

The Role of Cancer Information Services in Cancer Control

International Cancer Education
Conference

October 25, 2010

Chris Thomsen, USA

Monika Preszly, Germany



Overview



1. The need for cancer information
2. The role of a Cancer Information Service
3. ICISG resources

What we know



- More than 12 million people world-wide are diagnosed with cancer every year
- Estimated 16 million new cases every year by 2020
- Cancer causes 7.9 million deaths every year, or 13% of deaths worldwide
- 72% of deaths are in low or middle income countries

The need for cancer information



Patient studies show that the need for cancer information, support, and communication is especially urgent at time of diagnosis

“You know nothing about cancer and you are suddenly expected to become an expert”

The need for cancer information



Good information exchange can:

- Reduce anxiety and fear
- Bring back a sense of control during a vulnerable time
- Increase participation in decision-making
- Improve ability to cope and to communicate with family members

***“The more I learned about cancer,
the less it became...”***

International CIS Group



- Argentina
- Australia
- Bangladesh
- Belgium
- Bermuda
- Brazil
- Bulgaria
- Czech Republic
- Canada
- CIS - Russia
- Denmark
- Egypt
- Finland
- France
- Germany
- Greece
- Hong Kong
- Hungary
- India
- Ireland
- Israel
- Italy
- Japan
- Kenya
- Malaysia
- Mongolia
- Nepal
- Netherlands
- New Zealand
- Nigeria
- Norway
- Romania
- Serbia
- Singapore
- Slovakia
- South Africa
- South Korea
- Spain
- Sweden
- Switzerland
- Thailand
- United Kingdom
- United States
- Zambia

Cancer Information Service



- Trained information specialists
- Accurate, up-to-date information
 - Prevention, early detection, smoking cessation
 - Diagnosis
 - Treatment, side effects
 - Clinical trials and research
 - Complementary/alternative therapies
- Delivered by telephone, email, or in person
- One-on-one personalized interaction

Cancer Information Service



- Supports the doctor-patient relationship
- Provides information, not medical advice
- Is based on evidence, not opinions
- Refers to services in the community
- Ensures confidentiality
- Is free of charge



Benefits of CIS interaction



- **Assess** individual needs and provide tailored information
- **Encourage** general public to take steps toward prevention
- **Help** cancer patients understand cancer to inform decision-making
- **Suggest** community services to support them and their families

CIS: users and topics



- Women are the information seekers
- Callers are
 - Cancer patients, family, and friends
 - General public
 - Health care professionals, students, media
- Types of cancer reflect the incidence
- Topics are mostly on:
 - Treatment
 - Psychosocial issues
 - Diagnosis
 - Prevention

A day in the life of a CIS



How is lung cancer detected?

Can I be sure that I don't have breast cancer if my mammogram is ok?

How can I protect my family from cancer?

Can I get a mammogram with silicon implants?

What is the best treatment?



Can stress have caused my cancer?

How can I prevent cervical cancer?

I have a PSA-detected early prostate cancer – Should I have surgery or not?

How can I cope with fatigue?

CIS makes it easier to



- Understand cancer (diagnosis, treatment)
- Communicate with doctors, family
- Find services in the community
- Cope better
- Take steps toward prevention
- Make a decision

CIS is an effective source of information and education about cancer

IAPO Policy Statement on Patient Information

October 20, 2009



It is essential that patients are **empowered with the information they need to make informed decisions** about health care treatments and living with their condition. With **accurate, relevant and comprehensive information** patients can make informed lifestyle choices, take their medicines correctly and manage their condition

Focus on **how information is communicated** so that the communication method **helps patients to understand and make informed decisions** based upon the information content. This will ensure that information is suitable to patients' individual conditions, language, age, understanding, ability and culture.

International Alliance of Patient Organizations

Policy Statement on Patient Information

October 20, 2009

www.patientsorganizations.org

How ICISG can help



Members of ICISG can help with:

- Needs assessment
- Training of information specialists
- Resources and technology

By providing:

- Workshops or courses
- Materials in many languages
- Website and CIS Tool Box

CIS Tool Box



- Based on experience and materials from CIS programs around the world
- Web-based tool with links to resources
- Tips and tools on how to start or manage a CIS
- Samples of materials and tools from other CIS
- Practical lessons learned by members of ICISG

www.icisg.org

info@icisg.org

Contacting ICISG



- Visit our website www.icisg.org
- Or email at: info@icisg.org

Thank you!