiveness and efficiency of interventions. Thus, the CIS has a research portfolio that covers a broad range of cancer topics encompassing many phases of the research process (see Appendix C for list of projects, 1999-2004).

As the topics and nature of the research designs of studies conducted in cooperation with the CIS have been variable, so has been the role of the CIS in these studies. The CIS has demonstrated its capacity to implement research protocols in which Information Specialists deliver tailored educational messages or administer telephone surveys. Information service and Partnership Program staff have repeatedly demonstrated success in recruiting callers for research studies, including large clinical trials such as the NCI's National Lung Screening Trial. CIS staff have worked with researchers to develop research questions, protocols, and proposals; conduct formative research via focus groups and in-depth interviews; and review study materials to ensure the scientific accuracy of cancer information and health messages. Through this broad range of experiences, the CIS has developed the capacity to be involved in research studies from conception to implementation to the dissemination and diffusion of results.

NEW DIRECTIONS: THE CANCER INFORMATION SERVICE RESEARCH PROGRAM

By participating in a wide variety of research studies and playing many different roles in the research process, the CIS network has now firmly established itself as a valuable resource to NCI and to health communication researchers in the field. The CIS is committed to supporting and participating in health communications research by launching a new, more mature research initiative: **NCI's Cancer Information Service Research Program**. This Research Program directly supports the Healthy People 2010 objective 11-3: *To increase the proportion of health communication activities that include research and evaluation.*

The CIS Program is unique in that it is a service program operated within a research institution. This organizational structure places the CIS in an ideal position to bridge the critical chasm that exists between service and research. In addition, the CIS is capable of providing educational support and resources, and translating research findings and recommendations to patients – all functions which would augment and support patient-provider interactions. The CIS has often been described as a “living laboratory” for health communication research and as such, is ripe with opportunities to study communication processes and effects. Moving from a “Research Initiative” to a full-fledged Research Program will enable the CIS to formalize its commitment to cancer communication research and to improving and enhancing services delivered through the Information Service and Partnership Program.

The goal of the CIS Research Program is to partner with investigators to develop and implement collaborative research projects that will further the field of cancer communication and inform CIS service delivery.

To achieve this goal, the CIS is implementing a new model for collaborative research that includes some guiding principles as well as lessons learned from the successful efforts of the CISRC (Glasgow, Marcus, Bull, & Wilson, 2004). First, research projects should support investigators' research interests as well as address questions or themes on the CIS Research Agenda and inform CIS service delivery. Designing research projects so that they are mutually beneficial and reciprocal in nature fully supports the principles of the CIS Partnership Program. In addition, studies implemented with the CIS should be designed for dissemination within the CIS Program from the onset.

Second, the CIS should be involved in all stages of the research process: from development to implementation to data interpretation to publication. Appendix D displays the stages in the research process and the development and involvement of a research team that comprises

researchers and appropriate CIS staff. The CIS embraces the concept of a collaborative research team to guide research studies implemented with the CIS as a way to ensure that study findings can be incorporated into the CIS Program.

To demonstrate its commitment to the CIS Research Program, in 2005, the CIS funded four doctorally prepared Senior Research Coordinators (SRCs) located at regional CIS offices. The role of SRCs is to develop partnerships between the CIS and researchers that are mutually beneficial and collaborative throughout all phases of the research process. The SRCs will work with academic researchers to develop research projects, develop funding applications, coordinate the implementation of studies conducted with the CIS, prepare manuscripts for publications, and translate and strategically disseminate innovations and research findings. With their advanced educational degrees and training, these SRCs are well suited to be collaborators and even co-investigators of CIS-supported studies. Other CIS staff will participate in research teams as appropriate. The SRCs, as a group, will develop a strategic plan for promoting the CIS Research Program and agenda and will coordinate the implementation of studies throughout the network. Finally, the SRCs will work within their designated cluster of states as well as across clusters to develop a supportive CIS research network.

Benefits to Researchers

A CIS Research Program “toolkit” details for researchers the potential benefits of partnering with the CIS as well as step-by-step instructions about how to develop a collaborative research project. Briefly, the CIS offers researchers the ability to test health communication interventions within a premier cancer communication system. The CIS embraces innovative health communication research and provides an extraordinary venue for dissemination. The CIS also has unprecedented access to active information seekers and through the Partnership Program, the ability to reach minority and medically underserved populations. Through all its services and programs (i.e., the Information Service, Partnership Program, and Research Program), the CIS has trained, professional staff.

Almost all of the research conducted with the CIS in the past has been with the Information Service. As such, the Information Service has built the infrastructure necessary to support research studies. For example, the CIS has the technology to support both data collection and randomization to studies. Other infrastructure supports that can be used when conducting Information Service research includes a national training program and training coordinators and Contact Center supervisors who can help determine implementation strategies as well as adherence to study protocols. While few studies have been conducted in collaboration with the CIS Partnership Program, the CIS is eager to develop opportunities for research within this program component.

Finally, the NCI Project Office has a dedicated Project Officer to oversee the Research Program to ensure that studies support this Agenda and are beneficial to the Program. In addition, the Project Office will ensure that the CIS has the capacity to play the proposed role in the study and that the study does not compromise service. Finally, for collaborative research projects that help support the Research Agenda, the CIS Project Officer for Research will write a letter of support to be included in researchers' funding proposals.

Beginning in 2005, this new model for the CIS Research Program will be implemented. To guide the CIS Research Program, a CIS Research Agenda has been developed in an effort to focus these collaborative research efforts.

THE AGENDA SETTING PROCESS

The following process was used to develop the CIS Research Agenda. In January 2001, the CIS convened a meeting with researchers who had collaborated with the CIS on research studies to elicit their recommendations about the type of research that should form a CIS Research Agenda. Minutes from this meeting were reviewed. In addition, notes from in-depth interviews with CIS Project Directors about the future direction CIS should take in the research arena were reviewed.

After the recommendations and advice from these two stakeholder groups were synthesized, each study in the CIS research portfolio (1999-2004) was reviewed to examine both the focus of the study (i.e., intervention type, research participants) as well as the role of CIS in the study. This step allowed us to take a comprehensive look at the types of studies in which CIS had been involved. In addition, we considered foundational documents on which the CIS Program is based, national goals and objectives (Healthy People 2010, see Appendix E), as well as current NCI priorities.

Based on this comprehensive review, the CIS Project Office research team developed a pool of research questions that, if answered, would help the CIS improve service delivery and support the Director's Challenge Goal of eliminating suffering and death due to cancer. This initial question pool was reviewed and prioritized by the CIS Director and Deputy Director as well as Project Officers who oversee all components of the CIS Program. Based on this initial, internal process for vetting research questions, a first draft CIS Research Agenda was developed.

As part of this development process, CIS developed a "Literature Overview" to help identify existing research that addressed the initial pool of proposed research questions. The Literature Overview was developed as a tool to provide context for each of the proposed research

questions. In addition, the overview was designed to highlight the gaps in the existing body of research that could potentially be addressed through the CIS Research Program.

Next, input from key stakeholders to the CIS Research Program was sought. In May 2004, a meeting of NCI researchers familiar with the CIS Program was convened to elicit input and feedback on the first draft of the agenda. (For a list of internal reviewers, please see Appendix F). The draft Literature Overview was also presented to these reviewers and described as a tool to be used by the CIS network and research partners in identifying priority areas for collaborative research under the Research Program. Reviewers provided feedback on both the draft Agenda and draft Literature Overview. This feedback informed second drafts of the Agenda and Literature Overview.

In November 2004, stakeholder feedback on the Agenda and Literature Overview was sought from researchers external to NCI. Researchers from a variety of backgrounds were invited to participate in a day long review meeting. (For a list of external reviewers, please see Appendix F). Their feedback on both documents was incorporated to refine this current draft of the CIS Research Agenda.

OVERVIEW OF THE AGENDA

The priorities described in this Agenda are based on our responsibility to develop and implement effective health communication and education interventions that contribute to the Director's challenge of eliminating suffering and death due to cancer by 2015. Particular research areas were selected based on the communication and education processes in which CIS has a direct role. Research questions are relevant to all types of cancer, all stages on the cancer care continuum, including survivorship and end-of-life, all populations, and are relevant to research focused on individuals or communities. Priorities were selected based on gaps found in the literature and where answers to specific questions had the potential to inform current service or explore new methods of serving the public.

The CIS seeks to develop a research portfolio that supports this Research Agenda and includes health communication research across the cancer continuum and with a variety of populations. CIS is committed to and will actively pursue theory-guided research projects designed to positively affect cancer-related behavioral outcomes. CIS is dedicated to supporting mixed method study designs that use a combination of qualitative and quantitative data collection strategies. In addition, the CIS is especially interested in research that addresses cancer health disparities. CIS makes a special commitment to working with researchers funded

through the NCI's Center to Reduce Cancer Health Disparities Community Networks Programs. The North American Quitline Consortium (NAQC) also has developed a research agenda for quitlines. As a member of this consortium, the CIS will support investigations that further NAQC's agenda when feasible. Finally, studies that contribute to our understanding of and aid in informed decision making by the public are also important to furthering the information and education mission of the CIS.

The CIS Research Agenda comprises questions organized into four overarching research areas with many sub-questions under each area.

Research Areas:

1. **Testing Innovative Cancer Communication and Education Interventions** – Research in this area develops and tests cancer communication and education interventions to determine if they are effective in changing behaviors related to cancer prevention and control, informed decision making, clinical trials participation, and quality of life for cancer patients. Intervention research includes both effectiveness and efficacy studies. CIS is especially interested in health communication interventions that could be implemented within the CIS program.
2. **Increasing Access To and Appropriate Use of Cancer-Related Information and Education** – Discovering effective strategies to increase access to cancer-related information and education provided by the NCI and other credible organizations and resources is imperative to serving the Nation and especially the underserved and those suffering cancer-related health disparities. In addition, research that identifies and tests new ways to assist the public in understanding and using cancer-related information and education can help the CIS better meet their information and education needs.
3. **Discovering Effective Models for Disseminating Successful Cancer Communication and Education Interventions** – Part of NCI's mission is to disseminate scientific findings to the public. To this end, research that discovers effective ways to translate and disseminate effective cancer communication and education interventions into practice is critical to furthering the field of cancer communication and contributing to the NCI mission and Challenge Goal.
4. **Understanding Information Seeking** – A variety of descriptive studies focused on understanding who needs, seeks, and obtains cancer-related information will both contribute to the field and help the CIS better understand a primary group served by

the CIS: cancer information seekers. In addition, descriptive studies may help us understand the cancer information needs and behaviors of the general public and specific at-risk populations and may provide the formative data on which intervention research can be based. Synthesizing research related to health communication intervention studies, particularly related to interventions that might be disseminated within the CIS network, could provide the foundation for developing and testing new health communication interventions that can benefit the public.

As new priorities emerge from NCI and CIS, research questions reflecting these priorities may be added. Specifically, the CIS encourages research that will address the gaps in knowledge relevant to the research questions.

Testing Innovative Cancer Communication and Education Interventions

Developing and testing innovative cancer communication and education interventions will be critical in paving the way to meet the NCI Director's 2015 Challenge Goal of reducing suffering and death due to cancer. The CIS is interested in interventions that can be implemented within, or in partnership with, the CIS. Specifically, CIS seeks to test interventions that increase cancer prevention behaviors and improve cancer screening practices, especially for the medically underserved. CIS is interested in discovering effective interventions to increase participation in clinical trials and more thoroughly understand the role information and education play in cancer-related decision-making. Identifying the most effective messengers and channels to deliver information and education for different populations will be critical to improving and expanding our services to the public. Learning how decision-making varies among different cultures will help the CIS discover how to culturally tailor information. In addition, discovering effective strategies for delivering and adapting cancer-related information and education for those with limited health literacy will increase the likelihood that the CIS is meeting their cancer information needs. Finally, testing different models of smoking cessation interventions and services for different populations and discovering ways to optimize quit rates among quitline callers would contribute to the field, support NAQC's research agenda, and help the CIS enhance its delivery of smoking cessation services. Research questions concerning innovative cancer communication and education interventions are listed below. These specific questions focus on different elements of cancer communication and education interventions, and are components of a single overarching research question: *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?*

- Q1: Are new *public health informatics*¹ approaches (e.g., computer-generated message tailoring, multimedia interventions, e-health interventions) to delivering cancer-related information effective?
- Q2: What types of interventions are effective in aiding/improving cancer screening and treatment decision-making? How does this vary across different populations?
- Q3: 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?

- Q4:** What are the most effective ways to deliver cancer-related education and information 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 (including e-health applications) be effectively adapted for those with limited health literacy?
- Q5:** How effective are different types of 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 quitline callers' outcomes?

Increasing Access to and Use of Cancer-related Information and Education

To increase the use of cancer-related information and education, the public needs to be aware of national cancer resources, such as the CIS. Recent surveillance data have provided the CIS with baseline data on the public's level of awareness of the National Cancer Institute, the Cancer Information Service, and other national resources. Overall awareness of the CIS is low and significant variations among subpopulations were found (see Literature Overview.) Currently, levels of awareness among health care providers are unknown, as are baseline levels of health care providers' use and perceptions of the CIS. As a national resource for cancer information, it is critical for the CIS to understand the extent to which the public and health care providers are aware of our services as well as the perceived barriers to using the CIS. Such formative research findings can inform studies on the effectiveness of different promotional strategies among various population subgroups. The NCI is especially interested in testing interventions within health care systems and communities to increase access to and use of cancer-related education and information resources, such as the CIS, especially by minority and medically underserved populations. In addition, the NCI is interested in testing social marketing approaches to increase both access to and use of services (including the smoking cessation quitline). Currently, specific surrogate measures of access to cancer-related information and education resources are used (e.g., knowledge, awareness, perceived ease of use of specific resources, Internet connectivity, availability of telephone); however, comprehensive measures of access to cancer-related information and education resources are non-existent. Finally, little research had been conducted to explore the relationship between access to cancer information resources and actual seeking behavior. Research questions focusing on understanding the public's access to and use of cancer-related information are listed below. These specific questions focus on understanding awareness of, barriers to, and use of the CIS and other resources; they fall under a single overarching research question: *What strategies are effective in increasing access to and use of the latest, most accurate, and most appropriate cancer-related information and education by those in need, especially the underserved?*

- Q1:** 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?
- Q2:** 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 barriers to using CIS do providers

perceive? What types of interventions are effective at increasing providers' awareness of, referral to, and use of cancer education and information resources such as the CIS and smoking cessation quitlines?

- Q3:** 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 or education?
- Q4:** 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?
- Q5:** To what extent do community-based interventions increase access to and use of cancer-related education and information resources, such as the CIS and smoking cessation quitlines, by minority and medically underserved populations?
- Q6:** 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?
- Q7:** 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?

Discovering Effective Models for Disseminating Successful Cancer Control Interventions

While the gap between research and practice is well documented, how to incorporate evidence-based cancer control interventions into practice has not been adequately studied. A variety of theoretical frameworks have been developed to explain the process of knowledge transfer and diffusion of innovation; however the field of “dissemination research” frequently uses inconsistent definitions for basic *terms*² (such as diffusion, dissemination, adoption, utilization, and translation), which makes synthesizing research related to the dissemination of cancer control interventions problematic (AHRQ, 2003). In its Evidence Report on the Diffusion and Dissemination of Evidence-based Cancer Control Interventions, the Agency for Healthcare Research and Quality (AHRQ) identified the need for research on strategies to disseminate these interventions and to address methodological issues such as identifying the most appropriate study designs for dissemination research, determining the specific outcomes that are important to measure, and establishing criteria for reporting dissemination research. In fact, the Society for Behavioral Medicine has added these criteria to their recommendations for reporting on behavioral intervention studies. Glasgow, Marcus, Bull, & Wilson (2004) state that the gap between research and practice can be bridged if cancer control intervention studies are tested with intended populations and within settings and with community partners that are selected for representativeness. In addition, these researchers identify the need to design interventions for replication and dissemination by using channels, methods, modes, and resources that are “feasible in and exportable to the intended non-research setting.” As an information and education network, the CIS actively participates in the dissemination of evidence-based cancer control interventions by applying tools such as *PLANET*³ (Plan, Link, Act, Network with Evidence-Based Tools) and the *Guide to Community Preventive Services*.⁴ Given the reach and components of the Program, the CIS is ideally suited to participate in studies investigating how best to adapt, implement, and maintain evidence-based cancer control interventions in practice settings, including the Information Service and community settings supported by CIS Partnership Program efforts. CIS is also interested in research that discovers how to disseminate interventions tested within the CIS to external practice settings. Such studies would inform the CIS Program and the field of cancer control. Given the state of the field of dissemination research, the CIS proposes one broad research question:

- Q1:** What are 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?

Understanding Information Seeking

A variety of descriptive studies related to understanding the information needs and behaviors of the public are needed to help CIS understand the context of and factors influencing information seeking. The Research Agenda focuses on exploring the socio-demographic characteristics of seekers of cancer information and smoking cessation assistance through quitlines, determining when individuals seek information, and understanding the type of information/assistance they seek. In addition, how preferred channels and sources for seeking cancer information vary among population subgroups can help the CIS better meet the public's cancer information needs. Once information seekers obtain cancer information, we need to understand how such information is shared within a family and what resources can best support the role of the caregiver/family member in communicating with patients about cancer. Finally, the agenda proposes research to increase our understanding of the characteristics of individuals who do not actively seek out cancer information (non-seekers), barriers to seeking, and whether interventions designed to activate individuals to seek cancer information are effective and desirable. While new data collection efforts may be necessary to answer some of the proposed questions related to information seeking, many could be answered by analyzing data from existing sources such as the CIS Electronic Contact Record Form database, the 2004 CIS User Survey, market research data collected through existing omnibus surveys, and NCI's Health Information National Trends Survey (HINTS). In addition, a synthesis of study findings focused on cancer-related information seeking is warranted. Specific research questions addressing information seeking are as follows:

- Q1:** 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 the CIS compare to other cancer information seekers? How do repeat CIS callers/users differ from first-time callers/users?
- Q2:** 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 are the triggers at different points on the cancer continuum? What triggers information seeking for different audiences?
- Q3:** 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 phases along the cancer continuum? How do the information needs of repeat callers/users change from first contact with CIS to subsequent contacts?

- Q4: 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 that communication process?
- Q5: 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 and sources of information are perceived as credible among different populations? How is the Internet used for seeking cancer-related information?
- Q6: How can individuals' information-seeking behaviors across time and the cancer continuum best be measured/documentated? What type of systems or data collection devices/instruments could be used to best capture information-seeking behaviors?
- Q7: Who are non-seekers? What are their demographic and psychosocial characteristics? What are their 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 in health-related decision-making? How can cancer information resources and services be adapted to meet the needs of surrogate seekers and non-seekers?

SUMMARY

To contribute to the NCI Director's challenge of eliminating suffering and death due to cancer by 2015, the CIS Research Program has proposed a program of research that focuses on four research areas: testing cancer communication interventions; increasing access to and use of cancer-related information and education; improving the science of dissemination research; and understanding cancer information seeking needs and behavior. This agenda is aligned with NCI priorities and the research interests of NCI's Health Communication and Informatics Research Branch in the Division of Cancer Control and Population Sciences. The CIS is dedicated to supporting the newly launched CIS Research Program and to developing, implementing, and disseminating findings from collaborative research projects that address specific research questions found within this agenda.

This agenda has been developed to help guide the efforts of the CIS network when developing collaborative research studies with investigators. While research collaborations that address research questions other than those listed in this draft agenda are not precluded within the new CIS Research Program, research proposals submitted to the CIS Project Office that are designed to provide answers to these specific research questions will be given priority. Answers to the research questions posed in this agenda will enable the CIS program to adapt services to better meet the information and education needs of the public. By 2010, the CIS intends that its Research Portfolio will include a wide range of studies that address many of the research questions posed in this agenda, especially those related to addressing cancer health disparities. This agenda will be periodically updated to reflect emerging issues in cancer communication research priorities.

END NOTES

¹ Public health informatics is defined as the systematic application of information, computer science, and technology to public health practice, research and learning (Kukafka, 2005).

² The CIS uses the following definitions: **Diffusion:** The passive process by which a program or product is absorbed into more widespread use. **Dissemination:** The active promotion or support of a program to encourage its widespread adoption, dissemination involves the adaptation, evaluation, implementation, and maintenance of an intervention. **Replication:** This process moves a tested prototype to additional sites (or target populations) in keeping with the hard (invariable) and soft (variable) aspects of that program's components while remaining sensitive to the local context (Glasgow, Marcus, Bull & Wilson, 2004, p. 1240.)

³ <http://cancercontrolplanet.cancer.gov/>

⁴ <http://www.thecommunityguide.org/>

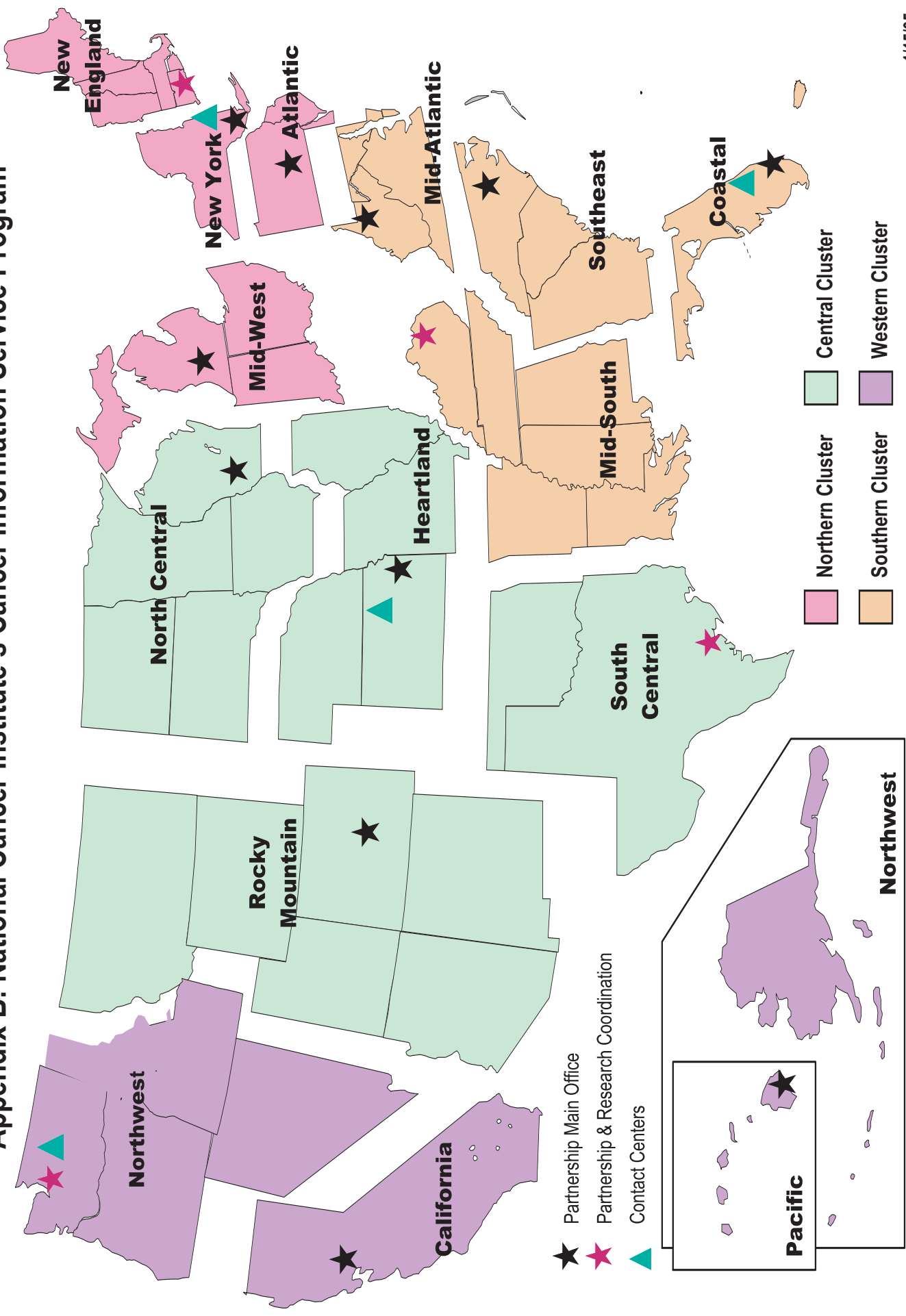
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Appendix A Services Provided by CIS Regional Offices

CIS Region	States in Region	Contractor	CIS Program Component
Atlantic	Delaware, New Jersey, Pennsylvania	Fox Chase Cancer Center	Partnership
California	California	Notern California Cancer Center	Partnership
Coastal	Florida, Puerto Rico, U.S. Virgin Islands	University of Miami School of Medicine	Partnership, Contact Center, Spanish
Heartland	Illinois, Kansas, Missouri, Nebraska	University of Kansas Medicine Center	Partnership, Contact Center, E-mail
Mid-Atlantic	Washington, D.C., Maryland, Virginia, West Virginia	West Virginia University	Partnership
Mid-South	Alabama, Arkansas, Kentucky, Louisiana, Mississippi, Tennessee	Univ. Kentucky Research Foundation	Partnership, Research
Mid-West	Indiana, Michigan, Ohio	Wayne State University	Partnership
New England	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont	Yale University School of Medicine	Partnership, Research
New York	New York State	Memorial Sloan-Kettering Institute for Cancer Research	Partnership, Contact Center, E-mail
North Central	Iowa, Minnesota, North Dakota, South Dakota, Wisconsin	University of Wisconsin System	Partnership
Northwest	Alaska, Idaho, Nevada, Oregon, Washington State	Fred Hutchinson Cancer Research Center	Partnership, Contact Center, Research
Pacific	Hawaii, U.S. Associated Pacific Territories	Cancer Research Center of Hawaii	Partnership
Rocky Mountain	Arizona, Colorado, Montana, New Mexico, Utah, Wyoming	Penrose-St. Francis Health Services	Partnership
South Central	Oklahoma, Texas	University of Texas, M.D. Anderson	Partnership, Research
Southeast	Georgia, North Carolina, South Carolina	Duke University	Partnership

Appendix B: National Cancer Institute's Cancer Information Service Program



Appendix C: CIS Research Projects (1999-2004)

Title of CIS Research Project	Investigator Names/Institution	CIS Region
Breast Cancer Stress Reduction	Antoni, Carver & Weiss, University of Miami (Center for Psycho Oncology Research)	Coastal
Impact of Health Information from the Internet on Self-Efficacy and Perceived Task Behavior in Newly Diagnosed Cancer Patients	Bass/Temple University	Atlantic
Treatment Decision Making by Men with Localized Prostate Cancer	Berry, University of Washington	Pacific
Breast Cancer Risk Notification	Bloom, Northern California Cancer Center	California
Increasing Breast Cancer Screening Risk Assessment and Preventive Services Among African American Women: Discovering the Feasibility of Web-based Outreach Services	Brawn, Wayne State University	Midwest
Cancer Patients Search For and Use of Information About Cancer	Broz & Cegala, Ohio State University, Department of Communication	Midwest
Smoking Cessation Strategies within a Detroit Medicaid HMO	Burack, Wayne State University; Strecher, AMC Cancer Center	Midwest
Instrument Development to Measure Socio-cultural variations Related to Mammography Screening Among African American Women	Champion, Indiana University Cancer Center	Midwest

Title of CIS Research Project	Investigator Names/Institution	CIS Region
A.C.N. Network Pilot – Understanding Knowledge, Attitudes, and Behaviors of Rural Appalachians Toward Cancer Treatment and Diagnosis	Coyne, West Virginia University	Mid-Atlantic
Brief Feasibility Study for CIS-Mediated Patient Activation Project to Promote Colorectal Screening in Rural Primary Care	Engelman, University of Kansas Medical Center	Heartland
Pacific Rim Cancer Screening Awareness through Congregations	Fox, University of California Los Angeles	Hawaii
African American Breast Cancer Survivors' Quality of Life	Giesler, Indiana University School of Medicine & Nursing	Midwest
HPV Study - Determinants of the Persistence vs. Transience of HPV Infection Among a Cohort of Women with Normal Cervical Cytology	Goodman & Hernandez, University of Hawaii Cancer Research Center	Hawaii
Digital Divide Pilot Project– Feasibility Study of CHESS Dissemination through the CIS Network	Gustafson, University of Wisconsin (Center for Health Systems Research and Analysis)	Midwest, North Central
Advance Cancer Patients Communications Needs - Pilot Study	Gustafson, University of Wisconsin (Center for Health Systems Research and Analysis)	North Central
CHESS - Effects of Alternate Decision Support Technologies on Breast Cancer Patients' Knowledge of Options and Satisfaction with Treatment	Gustafson, University of Wisconsin (Center for Health Systems Research and Analysis)	Midwest, North Central

Title of CIS Research Project	Investigator Names/Institution	CIS Region
CECCR - Center on Interactive Communications for Coping with Advanced Cancer: Integrating Computer and Mentor Based Systems for Breast Cancer (Pilot Study)	Hawkins, University of Wisconsin (Center for Health Systems Research and Analysis)	Midwest, North Central
Utilizing Radio to Enhance Colorectal Screening Intentions for the Washington, DC Latino Community	Huerta, MedStar Research Institute	Mid-Atlantic
Community Partnerships to Reduce Barriers to Cancer Information and Services	Jandorf, Mt. Sinai School of Medicine	New York
Native Hawaiian Elders Focus Group Study	Ka'opua, Cancer Research Center of Hawaii	Hawaii
Clinical Trials for Colorado Providers	Krebs, University of Colorado (School of Nursing)	Rocky Mountain
Increasing Accrual to Clinical Trials	Lara & Chen, University of California – Davis	California
CIS Research Consortium 2 (CISRC2) - 5 A Day	Marcus & Heimendinger, AMC Cancer Research Center	New England, New York, Mid-Atlantic, North Central, South Central, California
CISRC2 - Dissemination of Promising Cancer Control Interventions Tested in Effective Research	Marcus, AMC Cancer Center	NorthEast, Mid-Atlantic, North Central, South Central, California

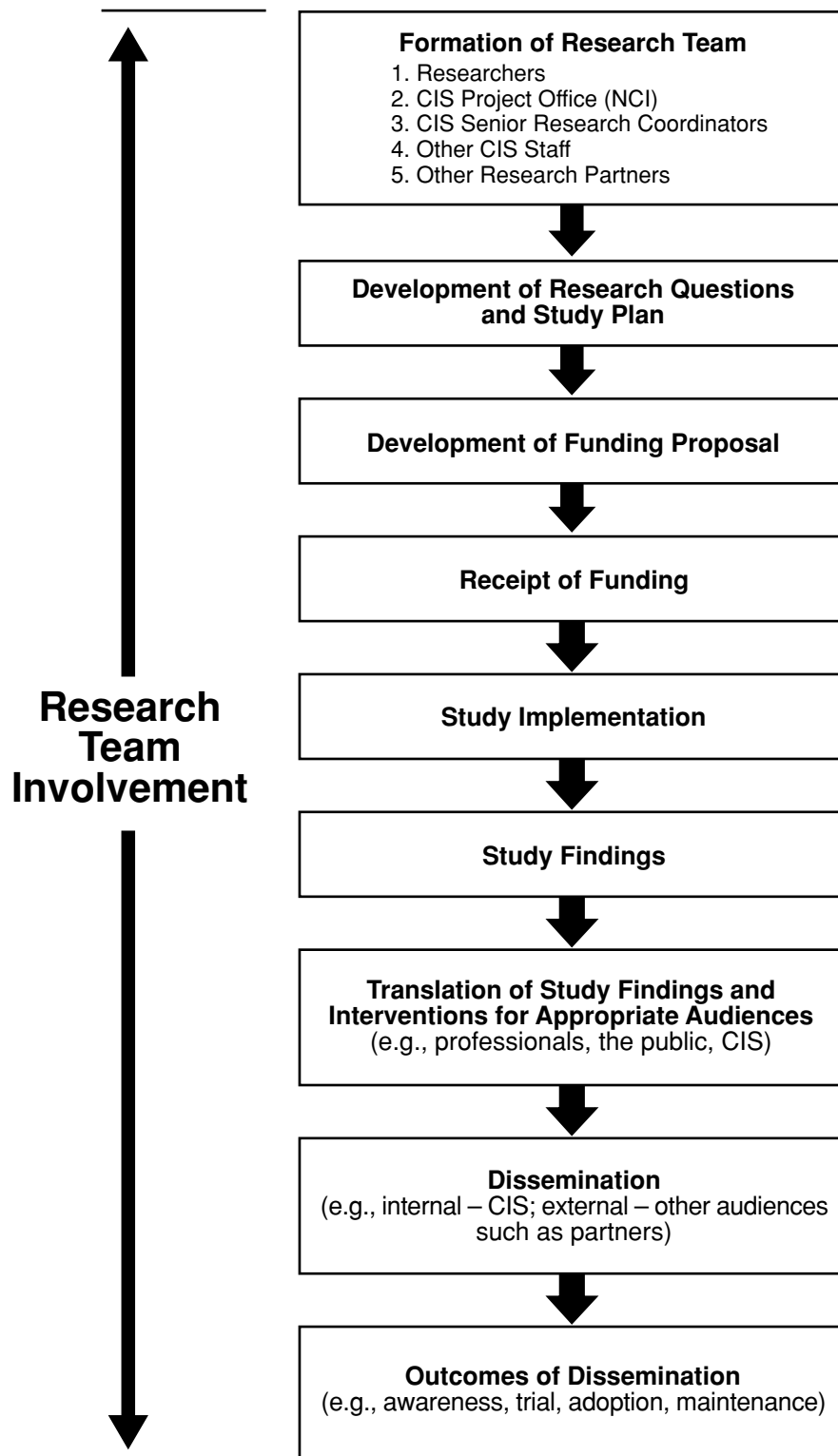
Title of CIS Research Project	Investigator Names/Institution	CIS Region
CISRC2 - Smoking Cessation	Marcus, AMC Cancer Research Center & Strecher, University of Michigan	Atlantic, Midwest, Rocky Mountain, Pacific
CISRC2 - Colorectal Screening	Marcus, AMC Cancer Research Center & Rimer, Duke University Medical Center	New York, Mid-Atlantic, South East, Mid South, Coastal, Heartland, North Central, South Central, California
Facilitating Breast Cancer Genetic Counseling Through Information Preparation and Referral	Miller, Fox Chase Cancer Center	Atlantic
CIS Interactive Outreach to Low-Income Cancer Patients (CIS Link)	Pasick & Kaplan, University of California – San Francisco	California
Digital Divide Pilot Project - Bridging the Digital Divide: Your Access to Cancer Information Project	Perocchia & Rapkin, Memorial Sloan Kettering Cancer Center	New York
Northwest Cancer Genetics Network	Potter, Bush & Bowen, Fred Hutchinson Cancer Research Center	Pacific
Molecular Biology-based Cervical Cancer Screening	Reed, Mary Babb Randolph Cancer Center	Mid-Atlantic

Title of CIS Research Project	Investigator Names/Institution	CIS Region
Women's Interactive Risk Education Study (WIRES)	Robbins & Bowen, Fred Hutchinson Cancer Research Center	Pacific
Women's Interactive Risk Education Study (WIRES): Healthy Neighbors Pilot	Robbins, Bowen & Bush, Fred Hutchinson Cancer Research Center	Pacific
Promoting Cancer Prevention and Control with Message Framing (Information Processing Styles: Need for Cognition) - Fruits and Vegetables 1	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing (Individually vs. socially oriented messages) - Fruits and Vegetables 2	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing - (Monitor-Blunting Coping Styles) - Fruits and Vegetables 3	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing (Regulatory Focus: prevention vs. promotion) - Fruits and Vegetables 4	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Psychologically Tailored Messages About Mammography (YD1) (Information Processing Style: Need for Cognition)	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Psychologically Tailored Messages About Mammography (YD2) (Health Locus of Control)	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England

Title of CIS Research Project	Investigator Names/Institution	CIS Region
Psychologically Tailored Messages About Mammography (YD3) (Monitor-Blunting Coping Styles)	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing (Need for Cognition: high vs. low) - Clinical Trial 1	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing (Regulatory Focus: prevention vs. promotion)- Clinical Trial 2	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Promoting Cancer Prevention and Control with Message Framing (Monitor/Blunter Coping Styles) - Clinical Trial 3	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Digital Divide Pilot Project - Community Technology Centers for Head Start Parents and Families	Salovey, Yale University, Department of Psychology (Health, Emotion, and Behavior Lab)	New England
Information Interests and Concerns of African Americans Calling NCI's Cancer Information Service	Sanders Thompson, St. Louis University, School of Public Health	Heartland
Increasing Colorectal Cancer Screening Among North Carolina and South Carolina Medical Consumers: A Comparison of Educational Strategies	Schenck, Medical Review of North Carolina	Southeast
Navigating Latinas through Breast Cancer Treatment	Sheppard, Georgetown University, Lombardi Cancer Center	Mid-Atlantic

Title of CIS Research Project	Investigator Names/Institution	CIS Region
A Pilot Study to Assess the Prevalence of Pain, Strain, and Co-morbid Conditions Among Cancer Patients and their Caregivers	Siegler & Keefe, Duke University	Southeast
Cancer Risk Intake System (CRIS) Pilot Study	Skinner, Duke University	Southeast
ECRF Breast Cancer Addendum	Stanton, University of California – Los Angeles	Heartland
Pain Management and Quality of Life Needs Assessment of CIS Callers - Pilot Study	Ward & Heidrich, University of Wisconsin	North Central
Tailored Barriers Intervention – Pain Study	Ward, University of Wisconsin (School of Nursing)	Heartland, North Central
Information Needs and Information Seeking Behavior: Impact of the Internet	West, Northern California Cancer Center	California
Adios Al Fumar Smoking Cessation Services for Hispanic Smokers in Texas	Wetter, University of Texas, MD Anderson Cancer Center	South Central
Digital Divide Pilot Project - A Computer-Based Multimedia Approach to Disseminating Early Detection Cancer Information aka (Low Literacy User Cancer Information Interface: LUCI)	Wilbright, Tulane University	Mid-South

Appendix D



APPENDIX E

Healthy People 2010 Health Communication Objectives

- 11-1: Increase the proportion of households with access to the Internet at home.
- 11-2: Improve the health literacy of persons with inadequate or marginal literacy skills.*
- 11-3: Increase the proportion of health communication activities that include research and evaluation.*
- 11-4: Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site.*
- 11-5: Increase the numbers of centers for excellence that seek to advance the research and practice of health communication.*
- 11-6: Increase the proportion of persons who report that their health care providers have satisfactory communication skills.

*Developmental objective.

Appendix F

CIS Agenda Reviewers

NCI Reviewers

Ken Chu, Ph.D.

Program Director
Center to Reduce Cancer Health Disparities
National Cancer Institute
6130 Executive Boulevard
Rockville, MD 20852
Phone: 301-435-9213
Email: chuk@mail.nih.gov

Lila Finney-Rutten, M.P.H., Ph.D.

Division of Cancer Control and Population
Sciences (DCCPS)
Health Communication and Informatics
Branch
National Cancer Institute
6130 Executive Boulevard
Rockville, MD 20852
Phone: 301-496-7924
Email: finneyl@mail.nih.gov

Brad Hesse, Ph.D.

Senior Scientist
DCCPS
Health Communication and Informatics
Branch
National Cancer Institute
6130 Executive Boulevard
Rockville, MD 20852
Phone: 301-435-2842
Email: hesseb@mail.nih.gov

Diana Jeffrey, Ph.D.

Program Director
Office of Cancer Survivorship
DCCPS
National Cancer Institute
6116 Executive Boulevard
Rockville, MD 20852
Phone: 301-594-5070
Email: jeffreyd@mail.nih.gov

Jon Kerner, Ph.D.

Deputy Director for Research Diffusion and
Dissemination
DCCPS
National Cancer Institute
6130 Executive Boulevard
Room 6144
Rockville, MD 20852
Phone: 301-594-7294
Email: kernerj@mail.nih.gov

Gary Kreps, Ph.D.

Director of the Health Communication and
Informatics Branch
DCCPS
National Cancer Institute
6130 Executive Boulevard
Rockville, MD 20852
(no longer with NCI)

Scott Leischow, Ph.D.

Chief, Tobacco Control Research Branch
DCCPS
National Cancer Institute
6130 Executive Boulevard
Bethesda, MD 20892
301-496-8545
Email: scott.leischow@hhs.gov

Ed Maibach, Ph.D.

Director, Center for Strategic Dissemination
National Cancer Institute
6116 Executive Blvd
Rockville, MD
Phone: 301 594-8193
(no longer with NCI)

Holly Massett, Ph.D.

Chief, Operations Research Office
Center for Strategic Dissemination
National Cancer Institute
6116 Executive Blvd
Rockville, MD
Phone: 301 594-8193
Email: massettth@mail.nih.gov

Appendix F CIS Agenda Reviewers

Helen Meisner, Ph.D.

Chief, Cancer Screening, Health Disparities,
Research Synthesis
Applied Cancer Screening Branch
DCCPS
6130 Executive Blvd.
Bethesda, MD 20892
Phone: 301-435-1505
Hm36d@nih.gov

Julia Rowland, Ph.D.

Director, Office of Cancer Survivorship
DCCPS
National Cancer Institute
6116 Executive Boulevard
Rockville, MD 20852
Phone: 301-594-5070
Email: rowlandj@mail.nih.gov

Ed Trapido, Sc.D.

Associate Director, Epidemiology and
Genetics Research Program, and
Program Director, Tobacco Epidemiology
Research
DCCPS
National Cancer Institute
6130 Executive Boulevard
Room 5113
Rockville, MD 20852
Phone: 301-496-9600
Email: trapidoe@mail.nih.gov

Sabra Woolley, Ph.D.

Program Director
Health Communication and Informatics
Branch
DCCPS
National Cancer Institute
6130 Executive Boulevard
Room 4078
Rockville, MD 20852
Phone: 301-435-4589
Email: woolleys@mail.nih.gov

External Reviewers

Glen T. Cameron, Ph.D.

Maxine Wilson Gregory Chair in Journalism
Research
Missouri School of Journalism
2 Eubanks Court
Columbia, Missouri 65203
Phone: 573 864-2897; Fax: 573 882-4823
Email: camerong@missouri.edu

Maria Fernandez, Ph.D.

Assistant Professor of Behavioral Sciences
The University of Texas Health Science
Center at Houston School of Public Health
7000 Fannin Street, Suite 2558
Houston, Texas 77030
Phone: 713 500-9626; Fax: 713 500-9750
Email: Maria_E_Fernandez@uth.tmc.edu

Vicki S. Freimuth, Ph.D.

Professor, Department of Speech
Communication
The University of Georgia
1672 Gober Road
Bishop, Georgia 30621
Phone: 706 542-0586; Fax: 706 542-3245
Email: freimuth@uga.edu

Robert S. Gold, Ph.D., DrPH

Dean, College of Health and Human
Performance
University of Maryland
Building 255 Valley Drive
College Park, Maryland 20742
Phone: 301 405-1362

Amy Latimer, Ph.D.

Health, Emotion and Behavior Laboratory
Department of Psychology
Yale University
2 Hillhouse Avenue
P.O. Box 208205
New Haven, Connecticut 06520-8205
Phone: 203 432-4225; Fax: 203 432-2386
Email: amy.latimer@yale.edu

Appendix F

CIS Agenda Reviewers

Alfred C. Marcus, Ph.D.

Chair, Behavioral & Community Studies
AMC Cancer Research Center
1600 Pierce Street–Robinson Building
Denver, Colorado 80214
Phone: 303 239-3397; Fax: 303 233-1863
Email: marcusa@amc.org

Suzanne Miller, Ph.D.

Senior Member, Division of Population
Science
Fox Chase Cancer Center
Behavioral Medicine Program
333 Cottman Avenue, Suite P1096
Philadelphia, Pennsylvania 19111
Phone: 215 728-4069; Fax: 215 214-1651
Email: SM_Miller@FCCC.EDU

David E. Nelson, M.D., M.P.H

Senior Scientific Advisor
Center for Disease Control & Prevention
Office of Smoking and Health
4770 Buford Highway, NE
Mailstop K-50
Atlanta, Georgia 30341
Phone: 770 488-2401; Fax: 770 488-5939
Email: den2@cdc.gov

Rena Pasick, Dr. P.H.

Associate Professor, Medicine
Associate Director of Education and Outreach
University of California San Francisco
UCSF Box 0981
74 New Montgomery St., Suite 200
San Francisco, CA 94143-0981
Phone: (415) 597-9316
Email: rpasick@cc.ucsf.edu

Annette L. Stanton, Ph.D.

Professor, Departments of Psychology and
Psychiatry & Biobehavioral Sciences
University of California, Los Angeles
405 Hillgard Avenue
1285 Franz Hall, Box 951563
Los Angeles, California 90095-1563
Phone: 310 267-2835; Fax: 310 206-3566
Email: astanton@ucla.edu

Kaisisomayajula Viswanath, Ph.D.

Associate Professor
Dana-Farber Cancer Institute
Harvard School of Public Health
44 Binney Street
Boston, Massachusetts 02115
Phone: 617 632-2225
Fax: 617 632-5690
Email: Vish_Viswanath@dfci.harvard.edu

Sandra Ward, Ph.D.

Professor
University of Wisconsin-Madison
School of Nursing, K6/348
600 Highland Avenue
Madison, Wisconsin 53792
Phone: 608 263-5277
Fax: 608 263-5458
Email: sward2@wisc.edu



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