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Bridging the Critical Chasm Between Service and Research: The Cancer Information Service's Collaboratory

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Abstract

As a *collaboratory* for cancer communication and education research, the National Cancer Institute's (NCI) Cancer Information Service (CIS) is in an ideal position to bridge the critical chasm that exists between service and research. This article describes the CIS' current research program as well as the CIS Research Agenda launched in 2005. The CIS' progress in developing and supporting recently funded studies that address this agenda is detailed. The unique resources and opportunities available to researchers, public health practitioners, health care providers, and community-based organizations interested in developing collaborative cancer communication and cancer education studies with the CIS are identified and described and an invitation to collaborate is extended.

For over 30 years, the National Cancer Institute (NCI) has implemented a high quality cancer information service. While the primary mandate of NCI's Cancer Information Service (CIS) is to effectively communicate the most up-to-date, evidence-based information related to cancer, it has also emerged as a productive laboratory for health communication research.

Four journal supplements describe the evolution of the CIS' research infrastructure and program as well as results from numerous studies in cancer communication. *The Journal of the National Cancer Institute, Monograph 14* (1993) describes the history of the CIS as well as results from the first studies conducted with the CIS such as an anti-smoking media campaign,¹ the initiation of proactive screening mammography counseling within the CIS,² and a survey about the cancer information seeking behaviors and needs of cancer patients' who called the CIS.³ A special issue of *Preventive Medicine* (1998, Volume 27, Number 4) describes the development, implementation, results, and lessons learned from a Cancer Information Service Research Consortium (CISRC) funded by NCI through a Program Project grant (PO1). This consortium, comprised of both CIS staff and academic researchers, was the foundation for developing the CIS' collaborative model of research. Also during 1998, results from a series of studies, which evaluated the effectiveness and impact of the CIS Telephone Service as well as its Outreach Program, were published in the *Journal of Health Communication* (1998, Volume 3, supplement). Finally, a dedicated issue of the *Journal of Health Communication* (2005, Volume 10, supplement 1) highlights the results of

the second CISRC⁴⁻⁶ and other studies that focused on tailoring materials and interventions for clients contacting the Information Service,⁷ eHealth systems and resources,⁸⁻¹¹ information seeking,¹² and informed decision-making.¹³ In addition to the four journal supplements previously described, between 1999 and 2006 the CIS supported research studies that resulted in an additional 33 publications.^a

Over the course of almost two decades, the CIS has developed a productive research enterprise with a sophisticated infrastructure to support collaborative studies that contribute to the science of health communication. Because the CIS is a service program operated within a research institution,¹⁴ it is in an ideal position to bridge the critical chasm that exists between cancer information and educational services and research, and to support studies across the full research continuum (eg, exploratory research, pilot studies, randomized controlled trials, dissemination studies, etc). As a “living laboratory” or “collaboratory” for health communication research, the CIS is ripe with opportunities to study communication processes and effects through both its Information Service and Partnership Program.⁵ The purpose of this article is to describe the CIS’ current research program, to describe the CIS research agenda, and to share examples of the recent projects that address this agenda.

THE CIS RESEARCH PROGRAM

From 1999–2004, the CIS worked with researchers through all stages of the research continuum.¹⁵ The CIS Research Program is built upon lessons learned from the two previous decades of supporting and implementing cancer communication research.^{16,5} The CIS embraces the concept of a collaborative research team to guide the development and implementation of research studies conducted with the CIS as a way to ensure that study findings can be incorporated back into the CIS Program.¹⁵

To facilitate the development of collaborative research teams, the NCI created new CIS positions and funded four senior research coordinators (SRCs) in 2005 who work with investigators to develop their research concepts and proposals. The SRCs are housed in four academic institutions and thus, are immersed in both the academic environment as well as the service environment of the CIS. Due to this positioning, they are able to explain research caveats to CIS staff and CIS-related service considerations to researchers with the aim of balancing the goals and requirements of both research and service.

The SRCs ensure that the proposed study supports the CIS research agenda, that the implementation of the study protocol does not compromise service to the public, and that the CIS staff are appropriately integrated in the design and implementation of the study. In addition, the SRCs serve as liaisons between the CIS staff (in the Partnership Program and the Information Service), the NCI Office of the Cancer Information Service, and the researchers; they play a variety of roles as part of the research team including co-investigator or consultant/advisor. For many studies, they have key responsibilities for study implementation, data analysis, or report writing and manuscript preparation. While other CIS staff also actively participate in research teams as appropriate, the coordination of the implementation of studies throughout the CIS network is the responsibility of the SRCs.

As a resource to researchers, the SRCs routinely provide a listing of funding opportunities and conferences relevant to health communication and cancer control and work with researchers to find appropriate grant announcements and dissemination opportunities. When

^aResearchers who are interested in keeping abreast of CIS research publications can find an updated bibliography at <http://cis.nci.nih.gov/research/research.html>.

working with researchers to develop their initial research concepts and proposals, the SRCs make available all publications from the CIS Research Bibliography (<http://cis.nci.nih.gov/research/research.html>) and information about the CIS' data collection system used to record demographics and subjects of interaction for clients contacting the Information Service. In addition, SRCs work with researchers to analyze data from the Information Service¹⁷ and NCI's Health Information National Trends Survey (HINTS) (<http://hints.cancer.gov/hints/>).¹⁸ They also connect researchers to resources such as Cancer Control PLANET (<http://cancercontrolplanet.cancer.gov/>) which helps researchers and public health professionals:

1. identify cancer-relevant statistics;
2. identify potential partners;
3. identify evidence-based interventions;
4. find research-tested programs and products;
5. connect to planning and evaluation resources.

Other unique resources that are available to researchers when developing collaborative research studies with the CIS include NCI's Consumer Health Profiles, a propriety database of health behavior, demographic, lifestyle, and geographic data for audience segmentation. Consumer Health Profiles combine information from the U.S. Census Bureau, Medstat's PULSE survey (a telephone survey of 100,000 households), the Center for Disease Control's (CDC's) Behavioral Risk Factor Surveillance System (BRFSS), Claritas Inc.'s PRIZM_{NE} Lifestyle Segmentation, and Simmons Market Research Bureau's Survey of Media and Markets.

All three components of the program (ie, the Information Service, Partnership Program, and Research Program), are staffed by trained professionals (eg, training managers, cancer content specialists, communications specialists, contact center managers) who assist researchers in developing educational materials and identifying effective recruitment strategies. Staff throughout the program are available to serve on study teams. In addition to trained staff, the CIS has a quality assurance program and national training program¹⁹ with the infrastructure and functions that enable researchers to efficiently and effectively train CIS staff who implement study protocols and interventions. Finally, a dedicated NCI/CIS project officer role was implemented 4 years ago to oversee the Research Program and to ensure that studies support this agenda and are beneficial to the program. The project officer ensures that the CIS has the capacity to play the proposed role in the study and that the study does not compromise services delivered through the program.

THE 2005 CIS RESEARCH AGENDA

The Need

The vast majority of previous research with the CIS has been investigator-initiated. However, given the success of this previous research and the concurrent emergence of the CIS as a viable laboratory for health communication research, the CIS embarked on a strategic planning process to define high priority areas for future collaborative research with the CIS. The end result of this effort was the formulation of the CIS research agenda, as described in this article. This agenda is intended to provide guidance and direction to researchers within the broader context of the CIS model for collaborative research.

The Development Process

A systematic process was used to develop the CIS research agenda. First, recommendations about the type of research that should form a CIS research agenda were offered from staff in the CIS network. Once synthesized, each study in the CIS Research Portfolio (1999–2004)¹⁵ was reviewed to examine both the focus of the study (ie, intervention type, research participants) as well as the role of the CIS in the study allowing for a comprehensive evaluation of the types of studies in which CIS had participated. Foundational documents on which the CIS program is based, national goals and objectives (eg, Healthy People 2010) and NCI priorities were also considered. Based on this comprehensive review, the CIS project office team developed a pool of research questions that, if answered, would help the CIS improve service delivery.

This initial question pool was reviewed and prioritized at the CIS national office at NCI. Based on this initial, internal process for vetting research questions, a first draft CIS research agenda was developed. As part of this process, CIS developed a literature review to help identify existing research that addressed the initial pool of proposed research questions. Developed as a tool to provide context for each of the proposed research questions, the literature review highlighted 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 feedback on the first draft of the agenda which was used to develop a second draft of the agenda. In November 2004, stakeholder feedback on the agenda was sought from researchers external to NCI. Researchers from a variety of backgrounds (eg, public health, psychology, informatics, communication) were invited to participate in a day-long review meeting. Their feedback was incorporated to refine the final version of the 2005 CIS research agenda briefly described below.

OVERVIEW OF THE AGENDA

The priorities described in the CIS research agenda are based on the responsibility of the NCI to develop and implement effective health communication and education interventions. 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 germane 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.^b Table 1 describes the four specific research areas that comprise the CIS research agenda which was launched in Spring 2005. Next, Progress in addressing these four areas since the agenda's launch will now be described.

PROGRESS IN ADDRESSING THE CIS RESEARCH AGENDA: 2005–2006

In just 2 years since launching the CIS research agenda, the CIS has made considerable progress in stimulating new research addressing each of the four focus areas of the research agenda.

^bFor a complete copy of the CIS research agenda and corresponding literature overview, please e-mail Dr. Linda Squiers, National Cancer Institute, Cancer Information Service (squiersl@mail.nih.gov) or go to <http://cis.nci.nih.gov/research/research.html>.

Research Area 1 - Testing Innovative Cancer Communication and Education Interventions

The CIS is collaborating on many studies that test innovative cancer communication and education interventions. For example, the CIS actively supports Dr. Peter Salovey's (Yale University) Promoting Cancer Prevention/Control with Message Framing grant (5R01CA068427-08). The goal of this set of nine studies over 5 years is to investigate whether the influence of CIS-delivered messages can be improved by framing them in gain (benefits) or loss (risks) terms and by tailoring them to individual differences in the psychological styles with which people process health-related information. These styles include individual variability in the preference to (a) ponder complex arguments, (b) monitor the environment for threatening information, (c) feel motivated by accomplishment versus safety, and (d) attribute the responsibility for maintaining good health to oneself or to health professionals. Behaviors under investigation include fruit and vegetable consumption,²⁰ information seeking for clinical trials,²¹ and physical activity.

The CIS Program will also play an integral role in connecting cancer patients to innovative cancer communication interventions through Dr. Alfred Marcus' third program project grant (2P01CA057586-09A2) entitled the CISRC: Years 2006–2011 (awarded in Fall, 2006). In this program project grant (estimated n = 2520), an interactive multimedia program will be tested for efficacy across three groups of cancer patients who call the Cancer Information Service (1-800-4-CANCER). Proactive follow-up telephone calls to breast cancer survivors by the CIS Information Specialists will also be tested. These studies will examine the effect of these interventions on patient outcomes such as cancer-specific distress, emotional quality of life, physical and interpersonal functioning, decisional conflict, and fear of recurrence.

Finally, in 2005, the CIS collaborated with Dr. Sandra Ward (University of Wisconsin) to test a Tailored Barriers Intervention for CIS callers in pain (5R01CA101907-02). Data analysis for this study has been recently completed and future manuscripts are anticipated.

Research Area 2 - Increase Access To and Appropriate Use of Cancer-Related Information and Research

To address the second research area on the CIS Research Agenda, the CIS worked with NCI's Division of Cancer Control and Population Sciences to develop a request for proposals entitled Exploratory Grants for Increasing Utilization and Impact of the National Cancer Institute's Cancer Information Service (RFP CA-015-60). The purpose of this funding opportunity was to stimulate research that explores effective messages, channels, outreach, promotional strategies, and/or other interventions that increase the utilization and impact of existing cancer information resources such as NCI's CIS by underserved populations. Forty-seven applications to this RFP were received and reviewed. In Fall 2006, the NCI awarded the following six 2-year grants:

- Dr. Suzanne Bakken: Improving Use of CIS in the Underserved Through Mobile Access and Decision Support (Columbia University School of Nursing) (1R21CA126325-01). The overall goal of this project is to determine if integration of resources from NCI's CIS into an existing personal digital assistant (PDA)-based mobile decision support system for Advanced Practice Nurses (MODS-APN) increases use of tobacco-related CIS resources by APN students and the underserved populations for whom they provide care.
- Dr. Celia Kaplan: CIS Initiated Calls: Can We Enhance Information Services for Latino Patients? (University of California, San Francisco) (1R21CA126390-01).

^cThe three patient groups are newly diagnosed breast cancer patients, newly diagnosed prostate cancer patients, and breast cancer survivors.

The overall goal of this R21 is to ascertain the acceptability and feasibility of a CIS-Proactive Call (CIS-PC) program and identify appropriate methods of dissemination to health professionals.

- Dr. Matthew Kreuter: Sustainable Strategies for Increasing CIS Use Among African Americans and Hispanics (St. Louis University) (1R21CA126326-01). The aim of this study is to develop and test new CIS resources that will be used by CIS Partnership Program Coordinators. These resources will be designed to increase awareness and use of the CIS by African Americans, Hispanics, and the community organizations that serve them.
- Dr. Laura Linnan: Promoting CIS Among Black Men in Barbershops (Lineberger Comprehensive Cancer Center, University of North Carolina) (1R21CA126373-01). This pilot study will utilize community-based participatory research methods to test barbershop-based intervention strategies that encourage Black men to call CIS' 1-800-4-CANCER for colorectal and prostate cancer information.
- Dr. Bonnie Spring: ACCISS: Activating Collaborative CIS Support Services. (Northwestern University Medical School) (1R21CA126450-01). The specific aims of this study are to examine whether a targeted physician mailing can increase calls to the CIS, enhance appropriate medical follow-up, and improve satisfaction with provider-patient communication at a follow-up medical visit among women just scheduled for colposcopy.
- Dr. Diane Weiner: Is CIS Reaching Connecticut Native Americans? Understanding Cancer Information Seeking. (Mashantucket Pequot Tribal Nation - Tribal Council) (1R21CA126321-01). This formative research study will focus on understanding Connecticut's Native Americans cancer-related information needs and how they seek, obtain, and share cancer-related information within families and their communities.

Currently, the CIS is collaborating with Dr. Rena Pasick (University of California San Francisco) on her study Interactive Outreach: CIS-Link to the Underserved (5R01CA104016-02). The goal of this study is to increase use of the CIS by public hospital cancer patients who are traditionally underserved through development of a culturally appropriate, low-literacy, bilingual kiosk that provides a direct link to the CIS. In addition, this study will test how to adapt the CIS response for underserved patients through modifying the current CIS telephone response for low literacy and multiple cultures, and developing a proactive telephone protocol to improve caller question-asking skills, increase information efficacy, intent to adhere to treatment, and awareness of clinical trials. Both the kiosk and adapted telephone protocol will be piloted for feasibility and efficacy. This study along with the six recently funded R21s should contribute to answering specific research questions under research area two.

Research Area 3 - Discovering Effective Models for Disseminating Successful Cancer Communication and Education Interventions

To contribute to the discovery of effective dissemination models, the CIS has trained its Partnership Program staff to utilize a variety of tools and resources including Cancer Control PLANET, CDC's Community Guide to Prevention (focused on evidence-based strategies), and NCI's Using What Works Program (focused on adapting evidence-based cancer control programs). The Partnership Program staff are trained public health professionals with expertise in cancer control who collaborate with an extensive network of organizations that reach underserved populations. The Partnership Program is an effector arm of the NCI and equipped to systematically disseminate cancer control interventions to both national and

community organizations. To this end, the CIS is working with others at NCI to study the dissemination of the Body & Soul - A Celebration of Healthy Living Program through the CIS Partnership Program and through other national organizations as well. The CIS Partnership Program staff are NCI's dissemination agents; they recruit partner organizations in their regions to work with churches to implement the program; they also train these organizations to provide vital technical assistance that churches will need to initiate and sustain the program. Initial evaluation of this dissemination initiative involves documenting the following: specific methods and strategies dissemination agents use to recruit organizations; barriers and facilitators to dissemination; and program reach.

Research Area 4 - Understanding Information Seeking

The CIS fosters a number of descriptive studies that focus on understanding cancer information-seeking and cancer information needs. For example, through a competitive pilot grant review process, the CIS' Mid-South Region, housed at the University of Kentucky, awarded pilot funds to Dr. Claudia Hopenhayn (University of Kentucky) to investigate the knowledge and attitudes about the human papilloma virus test and vaccine among those living in Appalachia Kentucky by adding specific questions on Kentucky's Behavioral Risk Factor Surveillance Survey. Results from this survey are currently being analyzed. In 2006, Mid-South funded a second researcher, Dr. Erin Kobetz (University of Miami, Sylvester Comprehensive Cancer Center) to examine the cultural variability in the cancer information needs of Hispanic CIS callers.

National Cancer Institute and CIS staff continue to examine the cancer information-seeking behaviors²²⁻²⁴ and awareness of the CIS through analysis of data from the NCI's HINTS.²⁵ It is anticipated that results from these descriptive studies will contribute to further the understanding of cancer information-seeking behaviors and the needs of the public at all points along the cancer care continuum.

IMPLICATIONS FOR READERS

The CIS Research Program 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. Over the past 2 years, progress has been made in stimulating collaborative research that addresses these four research areas. Results from these studies and new studies developed in the next few years will help develop a new generation of CIS programs and services. With the three components of the CIS Program—the Information Service, the Partnership Program, and the Research Program—the potential for integrating findings and lessons learned from these investigations into the CIS Program is great. In addition, each of these program areas has large professional networks of health care providers, educators, social marketing professionals, and public health professionals to which research findings can be disseminated.

The CIS offers researchers the ability to test health communication interventions within a premiere cancer communication system. Very few national cancer information and education programs have the commitment and resources to advance the science of cancer communication and education. Even fewer programs offer researchers, community-based organizations, public health practitioners, and health care providers the opportunity to collaborate in research ventures that have the potential to affect the public on such a large-scale and truly make a difference in the lives of those with and those affected by cancer. The CIS Research Program is a unique enterprise that bridges the worlds of service and research and continues to stimulate, develop, implement, and support collaborative cancer communication and education research.

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TABLE 1

The Cancer Information Service Research Agenda (2005–2009)

Research Area	Illustrative Research Questions
<p>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 behavioral outcomes 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. Health communication interventions that could be implemented within the CIS program are of particular interest.</p>	<p>Are new public health informatics approaches (eg, computer-generated message tailoring, multimedia interventions, e-health interventions?) to delivering cancer-related information effective?</p> <p>What types of interventions are effective in aiding/improving cancer screening and treatment decision-making?</p> <p>Who are the most effective messengers and what are the most effective channels in delivering cancer-related information and interventions for different populations?</p> <p>What are the most effective ways to deliver cancer-related education and information to individuals and communities with limited health literacy?</p>
<p>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 discovers 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.</p>	<p>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?</p> <p>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 types of interventions are effective at increasing providers' awareness of, referral to, and use of cancer education and information resources such as the CIS?</p> <p>How do individuals who receive information or education from the CIS or other cancer-related resources evaluate, assimilate, and use the information they receive?</p>
<p>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.</p>	<p>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?</p>
<p>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 programs: cancer information seekers. In addition, descriptive studies may help the understanding of 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. In addition, a synthesis of study findings focused on cancer-related information seeking is warranted.</p>	<p>Who are cancer information seekers? Who are nonseekers? What are their demographic and psychosocial characteristics?</p> <p>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?</p> <p>What are the preferred channels for seeking information for different populations across time and across the cancer continuum? What messengers and sources of information are perceived as credible among different populations? How is the Internet used for seeking cancer-related information?</p> <p>How can individuals' information seeking behaviors across time and the cancer continuum best be measured/documented?</p>