

# Use of emerging technologies in provision of Cancer Information Services:

## an international snap shot

research  
prevention  
support

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# International Cancer Information Service Group (ICISG): Our story

- The International Cancer Information Service Group (ICISG) is an independent, international organization composed of Cancer Information Service programs.
- The mission of ICISG is to assist organizations to provide high-quality cancer information and resources on all aspects of cancer.
- Founded 15 years ago consisting of international cancer experts from 50 organizations across 35 countries.



# Background

Wyke Stommel 2009

- Dramatic shift in communication technology over past decade
- The basic building block of good communication is the feeling that every human being is unique and of value
- Increasing recognition of importance and impact of web based communities for people affected by cancer
- Using computer technology is useful for isolated populations and groups that have restrictions on their time



# Background

Participation in creation of health information through blogging and social networking is thought to influence patients' health experiences more broadly than provision of information and support alone.

ZIEBLAND, S. and WYKE, S. (2012)

# Aim & Methodology

- Aim: Provide an international snap shot of how cancer information services are utilising emerging technologies to provide information or support to cancer communities.
- Online survey
  - Background information on CIS methods of information and support delivery
  - 2 areas of focus for information and support provision utilising emerging technologies
  - Benefits, challenges and lessons learned

# Contributing organisations

- Cancer Research UK
- Swiss Cancer League
- ~~Belgian Cancer Society~~ Belgian Foundation Against Cancer
- American Cancer Society
- Belgian Foundation Against Cancer

# Contributing organisations

- German Cancer Information Service, German Cancer Research Centre
- Danish Cancer Society
- CancerCare, Canada
- Cancer Council Victoria, Australia
- Canadian Cancer Society
- Cancer Society of Finland
- National Cancer Institute France

# Focus of Cancer Information Service

- Extensive range online support groups: majority professional facilitated / moderated
  - Chat groups: Cancer Information Specialists answer inquiries via web site
  - Online education workshops for cancer community
  - Blogs & bulletin boards
  - Twitter & Facebook to advertise upcoming information & support programs



# Benefits

- Reduced isolation and power of being linked to others in a similar situation without leaving home
- Accessibility as lead experts donate their time to Online Education Workshops
- Opportunity to collaborate with other organisations to reduce duplication, enhance referrals, co-facilitate

# Benefits

- Expansive outreach unable to be achieved through phone, face to face and email CIS contacts: eg.
- Canada's Education sessions 500-4000 participants per one hour workshop
- Cancer Research UK Online forums: 4000 active users, 1.2 million views, 16,700 messages in one year
- American Cancer Society cancer forums: 39,000 participants

# What makes these services unique compared with other CIS programs offered ?

- Real time interactive medium
- Availability: 24/7
- Benefits to speech or hearing impaired community: find their voice & feel connected
- Providing more choice: carers more likely to use online information and support option

# Challenges of using online / social media for patient support

- Tension between taking advantage of new technology and benefit to cancer community
- Inadequate resourcing to accommodate 24/7 nature of new technologies
- Increased range of information delivery requires coordination and quality monitoring across different communication medium

# Impact of new technologies on staffing

- A funding cut resulted in IT department responsible for website
  - Little expertise in responding to cancer posts
  - Duty of care to IT staff
- Lack of trained staff = lack of ability to expand online services
- Agreement that all online discussions require an organisational moderator: getting the right fit

# New technologies: Lessons learned

- Thorough planning and developmental strategy to ensure the full costs of running the service well understood, including staff training, success measures and marketing
- Be managed and moderated by staff with technologies
- Should be based on demonstrated need for the service that cannot be met by existing services

# New technologies: Lessons learned

- Risk management strategies from the onset
- The value of sharing ideas, experiences and resources with like minded organisations
- Build a robust and constantly maintained data base of health professionals to mail brochures and email promotion
- Involving IT from the onset; rather than just to fix IT problems

# New technologies: Lessons learned

- Ensure there is sufficient funding for the service to run well
- Ensure there is a match between the way the service is being delivered (eg. online or Twitter) and how the target group for the service wants to receive support / information
- Integrate new services with existing services
- Organisations need to provide IT infrastructure to support cancer information



Thank you to all our contributors.

*ICISG is here to help:*

**ICISG TOOL BOX MODULE**  
**Using Social Media in Cancer Information Services**

**Prepared by: International Cancer Information Service Group,  
November 2011**

Emerging technologies tool box  
<http://www.icisg.org/resources/socialmediaindex.html>

