

International Cancer Information Service Group

STRATEGIC PLAN 2008-10

A. CONTEXT

1. THE NEED FOR CANCER INFORMATION

Cancer is the second leading cause of death in developed countries and one of the three leading causes of adult mortality in low-income countries. Each year, almost 7 million people die from cancer and close to 11 million new cases are diagnosed; more than half occur in the developing world.¹ Globally, the incidence of cancer is on the rise because of increased exposure to risk factors such as tobacco and second-hand smoke, unhealthy diet, physical inactivity, viruses, UV rays, and environmental carcinogens.²

Throughout the world, there is a growing trend of 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. A 2006 survey in 10 European Union member states identified the need for accurate, relevant, and comprehensive information for patients and their caregivers to help them make informed decisions about treatment.³

With ongoing scientific advances and expanding knowledge about risk factors, early detection, diagnosis, treatment, clinical trials, supportive care and survivorship, the need for cancer information can only increase.

2. CANCER INFORMATION AS PART OF CANCER CARE

As information becomes available through scientific discovery about cancer and ways to improve health behavior, it is essential that collaborations exist to promote the development and dissemination of credible cancer information for the general public, cancer patients, family and friends, and health care professionals. Delivering the best possible care to cancer patients is essential and the provision of cancer information should be an integral part of cancer care. This is why a Cancer Information Service (CIS) has a critical role to play. The one-on-one tailored interaction with a trained information specialist can strengthen and accelerate the cancer control knowledge exchange and lead to increased abilities, skills, desirable individual behaviors and public health action.

3. THE INTERNATIONAL CANCER INFORMATION SERVICE GROUP (ICISG)

In 1996, several cancer organizations who operate a CIS formed an independent network to share their knowledge and expertise, raise the awareness of cancer information services, and support others to start a CIS. After 10 years, the ICISG membership includes more than 50 member organizations in 32 countries.

The ICISG's mission is to help cancer organizations around the world establish a cancer information service to provide high-quality cancer information and resources on all aspects of cancer, for those concerned or affected by cancer. ICISG achieves its mission by:

- Increasing awareness of Cancer Information Services
- Promoting collaboration between Cancer Information Services in different countries
- Sharing information and tools for management, training, quality assurance and evaluation
- Acting as a forum for exchange and discussion
- Establishing quality benchmarks for delivering cancer information
- Organizing courses on elements of a cancer information service.

In the next 3 years, ICISG will focus on the following strategic directions:

1. Expand the reach of ICISG
2. Provide expertise on CIS operations
3. Ensure the succession and sustainability of ICISG

¹ www.who.int/cancer/en, March 13, 2006

² The Cancer Atlas, American Cancer Society, 2006

³ International Alliance of Patients' Organizations, 2006

B. STRATEGIC DIRECTIONS 2008-10

1. EXPAND THE REACH OF ICISG

The ICISG will have a greater impact on the development of cancer information services in the world by expanding its reach. This can be accomplished by:

- promoting ICISG
- establishing key partnerships or collaborations
- increasing membership.

1.1 Promoting ICISG

To be successful, ICISG needs to continue to reach out to cancer organizations throughout the world to let them know about the services, expertise, and goals of the group. Presentations at cancer conferences, the enhancement of the ICISG website, and the dissemination of promotional materials are effective ways to broaden the ICISG profile.

a) Presentations at cancer conferences

Since its inception, ICISG has made several presentations at every UICC cancer congress. These presentations have proven beneficial in promoting ICISG and providing an opportunity for networking between cancer organizations interested in starting a CIS. In the next few years, ICISG will explore other conference venues, including patient forums.

In addition to presentations at conferences or professional meetings, ICISG profile can also be enhanced through exhibits at conference venues. The ICISG banner and pamphlet can be used for this purpose.

Goals 2008-10:

- Submit abstracts for posters or presentations at cancer conferences, patient forums, and professional meetings including the UICC World Cancer Congress, Society of Public Health Educators, the American Public Health Association, Oncology Nursing Society, etc.
- Identify opportunities to use the ICISG exhibit banner and make it available to members

b) Maintenance and expansion of the website

The primary communications tool for ICISG is its website and it is regularly updated by the ICISG secretariat. Through generous in-kind donations and volunteer work from member organizations, ICISG will continue to ensure infrastructure hosting support (servers, security, site maintenance), content management and new content creation.

In the next 3 years, the website will be enhanced with new content, publications, and a new section for media (articles and press releases for newsletters, PDF of ICISG pamphlet, photos).

Goals 2008-10:

- Review and expand website content
- Develop a new media section

c) Dissemination of promotional materials

In 2006, ICISG produced a promotional pamphlet describing the ICISG. This pamphlet is available in print and PDF on the website. It can be used by all members to explain ICISG mission and activities.

Goals 2008-10:

- Maintain brochure inventory; distribute to members as requested for broader distribution
- Use brochure to promote ICISG at appropriate meetings, with visitors, etc.

1.2 Establishing partnerships or collaborations

a) International Union Against Cancer (UICC)

As the only international non-governmental organization dedicated exclusively to the global control of cancer with a membership of 284 cancer-related organizations from 93 countries, UICC represents a key

partner to increase the reach of ICISG. With a shared commitment to providing cancer information and support services, ICISG and UICC have been working together on several projects since 2004. These include:

- A survey of UICC members regarding the interest in starting a CIS (completed in 2005)
- Launch of the CIS Toolbox at the UICC World Cancer Congress in 2006
- Pre-congress one-day courses on how to start a CIS (July 2006, August 2008)

To assist cancer organization start a CIS in their country, ICISG will explore with UICC the possibility of establishing an ICISG scholarship to foster exchange between cancer organizations, especially for those with limited financial support. This fellowship would be funded by external sponsorship or contributions from ICISG member organizations.

Goal 2008-10:

- Establish a ICISG scholarship under the auspices of UICC to foster training, workshops and exchanges between cancer organizations interested in starting a CIS.

b) European Cancer Leagues (ECL)

In the next 3 years, ICISG will explore the possibility of collaborating with the Association of European Cancer Leagues to promote the benefits of ICISG to its members. While some the ECL members are already ICISG members, the two organizations may find synergies in joint collaborations to promote the benefits of a CIS in Europe, and encourage cancer organizations that do not have a CIS to consider starting one.

Goal 2008-10:

- Explore areas for collaboration with ECL
- Make a presentation on ICISG to ECL members at one of their meetings
- Invite ECL to the ICISG reception in Geneva 2008

c) American Cancer Society - International

The American Cancer Society (ACS) has recently expanded its international program. Recognizing the importance of cancer information in the fight against cancer and the expertise of ICISG, the ACS initiated a discussion to explore areas for potential collaboration. This initiative will be pursued in the next years.

Goal 2008-10:

- Visit the ACS in 2008 to learn more about their international program
- Explore areas for collaboration with ACS International.

1.3 Increasing ICISG membership

The ICISG is a network of cancer organizations that already operate a cancer information services or are planning to start one in the next few years. A broad membership is essential to help foster support and exchange of expertise. In 2007, ICISG membership included 32 full members (organizations that operate a CIS) and 19 associate members (organization who are planning to start a CIS in the next 3 years) from 32 countries. The benefits of member organizations include:

- Sharing knowledge and expertise through a network of CIS
- Opportunities to participate in international exchange programs
- Access to a CIS toolbox, resources, and members' listserv

Goal for 2008-10:

- Recruit 10-15 new members

2. PROVIDE EXPERTISE ON CIS OPERATIONS

One of the main goals of the ICISG is to facilitate the development of CIS in developed and developing countries, advising them on the delivery of high-quality cancer information and resources on all aspects of cancer. The ICISG will assist countries interested in starting a Cancer Information Service by:

- Developing a course curriculum on how to start or manage a CIS
- Updating the CIS resources (core values, operating guidelines, CIS toolbox)
- Providing one-on-one consultation
- Fostering knowledge transfer.

2.1 Course curriculum on how to start or manage a CIS

Delivering a one-day course on how to start or manage a CIS provides cancer organizations with an effective way to learn about key elements of a high-quality CIS, to exchange with others in a similar situation, and to ask questions to experts. The joint UICC/ICISG course on *How to start a CIS* held at the UICC World Cancer Congress 2006 in Washington attracted participants from 21 countries.

ICISG will offer an updated course at the UICC World Cancer Congress 2008 in Geneva. The course will be delivered by ICISG faculty and will draw on the experience of Cancer Information Services in different cultural environments to describe a variety of ways to successfully meet the challenge of setting up or managing a CIS. The course will include a basic level and an advanced level.

The basic level will include topics for starting a CIS, specifically on:

- Planning
- Staffing
- Service delivery
- Quality management
- Promotion

The advanced level will include topics for managing a CIS, specifically on:

- Recruitment, retention, and burn-out
- Continuing education
- Call monitoring and quality management
- Call center management

To make the course curriculum more accessible to interested cancer organizations between conferences, ICISG will explore developing mini-course modules that could be delivered via the internet.

Goal 2008-10:

Prepare, deliver, and evaluate one-day CIS course at the UICC World Cancer Congress 2008 in Geneva.
Prepare, deliver, and evaluate one-day CIS course in another conference venue in 2010.
Explore delivery of mini-course module through the internet.

2.2 CIS resources

The ICISG has developed three primary resources

- CIS core values
- CIS operating guidelines
- CIS toolbox

The CIS core values will be reviewed every 3 years and the CIS operating guidelines will be reviewed annually. The web-based CIS toolbox will be updated as needed and new resources from cancer organizations who want to share their tools will be added as needed.

Goal 2008-10:

Update the CIS core values
Revise the CIS operating guidelines
Update and expand the CIS toolbox

2.3 One-on-one consultation

Cancer organizations face a variety of opportunities and challenges when trying to start or expand a CIS. Based on over 100 years of CIS combined experience, the ICISG board members can provide a wide range of advice and expertise on needs assessment, strategic planning, management, and operations through a tailored approach.

a) Assist with needs assessments and strategic planning.

The ICISG has posted on its website a needs assessment checklist as a first step to help organizations interested in starting a CIS. Organizations that join the ICISG can also access the CIS toolbox that has additional information, including a strategic plan outline. Organizations that complete their needs assessment or strategic plan can submit them to ICISG for case-by-case review. A small working group will contact the organization to ask additional questions as needed and provide feedback on the documents.

b) Ad hoc consultation

Organizations interested in starting or managing a CIS can also contact their ICISG board liaison when needed. The ICISG board liaison is a board member who is responsible to provide ad hoc support about CIS as requested by cancer organizations in a specific geographical area. Board liaisons will be available to assist, via e-mail or telephone or will identify another ICISG member better suited to provide support in a specific area (Board liaison list on www.icisg.org)

c) Workshops

At the request of a cancer organization, ICISG can develop a CIS workshop to be delivered at the cancer organization. Arrangements regarding time, place, faculty, expenses, and possible sponsorship will be discussed with the cancer organization on a case-by-case basis.

d) Visits to exchange best practices

The ICISG can help “match” a cancer organization that is starting or managing a CIS with another organization who has expertise with a CIS. Arrangements regarding time, place, faculty, expenses, and possible sponsorship will be discussed with the cancer organizations on a case-by-case basis.

Goal 2008-10:

Facilitate and provide ad hoc expert assistance to 3-5 cancer organizations who make the request per year. In 2010, conduct a survey to assess impact of ICISG with cancer organizations that have received help.

2.4 Knowledge transfer

a) Explore topics for joint research projects

Many cancer organizations that operate a CIS are conducting some type of evaluation or a research project to assess the impact of the CIS intervention. For example, these can include user surveys, prevention interventions (healthy eating, tobacco control) or supportive care interventions (evaluation of distress along the cancer journey). While CIS user surveys tend to be initiated by cancer organizations, typically, the research projects are initiated by principal investigators who partner with CIS to conduct research. Research results are then published in peer-reviewed journals by the research team.

b) Develop publications on CIS

Diffusion of information on ICISG to the health communication and cancer control communities is important to establish the credibility of Cancer Information Services and to promote its benefits. Publication of scholarly articles on CIS or ICISG in appropriate professional journals will inform stakeholders of the value and importance of providing credible cancer information to control the burden of cancer and the work that ICISG does to promote it.

Goals 2008-10

- Disseminate ICISG article published in the *Journal of Cancer Education* (completed in 2007)
- Explore topics for comparative studies between several CIS and publish findings in peer-reviewed journals.

3. ENSURE THE SUCCESSION AND SUSTAINABILITY OF ICISG

Since its inception in 1996, ICISG has relied on the dedication of the founding members, the Board of Directors, and the generous in-kind contributions of affiliated organizations. After many years of commitment to the establishment and advancement of ICISG, and with the increasing work demand from regular employment, the ICISG Board of Directors must address the succession and sustainability of the organization.

1. Seek out new members for the Board of Directors

Every 3 years, or to coincide with the UICC World Cancer Congress, members of the Board of Directors are elected by the members present at the Annual General Meeting. The Board consists of:

- President
- Vice-President
- Past president
- Minimum 4 and maximum of 9 Directors
- Ex-officio members as nominated by the Board from time to time.

The work of the Board of Directors and ICISG activities are supported by a Secretariat currently hosted at the President's affiliated cancer organization. In the Spring of 2007, at the time of its annual meeting, the ICISG Board of Directors held a workshop to discuss issues related to succession and sustainability.

1.1 Succession

ICISG's greatest strength is the dedication, expertise and in-kind contributions from the members of the Board of Directors to pursue the ICISG mission. As the time commitment to attend to ICISG governance and deliver ICISG activities is increasing for existing Board members, it is important to seek out individuals with CIS experience who share the same vision. Starting with affiliated organizations, and reaching out to other cancer organizations who are operating a CIS, ICISG will actively recruit dedicated and dynamic individuals to join its Board of Directors and faculty.

Goals 2008-10:

- Recruit 2-3 new Board members in 2008 and in 2010 as vacancies permit.
- Recruit 3-5 new faculty members to help deliver the course and provide expertise.

1.2 Sustainability

The philosophy of ICISG is to provide services to its members free of charge. Without membership fees, alternate sources of funding must be identified to support the ICISG secretariat, website, course development and materials, and other activities. Up to now, ICISG has been depending on the generous in-kind contributions from the Board of Directors' affiliated organizations.

Goals 2008-10

- Explore availability of UICC sponsorships for workshops and exchanges between cancer organizations interested in starting a CIS (e.g., new UICC Capacity Building Fund)
- Explore educational grants from international foundations or pharmaceutical companies for specific activities.
- Seek sponsorship from member organizations for hosting specific events (AGM, Board of Directors).

2. Recruit an Advisory Group

In addition to succession and sustainability measures, the ICISG would benefit from the guidance of an Advisory Group. Members of the Advisory Group would be recognized experts in cancer control and would champion the importance of cancer information through a CIS while providing the ICISG Board of Directors with advice to ensure success within a changing environment.

Goal 2008-10:

Identify and invite 2-3 CIS experts to join the ICISG Advisory Group

SUMMARY

The ICISG's mission is to help cancer organizations around the world establish a cancer information service to provide high-quality cancer information and resources on all aspects of cancer, for those concerned or affected by cancer. ICISG achieves its mission by:

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- Organizing courses on elements of a cancer information service

In the next 3 years, ICISG will focus on the following strategic directions:

1. Expand the reach of ICISG

- Promote ICISG (presentation at cancer conferences, website, promotion materials)
- Establish partnerships or collaborations (UICC, ACS, ECL)
- Increase ICISG membership

2. Provide expertise on CIS

- Develop a course curriculum
- Update CIS resources and tools
- Provide one-on-one consultation
- Foster knowledge exchange (joint projects, publications)

3. Ensure the succession and sustainability of ICISG

- Seek out new members for the Board of Directors
- Recruit an Advisory Group.