

# The International Cancer Information Service: A Worldwide Resource

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**Abstract**—The need for accurate and relevant cancer information continues to grow worldwide. While healthcare professionals are the preferred source of cancer information, their time is limited, and patients are often not sure what to ask and their questions do not always come to mind in the physician's office. In its 30-year history, the National Cancer Institute's (NCI's) Cancer Information Service (CIS) has shown that it can increase users' confidence in their ability to seek more information, understand the causes and risk factors for cancer, and participate in decisions about their treatment. In 1996 the International Cancer Information Service Group (ICISG) was formed to facilitate the development of CIS programs throughout the world. A network of nearly 50 cancer organizations from 30 countries, the ICISG strives to provide its member organizations with standards and resources to ensure that the cancer information is of high quality, credible, and up-to-date and that it is delivered in a personal manner that complements and supports the patient/physician relationship. The ICISG offers worldwide resources that can augment the healthcare professionals' offering of information and support to cancer patients and their families. *J Cancer Educ.* 2007; 22(Suppl.):S61-S69.

Throughout the world, there is growing interest in people taking more responsibility and involvement in their own health and having information that will enable them to understand how they can maintain a healthy lifestyle, manage disease, and achieve quality of life during illness. People with chronic illnesses, especially those with cancer, are participating in programs that encourage self-care. A recent survey, carried out in 10 European Union member states, involving perceptions of health care, identified the need for "accurate, relevant and comprehensive information for patients and their caregivers to help them make informed decisions about treatment."<sup>1</sup>

This need for accurate, relevant, and comprehensive information for patients and their caregivers is especially compelling for cancer, not only in the United States but also worldwide. For example, while extraordinary progress has been made in many parts of the world in preventing

and treating cancer, the worldwide statistics on cancer remain staggering. Each year, approximately 11 million people are diagnosed with cancer and seven million die of it—cancer causes 12.5% of deaths worldwide. By 2020, more than 16 million new cases and 10 million deaths are expected. There are more than 24.6 million cancer survivors worldwide who have been diagnosed within the previous 5 years.<sup>2</sup> Thus the information needs about the disease continue to grow as the number of cases and survivors increase globally.

Efforts to address this need for cancer information, whether conducted locally, regionally, nationally, or internationally, must recognize the specific needs for such information by cancer patients and survivors. Among newly diagnosed cancer patients, the most pressing is the need for information about the cancer diagnosis, available treatment options, potential treatment side effects, and long-term prognosis.<sup>3-7</sup> During treatment, these information needs often cluster around managing the treatment and its side effects at the moment.<sup>8,9</sup> In contrast, when patients complete their primary treatment for cancer, other psychosocial concerns will often emerge, including perceptions of uncertainty and abandonment, fear of recurrence, and anxiety, distress, and depression.<sup>10-12</sup> For many patients post-treatment, regaining a sense of control through behavioral and lifestyle changes that can promote health and well-being emerge as a central concern, while

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for others, facing the pre-eminent existential crisis of their mortality takes center stage.<sup>13-16</sup>

Unfortunately, many cancer patients and survivors, as well as their family and friends, often do not know where to go for credible information, especially at the time of diagnosis. Healthcare professionals are the preferred source of cancer information but their time is limited and a patient's questions are not always asked in the physician's office.<sup>17,18</sup> Other common sources of information include family and friends, books, the media, and the Internet. However, the quality of information from these sources varies and they are not always reliable or up-to-date.

It is precisely at this juncture where organizations dedicated to providing accurate and comprehensive information about cancer can help respond to this global need for cancer information. In the United States, as described elsewhere in this issue of the *Journal of Cancer Education*, the National Cancer Institute's (NCI's) Cancer Information Service (CIS) is responding to this need nationwide.<sup>19</sup> The success of this program has subsequently encouraged the development of similar CIS programs in many other countries, as evidenced by the formation of the International Cancer Information Service Group (ICISG) in 1996. In the remainder of this article, we provide a brief history of the NCI's CIS, and describe how this program has been adapted and continues to evolve internationally.

## CREATION AND REPLICATION OF THE CIS

As noted above, the first CIS was established in the United States by the NCI.<sup>20</sup> Although primarily telephone-based, the CIS also offers information services via the Internet, e-mail, instant messages, mailings of print materials, and community outreach through its Partnership Program.<sup>19</sup> The early architects of the CIS created a program that could present complex and diverse information accurately and compassionately to a wide variety of callers. This CIS, which took its first call in 1976 and is now in its third decade, has answered over 10 million calls from the public, patients, and healthcare providers about cancer causes, clinical trials, new treatments, and smoking cessation.<sup>19</sup>

Using the NCI's CIS as a model, a number of other similar programs have been created worldwide. In 1982, the Director of Press and Public Affairs at the German Cancer Research Center heard a presentation about the CIS and was determined to start a European initiative to develop a national telephone service based on the U.S. model. With the help of procedures, protocols, staff training materials, resources, and other information from the NCI's CIS, Krebsinformationdienst was founded in 1986, under the auspices of the German government.

In 1985, Cancerbackup started a CIS in the UK. Cancerbackup is a charity founded by Dr. Vicky Clement-Jones, an ovarian cancer patient. Soon after, The Cancer Council Victoria in Australia launched its CIS in 1990 and the Canadian Cancer Society established its CIS Helpline in 1996.

The commitment to helping cancer organizations establish a CIS has continued beyond the work started with the U.S. NCI's CIS. From the early programs, new CIS services have been established in Italy, Austria, Switzerland, Turkey, New Zealand, Singapore, South Korea, Japan, France, and expanded across Australia.

In 1996, the pioneer CIS programs participated in the International Union Against Cancer's (UICC) First World Conference for Cancer Organizations in Melbourne, Australia. A 4-day workshop, "Setting Up and Maintaining a Cancer Information Service," was planned and delivered by CIS leaders from Australia, England, Germany, and the United States. Providing practical advice and presenting different models of both cancer information services and disseminating information, the workshop attracted participants from 19 countries—some of whom already had developed services and many of whom were just starting their programs.

## INCEPTION OF THE INTERNATIONAL CANCER INFORMATION SERVICE GROUP

At the end of the 1996 UICC workshop, the participants agreed that an ICISG, an independent voluntary international network composed of CISes, be formed under the auspices of the UICC. Its mission was to help organizations start and operate a CIS that would provide high-quality cancer information and resources in all aspects of cancer.

The ICISG members agreed to work together toward the development of common elements for a program: a user profile database, quality standards, evaluation measures, and joint publications as well as the sharing of experiences, tools, expertise, and ideas. During the next 2 years, the ICISG created minimum standards for quality as well as operating guidelines for developing a CIS service.

At the UICC's Second World Conference for Cancer Organizations in Atlanta in 1999, members approved a governance structure for the ICISG, which includes a president, vice president, and 12-member board of directors. At the Third Global Conference, held in Brighton, England in 2001, the ICISG adopted minimum standards for operating a CIS.

Today, the ICISG is a network of nearly 50 cancer information and support service programs from 30 countries (Table 1). Its goals are to:

- promote collaboration between CIS programs throughout the world
- share information and tools for management, evaluation, training, and quality
- act as a forum for exchange and discussion
- develop and update service minimum standards
- increase awareness of CIS
- support the development of new services throughout the world.

TABLE 1. Members of the ICISG

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|  |
|--|
| Australia  |
| The Cancer Council Victoria                                  |
| The Cancer Council South Australia                           |
| The Cancer Council of Western Australia                      |
| The Cancer Council New South Wales                           |
| Bangladesh   |
| Khwaja Yunus Ali Medical College & Hospital                  |
| Brazil   |
| Associação Nacional de Informação e Apoio sobre Câncer de    |
| Mama of Sao Paulo  |
| Canada   |
| Canadian Cancer Society's Cancer Information Service         |
| Commonwealth of Independent States                           |
| Moscow Cancer Relief Society                                 |
| Czech Republic   |
| League Against Cancer, Prague                                |
| Denmark  |
| Kraeftens Bekaempelse Danish Cancer Society                  |
| Finland  |
| Cancer Society of Finland                                    |
| France   |
| Ligue nationale contre le cancer                             |
| Institut national du cancer                                  |
| Germany  |
| German Cancer Research Center (Deutsches                     |
| Krebsforschungszentrum)                                      |
| Greece   |
| Hellenic Cancer Society                                      |
| Hong Kong  |
| Hong Kong Cancer Fund  |
| Hungary  |
| Hungarian League Against Cancer                              |
| India  |
| Agra Cancer Society  |
| Cancer Aid and Research Foundation, Mumbai                   |
| Gujarat Cancer & Research Foundation, Ahmedabad              |
| South Asian Institute of Oncology and Cancer Research,       |
| Kolkutta   |
| Tata Memorial Hospital, Mumbai                               |
| VCare Foundation, Mumbai                                     |
| Ireland  |
| Irish Cancer Society   |
| Israel   |
| Israel Cancer Association                                    |
| Italy  |
| Associazione Italian Malti di Cancro Parenti e Amici (AIMaC) |
| Kenya  |
| Nairobi Cancer Registry                                      |
| Malaysia   |
| Hospital Kuala Lumpur  |
| Netherlands  |
| Dutch Cancer Society   |
| New Zealand  |
| Cancer Society Of New Zealand, Ltd.                          |
| Cancer Society of New Zealand, Canterbury West Coast         |
| Division   |
| Cancer Society of New Zealand, Wellington Division           |
| Cancer Information Service, Auckland Cancer Society          |

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(Continued)

TABLE 1. Continued

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| Nigeria  |
| The Bloom Cancer Care & Support Center, Lagos                |
| Radiotherapy and Oncology Center, Kudune State               |
| Society of Clinical Oncology and Cancer Research, Ibadan     |
| Norway   |
| Norwegian Cancer Society                                     |
| Serbia   |
| Ecumenical Humanitarian Organization "Rakinfo"               |
| Singapore  |
| Cancer Education and Information Service, National           |
| Cancer Centre  |
| Slovakia   |
| League Against Cancer in Slovakia                            |
| South Africa   |
| Cancer Association of South Africa                           |
| South Korea  |
| National Cancer Center Research Institute                    |
| Sweden   |
| Cancer Information Service, Radiumhemmet Karolinska Hospital |
| Swedish Cancer Society                                       |
| Switzerland  |
| Swiss Cancer League Krebstelefon                             |
| United Kingdom   |
| Macmillan Cancer Support                                     |
| Cancerbackup   |
| Cancer Research UK   |
| United States of America                                     |
| American Cancer Society                                      |
| Cancer Information Service, National Cancer Institute        |

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*Partnering with the UICC*

In 2004, the ICISG and the UICC entered into a formal partnership in an effort to strengthen the dissemination of cancer information around the world. With a shared commitment to providing cancer information and support services, ICISG and UICC signed a Memorandum of Understanding to work together on several projects to be promoted and shared among the memberships of each organization.

At the 2006 UICC World Cancer Congress held in Washington, DC, the ICISG and UICC held a 1-day, Pre-Congress Workshop on How to Start a CIS. The Pre-Congress Workshop was attended by 38 participants from 21 countries. Also at the Congress, the ICISG and UICC introduced a new, free online resource for cancer communications: a web-based CIS Tool Box. Designed to assist cancer organizations in setting up or improving a CIS, the CIS Tool Box was created based on the experience and materials of cancer organizations that are presently operating CIS around the world. The CIS Tool Box has information on assessing readiness for starting a CIS telephone service, resources on how to start and manage a telephone service, recruiting and training of staff, samples of materials from established organizations, practical lessons learned by members of the ICISG, and information about offering other services, such as e-mail (to view the CIS Tool Box, go to [www.icisg.org](http://www.icisg.org) or [www.uicc.org](http://www.uicc.org)).

The ICISG and UICC are planning to hold a Pre-Congress Workshop on How to Start a CIS at the World Congress to be held in Geneva in 2008.

### *Core Elements and Minimum Standards for a CIS*

There are variations in the structure and services offered by ICISG members. Some are involved in primary prevention and general education. Others focus primarily on people affected by a cancer diagnosis. Some services offer smoking cessation or other specialized programs.

Recognizing this variability, the ICISG has identified five core elements that comprise a CIS. A CIS is a program that:

- Offers one-on-one personalized information to the public, patients, family members and friends, and health professionals;
- Is staffed by qualified, trained information specialists;
- Provides accurate, up-to-date cancer information;
- Can provide information through multiple access points (mail, telephone, Internet, or face-to-face);
- Is usually part of an organization that already has some other programs such as public education, patient information materials, or patient services.

Although ICISG recognizes that there are different methods of delivering CIS services, quality criteria (minimum standards) are expected for all channels of delivery. Organizations operating a CIS must be:

- Sensitive to and respect the unique needs, values, and culture of the user;
- Respect the rights of persons to make informed choices in relation to their care;
- Promote and uphold the provision of quality service for all people;
- Provide a confidential and anonymous service;
- Respect and support the patient/doctor/health professional relationship.

Each ICISG member must commit to adhering to or creating similar minimum standards (Table 2) in its first 3 years of membership. Operational guidelines (see [www.icisg.org](http://www.icisg.org)) also ensure quality and consistency between CISs.

### *Profile of Users of the ICISG*

The ICISG experience is that the vast majority of users are women, usually accounting for around 80% of callers. This demographic has changed little since CIS started and varies little throughout the world.<sup>21</sup> Generally, the users' experience of CIS is positive and the topic of inquiries is similar among services.

Based on a 2005 ICISG survey looking at 14 member services,<sup>21</sup> the users of the service are:

- cancer patients - 40% (range 16% to 57%)
- their families and friends - 34% (range, 12% to 45%)
- health professionals - 10% of users (range 2% to 32%).
- between the ages of 35 to 60.

The top five cancer sites most inquired about are breast, colorectal, prostate, lung, and gynecologic, with the top five subjects of inquiry being treatment and side effects, psychological and supportive care, diagnosis and screening, prevention and risk, and referrals to community resources.<sup>21</sup>

### *Impact of the CIS*

Several CIS programs have looked at the satisfaction of their users and how the information has been used by callers. The NCI's CIS found that almost half of callers surveyed had discussed the information that CIS provided with a physician and that the information helped them make a treatment decision.<sup>22</sup> Research by services in Canada, the United States, Australia, and Germany found that the CIS:

- is an effective source of information and education about cancer;
- can help people feel better about their situation and talk to their doctors about their cancer;
- is successful in increasing users' confidence in their ability to seek more information, understand the causes and risk factors for cancer, and participate in decisions about their treatment;
- users are satisfied, feel that their information needs are being met, and derive many benefits for their interaction with a CIS Information Specialist.<sup>23-25</sup>

In an article in this issue, LaPorta<sup>26</sup> describes the results of a recent user satisfaction survey by the NCI's CIS, which included questions about both the telephone service and LiveHelp, an instant messaging service on the NCI website. Not only did these results show high user satisfaction of both channels, but "CIS users felt that their information needs were met and they reported increased knowledge about cancer and tobacco issues, increased confidence in talking to health care providers, understanding the causes of and risk factors for cancer, and (for patients) participating in treatment decisions." At the time of the survey, more than one-quarter of respondents had already discussed the information received from CIS with a health professional and another 43% intended to do so. Cancer Information Services was particularly effective in influencing smokers' behaviors and behavioral intentions. Nearly all smokers reported having quit or cut back, or said they planned to do so.

## **ROLE OF PHYSICIANS IN ICISG SERVICES**

Physicians have been part of the Cancer Information Service since its inception. Some are involved in an expert capacity on an advisory panel to review information and

TABLE 2. International Cancer Information Service Group Minimum Standards

The International Cancer Information Service (ICISG) recognizes that there are different methods of delivering CIS. Quality criteria or minimum standards are expected for all channels of delivery whether by telephone, face-to-face, video/DVD/audio tapes, text messaging, websites, e-mail, chat rooms etc. ICISG members delivering Cancer Information Services will be invited to share their minimum standards or develop a commitment to creating these in the first 3 years of ICISG membership (these will be available on the website - [www.icisg.org](http://www.icisg.org)—as part of the membership details).

Minimum standards for service delivery:

Sensitive to, and respect the unique needs, values, and culture of the service user.

- Service is not compromised because of a person's gender, spiritual values, disability, age, economic, social or health status, or any other ground.
- Service providers adopt a nonjudgmental stance in all encounters with service users.
- Respect for a persons needs includes the recognition of the individual's place in a family and community.

Organizations respect the rights of persons to make informed choices in relation to their care.

- Individuals are entitled to make decisions related to their own welfare based on accurate, evidence-based information from healthcare providers.
- Provision of accurate, evidence-based information from CIS organizations empowers the service user to take her/his own action.
- CIS organizations have a responsibility to inform service users of the information and services that are available to them, service users have the right to accept or reject such information.
- CIS organizations have a responsibility to ensure that the community services to which they refer are professional and credible and within the fiscal means of the service user.
- Illness and/or other factors can compromise a person's capacity for self-determination. Where possible, CIS organizations should offer service users strategies to expand the range of opportunities to maintain maximal self-direction and self-determination.

Organizations promote and uphold the provision of quality service for all people.

- Quality service is delivered by appropriately trained/qualified individuals. Promotion of quality service includes, valuing continuing education of all members of the services as a means of maintaining and increasing knowledge and skills. Continuing education refers to all formal and informal opportunities for education.
- Evaluation of the service and service delivery is important to raise the standards of service and to ensure that such standards are ethically defensible.
- Provision of a quality service includes implementation of appropriate mechanisms to receive, investigate, and respond to complaints about the service.
- Research is necessary for the development of individual CIS organizations and to benefit the ICIS community.
- CIS organizations should have access to the latest evidence-based information regarding all aspects of cancer.
- CIS organizations should resource and formalize a network of medical and allied health professional advisors who are available to provide information or comment on new trends or preliminary research developments when such information is not available elsewhere.

Organizations provide a confidential and anonymous service.

- CIS organizations hold in confidence any information obtained in a professional capacity and use professional judgment in sharing such information.
- CIS organizations respect the user's right to determine who will be provided with their personal information and in what detail. When personal information is required for teaching, research, or quality assurance procedures, care must be taken to protect the person's anonymity and privacy. Consent must always be obtained.
- CIS organizations have a moral obligation to adhere to practices that limit access to personal records (whether written or computerized) to appropriate personnel.
- Where a CIS organization does take steps to breach confidentiality of information shared by a service user, the legal, moral, or ethical reason must be able to be clearly stipulated and justifiable.
- CIS organization members do not give medical advice. Information provided by CIS organization members is general in nature and does not replace consultation with a physician. CIS organization members encourage callers to discuss medical and psychosocial issues with their doctor and/or health professional(s).
- CIS organizations support the client's current doctor/patient/healthcare professional relationship and may, when appropriate, inform a caller of her/his right to seek a second opinion.

Organizations respect and support the patient/doctor/health professional relationship.

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literature. Many CIS programs use clinicians to advise information specialists when they have difficult or controversial questions from callers. Some contribute medical expertise toward the development of resources, publications, and educational programs. Many act as champions and promoters of the CIS within their hospitals and professional groups as well as to the public.

In some CIS programs, such as in Germany and Denmark, physicians are employed as information specialists to answer inquiries. In Australia, a medical oncologist is employed by the CIS 1 day a week as a clinical consultant and is available to help the staff dealing with complex clinical inquiries. The role also facilitates collaboration between the CIS and the clinical facilities.<sup>27</sup>

One important role of physicians is to promote the CIS programs to other professionals working in oncology, making them aware not only of the services offered but also that the services are of a high standard, are evidence-based, and are regularly reviewed and evaluated. Physicians also act to encourage colleagues, including other health professionals to direct and refer patients and their families to the CIS. According to a market study with health care professionals in Canada, the likelihood for health care professionals to refer their patients to the Canadian Cancer Society's CIS depends on criteria that include: the use of trained information specialists with a health background, referral to services in the community, information reviewed by experts, and information on all stages of the cancer journey.<sup>28</sup> Physicians also have an important role in developing and participating in CIS research studies.

#### *Case Study: Australian Physicians and Referrals to CIS*

Physicians are recognized as the preferred source of information for cancer patients. However, they may not have sufficient time and other resources to adequately address all of their patients' information and support needs. A challenge is ensuring that all people who might benefit from CIS are aware of the program's existence and potential benefits.

In an Australian study, 464 cancer patients at their first outpatient consultation were given a promotional leaflet by their oncologist that advertised a cancer helpline.<sup>29</sup> Calls to the helpline made during the 6 weeks following the study period amounted to 4% of patients or family members that received the pamphlet. The authors concluded that a more proactive referral mechanism might be necessary. Importantly, they also recognized that physicians were willing to act as a referral source to CIS.

A subsequent study, investigating more proactive strategies to link people with the CIS at the Cancer Council Victoria in Australia, funded by the National Health and Medical Research Council, is recruiting men with newly diagnosed prostate or colorectal cancer. Men were selected as the study population because they are known to underutilize CIS and other support services. The study aims to determine the acceptability and psychosocial effects of a specialist referral and outcall program. The design is block

randomized, with three referral arms. In the "passive referral" arm, the patient's health care provider informs the patient about the CIS, though it is up to the patient to initiate contact with the service. The other two arms involve health care provider referrals to CIS and either one outcall, 1 week following diagnosis, or four outcalls, 1 week, 6 weeks, 3 months, and 6 months following diagnosis. For the outcalls, cancer nurses staffing the Australian CIS follow a standardized protocol, addressing a range of issues including information about cancer diagnosis, treatments, and side effects, as well as psychological and emotional issues and support services available.

Initial results suggest that patients are very satisfied with the referral process and with CIS contact. Almost all participants in the active referral arms have suggested that the timing of the calls was helpful. Physicians participating in the study also appear satisfied. The referral process did not have an impact upon the time of the consultation. Final results are awaited from this study.

It is hoped that this sort of approach may be an effective means of providing support to people affected by cancer. It may have particular applicability to geographically isolated populations.

## INTERNATIONAL COLLABORATIONS

The ICISG member organizations have collaborated on many programs, from information-sharing to cancer patient forums and cancer control planning.

In addition to providing cancer information over the telephone, by e-mail, in person, or on the Internet, international CIS programs have collaborated to offer support and guidance to other countries. Cancer information services can vary in their depth and breadth of service delivery. Resources vary from country to country and may range from print materials only, to support systems, to fairly sophisticated web-based services.

The ICISG members benefit from sharing information among both seasoned CIS operations and also countries that are just beginning to consider offering their public access to a CIS.

In April 2006, the ICISG presented an overview of cancer patient information needs at Turkey's first cancer patient forum. As a result of this meeting, the Turkish Association for Cancer Research and Control is planning to start a CIS program.

A collaborative educational campaign for cancer patients joins ICISG members from the United States with Italian colleagues to conduct a series of educational workshops on complementary and alternative medicine, clinical trials, and cancer survivorship in Rome, Italy over the course of 3 years. The first workshop was held in 2005.

In cancer control, ICISG members along with the NCI, the American Cancer Society, the U.S. Centers for Disease Control and Prevention, and the UICC are contributing to comprehensive cancer control planning—using integrated, evidence-based, and cost-effective interventions throughout

the cancer continuum (from research to prevention, early detection, treatment, and palliative care). International Cancer Information Service Group members, with their collaborative partners, are working with cancer agencies in Mexico, Brazil, and Peru.

### Evaluation

Evaluation is an essential component of a quality CIS program. Process evaluation can provide insight into service delivery and enhance understanding of the accessibility and quality of a CIS, user satisfaction, and how materials and information are disseminated.

In 2004, the ICISG developed a common 10-question evaluation tool for CIS programs worldwide to use in collecting key data about users of their service. (The evaluation instrument is available at [www.icisg.org](http://www.icisg.org).) By using this common evaluation instrument, CIS programs can:

- create a user profile of their service
- find the common elements among different types of service
- find how users locate the service
- find information gaps and needs
- assess timeliness, adequacy, helpfulness of staff and materials.

The value and impact of CIS programs are similar wherever the service is provided, irrespective of differences in

language or culture. A retrospective study conducted in 2004 comparing user surveys of CIS callers in Germany, the United States, and Canada indicates that users have a high satisfaction level with the CIS<sup>23</sup> (Table 3):

- overall satisfaction with the service ranged from 95% to 97.5%
- information needs were met: 86.4% to 89%
- quality of information provided: 94.7% to 99%.

Similarly, the impact of a call to the CIS was measurable. In the United States, 71% of callers reported their interaction with CIS led to a behavior change; in Canada, 92% of callers reported more understanding and help with coping or decision-making; in Germany, 81% of callers were more informed and able to cope.

### EMERGING AREAS: THE CIS AND RESEARCH

Application of existing knowledge has the potential to affect cancer prevention and control. Conducting health communications research in a service setting can greatly contribute to that body of knowledge. The United States and Australia CIS have been pioneers in implementing health communications collaborative research projects to further the field of cancer communication and to inform CIS service delivery.

TABLE 3. Results from Three National User Surveys of Cancer Information Service Users

|                                  | United States  | Canada   | Germany   |
|----------------------------------|--|--|---|
| Type of Survey*                  | Phone interviews   | Phone interviews   | Questionnaires  |
| Number of Participants           | 2485   | 904  | 300   |
| Type of User                     | Predominately white female, college degree or higher, evenly split in age below and above 40   | Predominately female, well educated, 40-59 age   | Users of telephone services and e-mail. Preliminary data  |
| Overall Satisfaction             | 95% (very or satisfied)  | 97.5% (very, mostly satisfied)   | 95.3% (very or helpful)   |
| Percentage of Clients' Needs Met | 89% (met or exceeded expectations)   | 86.4% (almost all or most)   | 89%   |
| Would Use Again                  | 96%  | 96.8%  | 96%   |
| Would Recommend                  | 96%  | 97.9%  | 86% regularly   |
| Information Specialist Knowledge | 98%  | 80.9% (very or knowledgeable)  | NA  |
| Quality of Information           | 99% (very satisfied and satisfied with materials)  | 94.7% (excellent, good)  | 91% (high)  |
| Trust in Information Impact      | 83% (a lot)<br>71% indicated CIS helped to affect positive intention or behavior change; communicate with doctor; quit smoking, increase knowledge of clinical trials, seek more information | NA<br>92% CIS helped to get information, understand, cope better, make a decision, communication with doctor or close ones, find a service, take steps toward prevention | 91.7%<br>81% understand situation better now treatment options, communication with doctor, cope better, find further resources for information and support; 65% influence treatment strategies, 48.9% get second opinion; 32% change life style |

\*While the intent of the questions were similar, the questions were worded differently, thus the difference in how the results are reported in this table.

The NCI's CIS laid the foundation for research in the early 1980's by establishing a national evaluation program with several components:

- Documenting what happened on a call and collecting information on caller demographics, the cancer topic discussed, and the actions taken by the information specialist to successfully complete the call;
- Evaluating information specialists' performance against established quality measures, by administering a national test call program;
- Measuring caller satisfaction through a national user survey.

This strong evaluation effort became the foundation and provided needed infrastructure to participate in the emerging research opportunities.

In the early 1990's, the U.S. CIS partnered with health communications researchers to establish the Cancer Information Service Research Consortium (CISRC). It was through the CISRC that an infrastructure to conduct large-scale research was created, and the U.S. CIS began to collaborate with health communications researchers. This union between research and service was established to not only maximize service to the public but to also incorporate the results of the research into CIS service delivery.<sup>30,31</sup> Four journal supplements—*Journal of National Cancer Institute* 1993, *Journal of Health Communication* 1998, *Preventive Medicine* 1998, and *Journal of Health Communication* 2005—published the results of the CISRC research projects, key lessons that had been learned as a result of the research collaboration, and the ultimate challenges faced by the collaborators.<sup>19,31,32</sup> This collection of research articles provided compelling data on the advantages of forming research collaborations in a service setting.

In 2005, the U.S. CIS enhanced the CIS Research Program to develop, implement, and disseminate the findings of research in four key areas:

1. testing interventions in cancer communications;
2. increasing access to and use of cancer-related information and education;
3. improving the science of dissemination research;
4. understanding cancer information-seeking needs and behaviors.<sup>32</sup> Studies to address cancer health disparities are another priority area for CIS research.<sup>33</sup>

Key to conducting research in the CIS is the expectation that CIS staff deliver the interventions. If the goal of the research is to improve service delivery, then the delivery of the intervention should in fact mirror what takes place in the usual CIS interaction with the public. Cancer Information Service staff members have developed the capacity and experience to implement research protocols in a usual service environment, to conduct pilot research studies, to oversee quality control in protocol implementation and data collection, and to publish the results of research findings with investigators.<sup>30</sup> Examples of such studies include

use of the telephone and tailored print materials, eHealth communication for seeking information about cancer, research on bridging the digital divide, and informed decision-making.<sup>31</sup>

## IMPLICATIONS

Obtaining accurate and comprehensive information about cancer is a worldwide problem. In most countries, expenditure on health focuses on essential treatment, research and care, with few additional funds available for information and support. As recently as 10 years ago, using the CIS as an information resource was a new concept for health care professionals and the public. In certain parts of the world, this remains true today. However, with increasing innovations in cancer treatments, care and support services, and with the diminishing number of cancer specialists available to spend time with patients and their family members, a growing number of health professionals and an increasing number of patients and family members are recognizing the potential of this high quality resource. In some countries, the CIS is being used as a complementary service to care. Cancer organizations are also beginning to recognize the value of good communication skills and information as an important part of staff training.

The ICISG encourages and benefits from diversity while maintaining essential standards and quality assurance. The strength of the individual international CIS is in their uniqueness—which allows them to be tailored to individual countries and cultures—as well as their similarity, which allows them to assure that a high quality service is offered to any patient, family member, or friend wherever it is being provided. As seen in the other articles in this issue, the CIS has learned that in order to deliver a high quality service that helps those who are seeking cancer information, it must have access to the latest scientific information, adequately and continually train its staff,<sup>34</sup> conduct program evaluation, and monitor for quality assurance.

Research remains an important complement to the CIS. In the United States and Australia, research continues to enhance service. In recent collaborations with researchers, the CIS has served as a viable laboratory for health communications research and has embraced health communications research as a strategic tool for quality improvement. It is important that other CIS offices around the world also consider participating in communications research. The topics for such research are many, and can span the full spectrum of the cancer continuum. For example, by making appropriate lifestyle choices, up to one-third of all cancers could be prevented; through early detection and effective treatment, lethal consequences could be avoided in another third; and pain relief and palliative care could increase the quality of life of cancer patients, even in low-resource settings. All of these are areas where information and education from a CIS can make an impact.

In addition, there is an urgent need to research the barriers to, use of, and cost of shared decision-making and the



role of accurate information/knowledge by a staff trained in communication skills to support patients participating in the process.<sup>35</sup> There is also a need to evaluate the value not only to the individual but also to the health care system of providing accurate, supportive, and skillfully communicated information.

Lastly, health professionals need to play a greater role in helping patients find the resources to access reliable information. One of the easiest ways to accomplish this is to endorse and refer patients to CISes that are now available worldwide—services that provide credible information, support the provider/patient relationship, offer high quality assistance for patients, their families, and friends at critical times in their cancer experience.

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