

The NCI's Cancer Information Service's Research Continuum Framework: Integrating Research into Cancer Education Practice (1999-2004)

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Abstract—Between 1999 and 2004, the National Cancer Institute's (NCI) Cancer Information Service's (CIS) Research Initiative supported over 50 research projects representing a broad range of activities from research capacity building, development, implementation to diffusion and dissemination. These research activities are represented in the CIS Research Continuum Framework which the authors describe through a number of short case studies. Based on the experiences and successes of the CIS, other professionals working in the cancer field might consider establishing collaborative relationships across the research continuum and participating in research that has relevancy to advances in cancer education. *J Cancer Educ.* 2007; 22(Suppl.):S41-S48.

Ideally, advancements and innovations in cancer education evolve from research-tested interventions. And program relevant research is more likely to be successful when it is developed with the collaboration and participation of cancer education professionals who understand the realities of "real world" settings.¹ The integration of research within a service environment relies on the mutual goal to ultimately improve best practices and requires the recognition of the challenges of research in "real world" settings as well as the cultural differences between the worlds of research and service.

The goal of the National Cancer Institute's (NCI) Cancer Information Service (CIS) is to educate the public about cancer prevention, risk, symptoms, diagnosis, treatment, and quality of life by interpreting and explaining research findings in a clear and understandable manner, and providing personalized responses to specific questions about cancer.² Researchers are focused on conducting high quality research within their area of expertise that will result in meaningful improvements in knowledge and practice. There are obvious synergies between these viewpoints, but also challenges. For the CIS program, which is serving people who have critical health needs in times of intense stress, research protocols

must be carefully planned and executed in order to limit any negative impact on the public's need for cancer information and education. The CIS experience has shown that these research collaborations can be quite successful, particularly when the research is based on a number of key characteristics, such as: organizational value of research and its benefit to service delivery, proactive planning to address both research and service goals, ability to make adjustments based on the needs of the public being asked to participate, consistency of research protocols with current practices, defining and structuring roles and relationships in the research partnerships, and recognizing the impact of research at all levels of the organization.^{3,4} Moreover, these research partnerships provide great benefits to both parties, including broader access to populations, increased utilization of resources and content expertise, and evidence for new, innovative, and effective service programs.

The NCI's CIS program has a long history of collaborating in research. In 1987, the NCI's Division of Cancer Prevention and Control funded five Cancer^{5,6} Communications Systems research studies that focused on the CIS.⁷⁻¹¹ Building upon this early success, the CIS Research Consortium (CISRC) was established in 1993 with funding from the NCI.⁴ The CISRC became the first nationwide research program based on a true partnership and collaboration with the CIS service program. Cancer Information Service leadership from the national and regional offices was intimately involved in the CISRC's planning, decision-making, and study implementation and reporting. Most importantly, the goal of the research was both to extend scientific understanding of how to impact health behaviors to reduce cancer risk and to test new innovations and interventions that truly had the potential to improve service within the CIS. The CISRC has subsequently conducted

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six randomized trials involving over 12,000 callers to the NCI's CIS.^{7,9,12-14}

The collaborations cited above provided the pioneering groundwork which enabled the CIS to launch a much broader research initiative. From 1994-2004, the CIS Research Initiative encompassed 55 regional research projects with over 20 investigators supported by an infrastructure to review, maintain, and monitor these efforts at both a national and regional level. The CIS Research Initiative covered a wide spectrum of projects focused on relevant topics (eg, smoking cessation, cancer risk, message testing, the digital divide, cancer screening, cancer clinical trials, and health literacy) and populations (eg, general, medically underserved, cancer patients, and providers). The role of the CIS in these projects varied considerably. The most common role was the delivery of the research intervention (39%) in conjunction with usual service (see Figure 1).¹⁵⁻¹⁹ Another 39% of the research projects focused on developmental activities such as providing background data and materials for proposal development, developing focus group research,^{20,21} developing interventions implemented in underserved populations through the CIS Partnership Program,²²⁻²⁴ and recruiting subjects and implementing surveys for descriptive studies.^{25,26} Additionally, 15% of the projects involved the CIS in developing and delivering training programs to research staff on a variety of topics, such as clinical trials for providers.²⁷⁻²⁹ Although a less common (< 10%) activity, the CIS also codeveloped and assisted in testing media campaigns.³⁰

The development of the CIS Research Initiative was strategic and well planned. Recognizing the programmatic benefits of the research collaboration with the CISRC, the CIS national program office took a proactive stance to develop a comprehensive Research Initiative. In the early stages (2001) of this increasingly prominent role of health communications and behavioral science research within the CIS, the CIS national office at NCI invited a number of CIS regional management staff to participate in the development of a CIS Research Strategic Plan. The two main goals of this plan were to encourage new research opportunities and build additional research capacity and infrastructure within the CIS regional program. The specific objectives of this plan were to develop partnerships with researchers, to implement a research agenda of impor-

tance to the CIS program and the cancer control community at large, to translate research findings into new or enhanced service programs within the CIS, and ultimately, to improve CIS service using theory-based cancer education and communication interventions that have been tested in research. Based on this plan, a variety of tools were created, strategies were implemented such as staff continuing education and research skill building, policies and procedures were established, and research staff became integrated into the regional CIS program. The underlying premise was that these research efforts would ensure that the CIS was a full partner in the research endeavor and that integrating research activities/projects within service environments would advance both science and practice. From the beginning, this dual approach of improving science and service was paramount to this research initiative.

In recognition of this expanded capacity for research within the CIS, the authors of this report developed a framework to guide and describe the specific ways in which CIS regional offices support and participate in CIS-based research initiatives. The Research Continuum Framework (described later) identifies the types of participation and support that can be provided across the research continuum, from development to dissemination. It can also provide other organizations with a way to conceptualize the range of opportunities in which to participate in research. Thus, the role of the service organization can vary in scope and complexity depending on the specific research project. However, regardless of the level of participation, the goal is to promote collaboration in research that will benefit the service and utilize the experience and resources of the service organization.

CIS RESEARCH CONTINUUM FRAMEWORK

The CIS Research Continuum Framework (see Figure 2) addresses five key stages of the research process: capacity building, project development, implementation, diffusion, and dissemination. Capacity building activities can focus on staff and resources within the organization, as well as collaborating investigators in other organizations. These activities include establishing research partnerships, education and skill building in research, and for collaborating investigators improving their understanding of the service organization and its mission, culture, and program strengths. In the case of the CIS, capacity-building also includes introducing these researchers to NCI and raising awareness concerning CIS resources for research and CIS experience with reaching underserved populations. Project development activities include participation in formative research to develop and refine concepts for research, and providing program or administrative data to support this effort. In contrast to the above, implementation focuses on the actual implementation of a research project, which in the case of the CIS, can include developing protocols and interventions, recruiting research participants, implementing the interventions and quality control, data collection, and training CIS and research staff for program implementation.

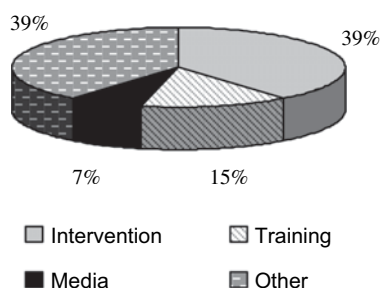


FIGURE 1. CIS Roles in Research # (N = 55 studies).

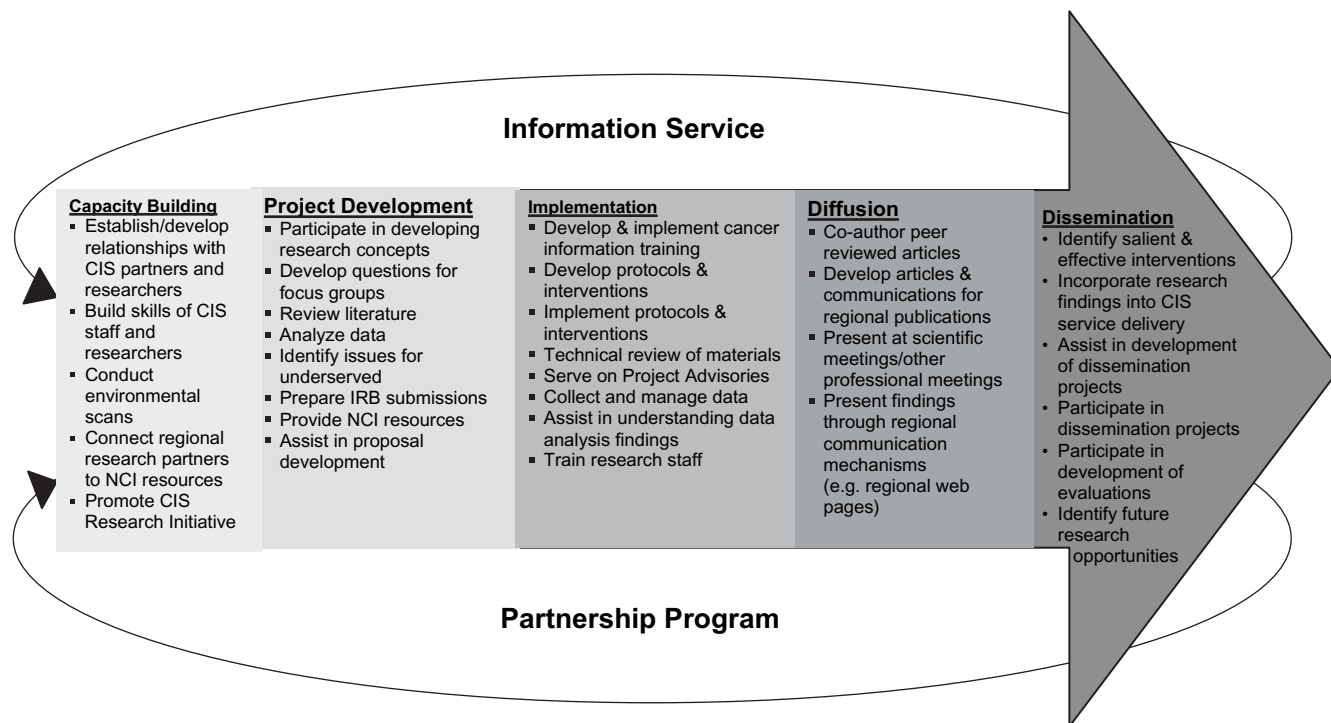


FIGURE 2. CIS Research Continuum Framework.

Finally, at the completion of the research project, two stages of the continuum (diffusion and dissemination) address the short- and long-term implications of the research findings. This continuum mirrors the NCI’s definitions of diffusion and dissemination, with the former representing the more passive sharing of research findings and the latter representing the deliberate and strategic implementation of research interventions and findings. The CIS has been intimately involved with both of these activities by coauthoring numerous peer-reviewed publications and presentations³¹ and integrating research findings and interventions into standard CIS practice.

To exemplify the various roles and to illustrate the range of the Research Continuum Framework, a series of case studies are presented. These case studies include the development of grant-writing workshops to build capacity for research, formative evaluation to support project development, implementation of a randomized trial, and dissemination of tested and effective interventions into service. As noted above, these exemplars are intended to illustrate the range of potential collaborations in research that are available to service organizations, as exemplified by the CIS, as well as the lessons learned that can be utilized and adapted by other cancer education programs seeking to integrate research into service.

Capacity Building for Research - The Coastal CIS’s Grant-Writing Workshops

In order to actively support NCI’s priorities in the area of cancer control and health communications research, the

CIS regional offices often work with organizations and individuals in the community to build their capacity to effectively pursue NCI and NIH funding. To this end, the CIS facilitated several grant-writing workshops with a variety of professionals (including community cancer control planners and early career academics) around the country. These workshops have taken many forms. In some cases, the CIS has worked to train minority researchers and build skills on how to achieve funding from a variety of NCI grants, while in other cases the CIS has taken an active role in linking community-based partners with research investigators to address common areas of interest, and to create opportunities for participatory research. In the end, each grant-writing workshop has focused on offering tools, providing training and building skills with an aim toward securing NCI funding and building capacity to conduct innovative cancer control research.

One example of these grant-writing workshops occurred in March 2002 and was developed and implemented by the Coastal Regional CIS office, located at the University of Miami’s Miller School of Medicine. The Coastal CIS worked collaboratively with their long-standing partner, the University of Puerto Rico’s Cancer Center (PRCC), to coordinate this 2-day grant-writing workshop designed to provide a detailed, hands-on approach to writing successful grants. The overall objective of the workshop was straightforward—provide those early career PhD level scientists on the island who are actively seeking funding with both the knowledge and the skills to effectively secure NCI funding. Although this audience already had some experience in research,

the limitations of the research resources in Puerto Rico and limited success in funding suggested that this was a strategic opportunity.

In bringing together a group of researchers in Puerto Rico to assess their needs, the Coastal CIS found that some researchers had experience in writing grant applications, but were not yet as successful as they would like to be in securing funding for their research. Some, who had attended basic National Institutes of Health (NIH)-type grant-writing training, felt they needed more in-depth information to participate more fully in the NCI research process and to take fuller advantage of NCI funding opportunities. The group wished to have specific instruction and training in order to improve the quality of their applications as well as to improve their ability to conduct high quality research with the Hispanic population in Puerto Rico.

To meet this need, the NCI Division of Cancer Control and Population Science's Behavioral Research Program was asked to join the initiative and worked closely with the Coastal CIS and the PRCC to tailor the workshop to meet the specific needs of the researchers on the island. The eligibility criteria were specific - all PhD level attendees had to have submitted a grant proposal in the last year or were planning to submit within the next year. Additionally, they were required to submit an abstract of their submission in advance to the NCI Program Directors for individual discussion and review at the workshop.

The 2-day conference provided skill-building activities, a comprehensive overview of NCI and research opportunities, program announcements, and major initiatives at NCI. Twenty-one members of the research community in Puerto Rico participated. In post-conference evaluations, participants reported increased knowledge and understanding of the NCI grant process, and relationships between NCI Program Directors and participants were enhanced. In addition, two grant proposals were submitted to appropriate funding agencies.

The Coastal CIS worked with the UPRCC to conduct this grant-writing workshop as part of a larger comprehensive strategy to expand the research capabilities and infrastructure in Puerto Rico. Identifying and training independent investigators to conduct basic, clinical, and epidemiological research projects aimed at understanding the burden of cancer in Puerto Ricans was a critical first step in this strategy. Since the time of the grant-writing workshop in 2002, the CIS and the UPRCC along with several other key partners (Intercultural Cancer Council, American Cancer Society and the Center for Disease Control (CDC)) have successfully conducted three large-scale comprehensive cancer control conferences bringing together leaders from Puerto Rico and experts and national investigators in Hispanic/Latino populations to discuss collaborative research efforts. The early grant-writing workshop served as a catalyst for these larger, national efforts and successfully identified key researchers that have gone on to play a critical role in the research agenda in Puerto Rico today.

Concept Development - California CIS's Breast Cancer Risk Notification Project

Another important role played by the CIS is to support researchers in the development of research concepts and proposals. The CIS, through its variety of services to the public, has access to NCI resources and a broad-based understanding of cancer issues. The Breast Cancer Risk Notification Project, conducted in 2002 with the California Regional CIS office,¹⁶ provides an excellent case study of the CIS involvement in the developmental phase of a research project. The project included two parts: 1) developing counseling protocols to notify the sisters of women who had been diagnosed with breast cancer about their own increased risk of breast cancer, and 2) translating risk notification and counseling components into an ongoing service setting. The major goal of the study was to help women make a more accurate estimate of their breast cancer risk, get breast screening at appropriate intervals, and consider breast cancer prevention options. The relationship between researchers and CIS staff was facilitated by the fact that both groups were located at the Northern California Cancer Center. Frequent communications, meetings, and interactive work sessions were held early on in developing the translational aspect of the study.

Cancer Information Service involvement in the research project development was essential in several areas: training development, intervention script development, and logistics for data collection and intervention implementation with CIS Information Specialists. Both the initial staff training and the counseling intervention had to be shortened considerably to fit within the practical considerations of the ongoing service setting. The length of the counseling intervention for the first part of the study was over an hour. Cancer Information Service staff and researchers working together were able to shorten the research data collection and protocol implementation to a total of 20 minutes because CIS Information Specialists are already well trained in breast cancer.

To integrate research and service data collection, a link was created between data items collected by the CIS Contact Record Form and the specialized research data collection software. The intervention protocol was integrated into the data collection software, so that appropriate scripts would pop up based on the responses by callers to the research questions, similar to a computer-aided telephone interview system. Cancer Information Service information specialists were thus able to easily implement the research protocol without having to recall specific skip patterns or refer to lengthy reference materials.

Cancer Information Service involvement with researchers in developing the training, intervention, and logistics for data collection was essential to the success of this project. It would have been impossible to successfully translate the risk notification study to the CIS service setting without involving CIS staff early in the development process.

Implementation - The CIS Atlantic Region's Facilitating Breast Cancer Risk-Assessment Study

The CIS has participated in a number of descriptive and randomized studies through the recruitment of subjects and/or delivery of the study interventions. In these projects, the CIS plays an integral role in the research while maintaining the balance of providing high quality service. One example of this level of participation is the Facilitating Breast Cancer Risk Assessment study implemented by the Atlantic Region CIS under the scientific leadership of Suzanne Miller, PhD, Director of Behavioral Medicine, Fox Chase Cancer Center. This randomized trial, funded by the Department of Defense, relied on the collaboration of the research team and regional CIS from the onset; working together to design and implement the study intervention and evaluate the research findings.

Few services exist to help women make informed decisions about whether or not they are appropriate candidates for genetic risk-assessment programs. During the development of this research project, there was interest in exploring whether the CIS could serve as a first step in the process. Callers requesting information about breast/ovarian cancer risk, risk-assessment services, and genetic testing were randomized to either: 1) standard care, or 2) an educational intervention. The standard care group received usual CIS service that focuses on basic information on genetics and cancer risks, as well as referral to approved high-risk programs. The second group received an enhanced, theory-guided intervention that was designed to increase callers' understanding of: 1) the kinds of information that are required to determine inherited risk; 2) their own personal family history of cancer; and 3) the benefits and limitations of genetic testing.¹⁵

The role of the CIS was three-fold: 1) to assist in the development of the intervention and staff training; 2) to implement the study; and 3) to participate in the analyses and publication of the study findings. The CIS regional staff worked closely with the research team to conduct a formative evaluation with genetics counselors to determine the most salient messages and issues to address in the intervention. The intervention was implemented through a computer-assisted telephone interview (CATI) and the CIS staff participated in the beta test and usability testing with the researchers and programmers. Since the topic was quite complex, a training program was needed to provide more in-depth knowledge of genetic implications and testing as well as the study procedures and systems. The trainer at the CIS regional office developed the training program in collaboration with the research team. This extensive project development phase was critical to the overall success of the intervention.

Once the study was ready to launch, the CIS Information Specialists were trained to identify eligible women and obtain informed consent at the end of usual service. Information Specialists then completed the intervention, which took from 20-40 minutes depending on the questions and

concerns of the caller. The study required almost 2 years for accrual since inquiries to the CIS regarding genetic risk are infrequent. At the conclusion of the study, the CIS staff played an integral role in the review of the analyses and publication preparation.¹⁵

From a service perspective, the research had value to our staff and callers who often were unclear about how to address such a challenging issue. However, the long duration of the study and the complexity of the intervention protocol presented unique management issues. Even with these challenges, the CIS regional staff was committed to the success of the project because of their involvement in the development of the project and the collaborative relationship that was established with the investigators. Moreover, the CIS regional staff believed that the research had benefits to callers and had the potential to improve service if the time it took to conduct the assessment and intervention were reduced.

Diffusion of Research Findings

Diffusion is the passive process by which a growing body of information about an intervention, product, or technology is initially absorbed and acted upon by a small body of highly motivated recipients who value the rewards of finding the information and for whom the search costs of finding the information are relatively low.^{32,33}

The CIS has been successful in the diffusion of study findings through both peer-reviewed publications and presentations. Over half of the studies previously mentioned (n=28) have had results that were published in professional journals with a total of 43 publications in all. Many of the studies have been presented at professional meetings, such as the American Public Health Association's Annual Meeting, with the CIS staff included in the authorship.

Dissemination—The Development of the CIS Smoking Cessation Service

According to the NCI, dissemination is different from diffusion. Dissemination is a process through which target groups are made aware of, receive, accept, and use information and other interventions.³² The dissemination process fosters the implementation of tested approaches through the identification of and assistance in overcoming barriers to the application of new knowledge obtained from a disseminated message.^{33,34}

Dissemination of tested interventions is extremely challenging and difficult to actualize even in ideal environments. The CIS experience highlights both the rewards and challenges in the systematic dissemination of research-tested interventions. Through the NCI's Dissemination Grant mechanism, the CISRC-tailored fruit and vegetable intervention was adapted and tested as part of routine service.³⁵ Although the results were promising, the complexity of operationalizing the tailored print materials as part of ongoing practice has proven to be challenging.

As in other evidence-based approaches, adaptation is often required to transform a tested intervention for the field. The CIS' current smoking cessation services are a prime example of this adaptation process and reflect the experience of the CISRC Multiple Tailored Messages for Smoking Cessation Study (1999-2003) and the best practices in telephone-based smoking cessation counseling.³⁶ In 1999, when the CISRC Multiple Tailored Messages for Smoking Cessation Study was initiated, there was no standardized smoking cessation protocol, although CIS Information Specialists were trained in current smoking cessation strategies and provided NCI resources and self-help guides to callers interested in quitting. A standardized "control" protocol was required for the study. The research team and CIS management staff worked together to create a standardized approach to smoking cessation counseling, which included initial needs assessment of the caller (eg, their stage of readiness, previous attempts), standardized messages and goals of the encounter, and detailed data collection. In addition, to ensure that the smoking cessation inquiries were handled by the four regional CIS offices who were participating in the study, the telecommunications system was reprogrammed to triage all smoking calls to these regional CIS call centers. The tailored print intervention was successful in improving smoking cessation rates at 12 months.¹³ The standardized control intervention (which was based on current evidence in telephone-based smoking cessation counseling) had a modest quit rate of 15% at 12 months. Although the tailored approach was superior, the standardized control intervention was feasible to integrate into routine services and the establishment of the four smoking cessation call centers for the research study served as the structure for a new specialized service.³⁷ As new proactive approaches to telephone-based counseling were being evaluated and shown to be successful, the CIS program enhanced the smoking cessation services² and integrated these new evidence-based approaches supporting the iterative and ongoing nature of dissemination.

DISCUSSION

Over a 5-year period, the CIS Research Initiative expanded to include 55 regional research projects with over 20 investigators exceeding the expectations of the initiative's goal to increase research participation within the CIS program. The success of this initiative is based on the exceptional achievement of the CIS Research Consortium, the establishment of a research strategic plan, organizational infrastructure to manage research, and a commitment to support and participate in research from development to dissemination.

The case studies presented in this article represent the various phases of research, providing a wide range of participatory roles. There are multiple ways an organization can engage in research to position the program as a resource to researchers (grant-writing workshops, formative evaluation) and extends the program's ability to be innovative

(interventions to improve informed decision-making about genetic risk assessment). From a research perspective, this partnership can enhance the applicability of the intervention in the "real world." The CIS experience has shown that these research collaborations have increased the experience of both researchers and CIS staff as well as fostered stronger relationships with the academic and research organizations that implement the regional CIS program.

The CIS experience with the dissemination of research interventions underscores the many challenges of transforming research interventions into practice. It has had some success in the dissemination process, but has also found that there are many practical barriers that limit the application of these interventions into practice. In response to these challenges, a group of CIS research and program staff has been established to review completed CIS research projects and determine the appropriateness and feasibility of dissemination. Future research interventions will be required to address dissemination issues up front prior to the initiation of the study.

One of the interesting consequences of the development of the CIS Research Initiative is the profound change in perspectives and interest in program-relevant research among CIS staff. No longer is research something outside the program, but rather research is now integral to the program's success. This enhanced value of research has become one of the foundational elements of the current CIS Research Agenda discussed by Squiers.³⁸ It has become clear that a CIS Research Agenda that addressed the emerging research questions in the field of health communications coupled with the program goals of the CIS was necessary to ensure a more focused research portfolio. In addition, research interventions are now designed with dissemination in mind—with the goal to more easily implement research-tested interventions into ongoing service.

IMPLICATIONS FOR READERS

If innovation and improvement of cancer education services is a goal, research within the service program is an important initiative to undertake. Cancer education organizations can develop relationships with researchers and implement research that is relevant and feasible. Service organizations bring an abundance of knowledge about the issues and create access to populations and resources. Likewise, researchers bring innovative ideas, resources, and interventions to improve services. However, both parties need to be willing to understand each other's culture and mission and share the commitment required for success. The rewards can be substantial by improving service and creating more value among sponsoring organizations, while expanding the researchers capacity to conduct research.

The CIS experience can serve as a guide for other cancer education service programs interested in participating in research. Perhaps one of the most critical first steps is to identify researchers who are committed to a collaborative approach and interested in research that has application in

the field. It is also critical to build an organizational infrastructure to manage the research projects, ensure quality, and foster a research agenda that is conducive to the service program.

Ultimately, the goal is to actively disseminate these research findings into practice. In fact, closing the gap from development to delivery is critical from a funding agency perspective.³⁹ With limited resources, it is even more imperative to adapt evidence-based approaches and interventions. In addition, cancer educators can develop research partnerships to design interventions that have relevance to their mission and constituencies. Building research into cancer education services is important to long-term innovation and improvements in service. The CIS experience is a model for other programs highlighting the feasibility and short- and long-term benefits to service and research.

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