e-Lessons of yesterday
point the way ahead

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From Harlem to Helsinki, from Stirling to Sarajevo, the Internet is being put to novel uses in the cause of cancer prevention and care. The lessons learned have now been used to map out an action plan for Cancer on the Internet.

New information and communication technologies have been used by and for cancer patients for more than a decade. But it wasn't until June 2003 that members of the cancer community first got together to formulate a common approach to Cancer on the Internet, at a conference in New York called by the European School of Oncology.

Last September a second conference was called, again in New York, which went one step further. Over the course of two days, 150 delegates from 13 countries, representing very varied levels of Internet use, shared experiences and drew up suggested areas for action under the headings: Promoting Digital Inclusion, e-Cancer Care, e-Cancer Patients, and Fostering Global Collaboration. These were incorporated into the revised New York Statement, which is published on p. 64.

"Our goal was to bring people together from all over the world who are interested in improving cancer care, from prevention to end-of-life care, using information and communication technologies," said Alex Jadad, a conference co-chair and the director of the Program for eHealth Innovation at the University Health Network and University of Toronto in Canada. "There are many success stories that people don't know anything about, and we cannot afford that… Only by sharing knowledge and learning from one another's mistakes can we move forward."

DIGITAL INCLUSION

Delegates heard about a variety of initiatives in different communities across the world that aim to increase the number of people able to benefit from Internet access.

In India, doctors and nurses in underserved areas are getting access to cutting-edge information through an initiative undertaken in partnership between the WHO's Health InterNetwork (HIN) and the publishers of Indian biomedical journals. Joan Dzenowagis, project manager of the HIN, described how the project has brought computers to primary health centres in the states of Orissa and Karnataka. HIN staff worked with the community to create the infrastructure – as basic as phone lines – needed to support the computers and the Internet access, and together with local institute

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staff, they also trained more than 300 local public health personnel, so they could access and use the journal articles and other health information.

In the very different setting of Harlem, New York, a project has been running to teach consumer and healthcare providers a 'cancer education curriculum.' The aim is to provide health information in English and Spanish and teach community members how to find information online, as well as help healthcare providers identify credible health websites.

Rosemarie Slevin Perocchia, Director of the National Cancer Institute's Cancer Information Service of New York at Memorial Sloan-Kettering Cancer Center, who helped launch the project, described how she and her colleagues had got together with local groups to hold training workshops, educating 256 consumers who were residents of this underserved area and 256 health care providers from around New York City. While the workshops were successful, Perocchia reported that the project had struggled with enrolment, and observed that a 'champion', such as a local celebrity, might have helped boost participation.

Another initiative, this time in Bosnia Herzegovina, aims to provide simple, quality information to cancer patients in a language they can understand. Anes Pasic, of the Institute of Oncology at the Clinical Centre of the University of Sarajevo, described his efforts to build a cancer support webpage for his hospital's patients and their family members. The website, he says, is needed because physicians in his

overburdened hospital don't always have the time needed to explain the disease as fully as they would like. Currently only around 5% of Bosnians use the Internet for health purposes. While this is likely to improve once information becomes available in their own language, the high cost of Internet access remains a problem, he said.

A series of reports from the field offered conference participants the chance to hear about other efforts around the world, including a cancer portal in Spain developed to reach people with cancer and to provide preventative information to those without cancer; a new search feature on the National Cancer Institute (NCI) website called 'Best Bets' that helps visitors find the most pertinent information; and a Danish project that assessed the usefulness of Internet support in a cancer rehabilitation centre.

OPTIMISING CANCER CARE

The conference also heard about innovative techniques being piloted in recent years to use information technology to improve the care of cancer patients.

In Scotland, handheld computers and cell phones were used in a study to assess patients' symptoms while they were receiving chemotherapy. Nora Kearney, a professor of cancer care at the University of Stirling, who headed up study, explained how the technology had enabled healthcare professionals to establish patterns of severity of symptoms over time and allowed them to compare how

A website in Bosnia Herzegovina provides information to cancer patients in their own language

The 'Kardian PM' is a portable mobile electrocardiograph, which can display a cardiogram instantly, memorise it and transmit it to any medical institution through a mobile phone. Cancer patients in Scotland have used similar techniques to record and transmit information about their symptoms while on chemotherapy. The information has been used to identify best practice in symptom control in a bid to improve this essential aspect of cancer care

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New York Statement:
Using the Internet to optimize cancer control

e-Cancer Patients

The Internet is the cornerstone of the techno-cultural revolution that is starting to transform the nature of cancer control. Patients have been at the forefront of this revolution and many are now regularly using the Internet to obtain information about their disease and its treatment, seek support from on-line patient communities and support groups, share knowledge and experiences with other patients and communicate with their professional carers and loved ones. There is a great deal of confusion and many concerns as to the quality and appropriateness of online patient resources; however, it is impossible to police the Internet. In order to address these concerns, many governmental and non-governmental organizations have developed guidelines for quality health websites and on evaluating health information on the Internet. Unfortunately, implementation of these guidelines has been patchy. Moreover, there is little or no government protection for e-consumers of health sites particularly in terms of privacy, security and confidentiality.

Suggested actions:
■ Raise awareness of quality criteria for health websites that have been developed by a number of reputable agencies. Facilitate widespread dissemination of these guidelines via established networks and encourage compliance amongst cancer website developers.
■ Promote research into tools that can help consumers find quality health information and undertake an inventory of currently available resources that can help patients hone their critical evaluation skills (e.g. the US National Cancer Institute's document on how to evaluate health information on the Internet, MedCIRCLE etc).
■ Lobby for standards for e-health and ICTs, while maintaining freedom to innovate.
■ Urge governments to take action if website providers undermine cancer patients' rights.
■ Encourage sharing of best practice on running effective online patient support communities (both peer- and facilitator-led).
■ Foster discussion and debate amongst all stakeholder groups on ways the healthcare sector can become more responsive to the needs of e-cancer patients.

e-Cancer Care

The Internet provides an important tool to facilitate clinical practice and cancer research. Professional access to and use of content and Internet applications is an essential part of providing appropriate cancer care; however, it has lagged for reasons of cost, effort, policy and other barriers.

Suggested actions:
■ Raise awareness of ways in which the Internet can impact on diverse cancer outcomes and stimulate large-scale research in this area.
■ Promote the potential of ICTs to reduce workload and costs and improve communication and continuity of care.
■ Identify workable solutions to the technological, legal and attitudinal barriers to patient-physician communications via e-mail.
■ Point to the usefulness of the Internet as a means of providing continuing professional education and facilitating mentorship initiatives. Encourage education providers to use web-based education approaches more widely.
■ Call on the relevant authorities to include a short course on the relevance and application of ICTs in healthcare in the undergraduate curriculum and promote coverage of this topic as a fundamental component of continual medical education activities.
■ Support efforts to establish clinical trials registries that are freely accessible to the public, accurate, inclusive and electronically searchable.

Participants at the International Conference on Cancer on the Internet are committed to promoting and developing the potential of the Internet in support of cancer efforts worldwide, from the global to the individual level. This statement was drafted at the first international conference in June 2003 and revised at the second conference in September 2004. The New York Statement identifies key areas for action, advocacy and collaboration in realizing the potential of the Internet for cancer control. Conference participants believe that cancer control can be improved, in all countries and for all people, through the efficient and effective use of the Internet. This applies to the whole cancer continuum from prevention through diagnosis, treatment, survivorship and palliative care. Information and communication technologies (ICT) have helped cancer control in many different ways and the benefits are being rapidly extended as the Internet grows. Internet applications and content resources for all cancer communities are an essential part of improving cancer control. This statement recognizes the significant potential benefits the Internet has for the many stakeholders involved in cancer control efforts: patients and their loved ones, citizens, health professionals, researchers, policy makers, educators and organizations.

Promoting Digital Inclusion

Internet access is becoming a reality in many countries worldwide as basic infrastructure and services continue to improve, but there are major obstacles in ensuring access is available and affordable so that all can benefit. These obstacles include cultural and economic factors, infrastructure, literacy, and language. An affordable, reliable, durable and high-speed infrastructure is required and relevant content will motivate Internet use. Moreover, skills to use and manage connectivity and content are essential. Global, national, and local efforts for e-inclusion are an important means to extend the benefits of ICTs to all citizens.

Suggested actions:
■ Work beyond the cancer sector to encourage electricity and phone providers as well as government departments to improve connectivity, even in the remotest settings.
■ Find local solutions for developing relevant and culturally appropriate content.
■ Encourage the application of the principles of good health communication by those developing content for the Internet and raise awareness of the need to tailor online information to meet the needs of people with health literacy or other communication difficulties.
■ Intensive training efforts are required to equip underserved members of the cancer community with the skills they need to use the Internet in an optimal manner.

Fostering Global Collaboration

Many organizations have as their mandate global cancer control and international activities. Their efforts can be facilitated through collaboration in developing and disseminating standards and research, sharing experience and best practice, and facilitating technology development, testing and deployment. National and international co-ordination can optimize use of limited resources and avoid duplication of effort.

Suggested actions:
■ Help develop the eUICC as a global resource for collaboration.
■ Identify other innovative ways to promote collaboration amongst international, regional and national cancer organizations in efforts to harness the power of the Internet in the fight against cancer. Mapping Internet-based resources created by cancer organizations worldwide should be a priority.
■ Think globally; act locally – identify and support local champions to ensure the sustainability of initiatives and optimize local involvement, especially around prevention and health promotion activities.
■ Explore the feasibility of establishing an international organization for people interested in collaborating on initiatives relating to Cancer on the Internet, including those targeted at low-income countries.
■ Develop a workable mechanism to facilitate the sharing of best practice amongst people active in the cancer-related ICT arena.

successfully nurses in different locations were managing symptoms. A different sort of comparison, this time between US and Finnish survival statistics, was made possible through a website, www.finprog.org, which develops survival curves based on breast cancer risk factors. The creator of the website, Johan Lundin, of the Biomedical Informatics Group at the University of Helsinki, explained how it could be used by clinicians to help with treatment decision-making.

The Internet is also being used in an effort to boost participation in clinical trials, which is currently running at just 5% among US cancer patients – a situation that Cindy Lollar, of the Office of Cancer Information Products and Services and Systems at the NCI, attributed largely to the fact that around 80% of patients know nothing about them. In an effort to boost participation, said Lollar, the NCI has added to

"may help us find sustainable solutions to many of the seemingly intractable problems that now plague all modern healthcare systems."

FORWARD THROUGH GLOBAL COLLABORATION

Not all speakers agreed over how many online cancer patients actually visit health sites, or about how much benefit is gained by those who do. It was clear, however, that most cancer organisations across the world – around 90% according to a study conducted at the University of Toronto – are now geared up to using the Internet to fulfil their missions of providing information, promoting research, holding scientific meetings and publishing research data.

This opens up great possibilities for building global collaboration over any aspect of cancer information, care or prevention. Already 280 cancer organisations affiliated to the

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its website comprehensible summaries of open trials, together with a search facility that enables patients to search for trials relevant to their condition. Similar information has also been made available through the Cochrane Center Register of Controlled Trials (CENTRAL), which lists more than 30,000 trials.

But perhaps the most important impact of the Internet in improving cancer care, argued US Cochrane Director Kay Dickerson, has come about as a result of empowering patients. In particular, she attributed the move towards evidence-based medicine largely to pressure from patients who, thanks to the Internet, became able to take a more critical attitude towards their own treatment.

Tom Ferguson, of the Pew Internet & American Life Project, who has been championing the cause of e-patients for more than 15 years, believes that well-informed patients have a great deal to offer the cancer world. "These new medical colleagues," he says,

International Union Against Cancer (UICC), in more than 80 countries, are using the Internet for the dissemination of information, such as its tobacco control programmes. Other international cancer organisations have built their own networks.

The challenge for the future, it was argued, was not to build new networks from scratch, but to work with what we have and seek to extend existing networks. Adapting big business marketing techniques and building partnerships with technology companies are two ways in which this is being achieved.

"The Internet is already changing the way we are approaching cancer control: from the global to the personal level," said Dzenowagis from WHO, commenting on what she had heard over the two days. "We have new opportunities to work together and contribute. This conference was an important venue for highlighting some of the most promising innovations for patients and clinicians."