

As Canadians - concerned with maintaining a healthy lifestyle or caring for family members - attempt to sift through the mountain of health tips and "professional" advice bombarding them in the media and on the Net, they're finding it increasingly difficult to sort solid, reliable health information they can trust from promotional pitches trying to sell them a product or a cure.

That's where Health Canada is playing a lead role, in ensuring that Canadians of all ages have access to accurate, up-to-date, health information.

In its landmark report of 1999, *Canada Health Infoway: Paths to Better Health* - which laid out the key steps for developing an electronic "health information highway" in Canada - the Advisory Council on Health Infostructure emphasized that health information "is an *essential public good* which should be readily available and accessible to all Canadians".

One of the goals of the Canada Health Infoway is to provide Canadians with "credible information that will be useful to them as citizens, as patients, as informal caregivers or simply as laypersons interested in making healthy choices about nutrition or lifestyles".

Eventually, this electronic information network will also include local directories of health services, "report cards" on Canada's health programs and services, and assessments of treatment options that Canadians can access at the click of a mouse.

Empowerment: A Key Watchword

Empowering Canadians by providing them with reliable health information is a top priority for Health Canada, and for Canada's provinces and territories.

In the *Blueprint and Tactical Plan* that Health Canada and its provincial and territorial partners developed to guide the implementation of the Canada Health Infostructure, they indicated that a fundamental objective of the Infoway was to "empower individuals and communities to make informed choices about their own health, the health of others and Canada's health system" and to enable Canadians to "take greater responsibility for their own health and participate meaningfully in decisions about the health system".

Underlying this objective is the belief that better health information for Canadians will create a more *effective* "health market", where all parties will be able to participate more fully in decision-making about their health and well-being.

This will bring more equality to the health system where, currently, the lion's share of information is in the hands of providers. The Internet has been a catalyst in achieving this "rebalancing".

Taking Responsibility for Their Own Health

The World Wide Web has escalated public interest in health topics. Last year saw a 30 per cent increase in the number of Canadians using the Internet for health-related purposes. Slightly more than half of these users were in the 25-to-44 age bracket. Gen Xers (aged 18 to 34) are also becoming a growth market.

Canadians are becoming more informed, and demanding accessible, quality health information. They want to be partners in decisions affecting their health, such as whether to take medication, which medication to take, and which course of treatment to follow. These empowered consumers are increasingly *sceptical* of authority of any kind and are demanding greater accountability from the health system.



-WILLIAM J. PASCAL -

PROVIDING THE PUBLIC WITH RELIABLE HEALTH INFORMATION: A Key Priority for Health Canada

Bill Pascal, P.Eng, C.M.A, is the Director General, Office of Health and the Information Highway, Information, Analysis and Connectivity Branch of Health Canada in Ottawa.

www.nc-sc.gc.ca/ohih-bsi/

It is my belief that a more knowledgeable and involved public, who are active *participants* in decisions about their health rather than passive *recipients* of the decision-making process, will result in better health care - and better health - for all Canadians.

Keeping Up with the Information Explosion

But it is not only lay people who want reliable, up-to-date health information. Health care providers need to have this information, too, for their own professional development if they are to keep abreast of the global explosion in health knowledge, and to be able to discuss health issues with informed patients.

According to one estimate (and these figures may already be dated), health care practitioners would need to read 19 articles a day, 365 days a year, just to keep up with the information being generated in their field of practice.

The percentage of *physicians* using the Net has grown by leaps and bounds. The use of electronic databases by physicians, such as the search services of the Canadian Medical Association that link them to current clinical practice guidelines, is changing the way they practise their profession.

More than half of Canada's doctors now use E-mail regularly, and are starting to use it to communicate with patients. This new means of communication will help foster a different kind of partnership, where the professional becomes more of a coach or a facilitator, rather than the final authority.

As the following example illustrates, when an informed patient and an informed caregiver are *equally* involved in decisions about treatment, it can be very rewarding for both parties:

After being diagnosed with breast cancer and advised to undergo surgery, a patient seeks more information to better understand her condition and the treatment options available to her. She searches the Internet for reliable sources of information about breast cancer, its treatment and the alternatives she faces. Through the Internet she also finds support groups for women with breast cancer and gets in touch with others who have faced the same situation, who steer her to a Web site that provides report cards and assessments on treatment options. After gathering this information, the patient is able to discuss it with her caregiver, and talk it over with her family and support group to make an informed decision.

In the meantime, her doctor has consulted the latest medical databases to review current research on her condition. Together they decide on the appropriate course of treatment. The physician has the satisfaction of knowing he gave the patient the best possible advice, and she is assured that the decisions made about her care are based on the latest information that takes her needs into consideration.

Ensuring Good, Balanced Health Information

How do you ensure that the consumer (or health professional) gets good, balanced health information?

As a recent Angus-Reid survey confirmed, Canadians are concerned and sceptical about the credibility and trustworthiness of health information on the Internet.

Although they find the Net a useful tool to obtain health information, the amount of information is often "overwhelming" and "hard to digest".

When participants at an OHIH workshop on "citizen

empowerment" were asked about the quality and accessibility of health information for consumers, they said it was "hard to distinguish reliable information from that developed to promote a product or a crank remedy".

You almost need "a degree in sports medicine and nutrition", some said, to pick your way through all the expert advice available about exercise programs, healthy diets, vitamin therapies and other treatments, or the media stories that appear almost daily about some new allergenic, antibiotic-resistant bacteria; the carcinogenic effects of some food staple; or the environmental hazards of another common product.

Health Canada tackled the issue of quality health information with its federal, provincial and territorial health partners at a meeting (of the National Conference on Health Info-Structure) in Edmonton, in 1998. Participants agreed that "*national leadership* was required to provide guidance to consumers about the quality of information available through the health infrastructure, including a rating procedure to identify recommended sites."

Likewise, the report *Canada Health Infoway: Paths to Better Health* recommended that, to "help the public distinguish objective, empirically based health information from promotional data, Health Canada, in partnership with provincial and territorial health ministries, should take the lead in ensuring the development and implementation of standards for such information".

Health Canada took a major step towards putting reliable health information in the hands of the public when it created the *Canadian Health Network* (CHN), in the summer of 1998.

The Canadian Health Network: A New Standard for Health Information

This bilingual Internet-based health information service, funded by Health Canada, will go a long way to fulfilling the public's health information needs.

Through its "network of networks" of health information providers across the country, CHN aims to establish its Web site as the "*premiere source for Canadians to access health information you can trust*". It provides users with access to timely, credible information on health promotion (healthier lifestyles) and disease prevention from respected government and non-government organizations, in a *non-commercial* format. The CHN Web site has approximately 6,000 Web documents and features 26 major health topics or "health centres", and population groups. It also links to more than 10,000 Internet-based resources.

CHN does not recreate services that already exist. Instead, it pulls together the best health information from more than 700 non-profit organizations, and connects Canadians to high-quality local, regional and national health information and resources from these partners.

For example, CHN's partner for information about cancer is the Canadian Cancer Society; for *women's health issues*, the Canadian Women's Health Network; for *relationships*, the B.C. Council for Families; and for *substance abuse*, the Canadian Council on Substance Abuse. Other partners include other federal departments, provincial and territorial governments and community-based organizations, libraries and universities.

The CHN site contains a number of helpful *interactive* resources such as a "newsstand" and discussion groups that link visitors to its site with others who have common interests. This offers much-needed support for those coping with problems.

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To ensure the health information it provides Canadians is of the highest quality, and that it is “relevant, credible, accurate, up-to-date and accessible” (easy to retrieve, phrased in plain language), CHN adheres to rigorous *quality control* standards. Its partners also have their own quality assurance standards to make sure the information they provide meets the same stringent criteria.

In the words of Susan Margles, Executive Director of the Canadian Health Network: “We aim to ensure that CHN is a useful tool for Canadian consumers. It’s a way of helping manage the increasing consumer demand to be involved and be informed, and a good place to start, to reach an informed health decision.”

CHN offers a convenient “antidote” to reams of computer printouts. It provides users seeking health information with “manageable chunks of quality-assured information”.

Some Interesting Statistics

According to the latest public opinion research, most Canadians who are searching health-related Web sites are looking for disease-specific information; information on diet and nutrition; general health information; and fitness information; whereas Gen Xers are mainly interested in prevention (fitness, nutrition, women’s health).

Internet users seem to show a clear preference for Canadian health Web sites. More than half of Canadians surveyed who sought health information on-line had visited a Health Canada site; and more than a quarter, CHN’s site.

The Internet is facilitating the ability of health stakeholders to move information more efficiently and effectively. Canadians are also relying increasingly on it as a key source for health or medical information.

The number of Canadians seeking health information on the Net rose by 30 per cent in the past year. While non-profit and professional medical association Web sites scored higher as a source of health information for Canadians, government sites came a close second.

Respondents to a recent Angus-Reid survey reacted positively to the idea of a planned Canada Health Portal as a single-entry point on the Web for health information and services in Canada - so long as the site provides credible information and improved organization (compared to other sites).

Seventy per cent of visitors to Canadian health Web sites agreed that a single-“window” - such as CHN - makes it easier for them to find the right information. However, Internet users do not rely totally on the Web for health information. Close to half follow up with a doctor to check the accuracy of the information they find.

All governments in Canada are trying to capitalize on the power of the Internet. Over time - as part of their overall vision for health care in Canada - they want to create a means of access to health information for all Canadians, no matter who is seeking the information, whether they are an individual, a health care provider, a health researcher or a hospital administrator.

Issues and Challenges

The provision of solid, reliable health information to the public raises a number of important issues and challenges.

ISSUE #1: WHO SHOULD PROVIDE HEALTH INFORMATION TO THE PUBLIC?

The general consensus among Canadians, from a recent Angus-Reid survey, is that the federal government is in the best position to manage Web-based health information for the public by overseeing the implementation and daily operation of a “Health Portal”.

Canadians see such an undertaking as a possible partnership venture between various levels of government and not-for-profit organizations and universities. This would add credibility to the site and provide useful checks and balances with respect to ensuring accuracy of information and guarding against any vested interests.

ISSUE #2: HOW DO YOU MAKE HEALTH INFORMATION MORE ACCESSIBLE FOR CANADIANS?

This is tough challenge for Canada’s health information providers. Time and again, Canadians told the National Forum on Health that uneven access to health information - due to differences in language, literacy, culture and age - make it difficult for them to obtain information.

Getting health information in a minority language such as certain aboriginal languages, or in a bilingual format, or in English for Anglophones in Quebec can be a problem.

Currently, the Internet offers far more information in English than in French. The Canadian Health Network site is committed to providing health information in both official languages and works closely with its affiliate partners to provide information in both English and French.

Equity demands that governments become involved in seeing that Canadians’ linguistic needs are met. The Canada Health Infoway clearly advocates that Health Canada should take a leadership role in ensuring that health information and health care applications for the public are developed to be accessible to all citizens, “irrespective of their geographic location, income, language, disability, gender, age, cultural background or level of traditional or digital literacy”.

It also suggests that Health Canada work with federal departments and agencies, and specialists, to encourage development of an Internet search capability specific to health that meets the needs of both communities equally.

For patients or caregivers who require assistance at any hour of the day and night, telephone hotlines such as Quebec’s Info-SantÉ service, provide access to skilled nurses by telephone 24 hours a day, seven days a week; this may be the best way to provide information.

Not only has this service dramatically reduced the number of trips to Quebec hospital emergency rooms; it has also helped individuals take charge of their own health. In 1997-98, 95 per cent of the 2.4 million Quebecers who used this service said it helped them find a solution.

Since 1998, the Government of Canada has been focussing on developing a *citizen-centred* service strategy, based on detailed surveys of citizens' needs and expectations. Getting Government On-Line has been a key enabler in improving access to health and other information, as well as in improving service to Canadians.

However, the "digital divide" between Canadians who do and those who do *not* have computer skills is a concern. Even though 60 per cent of Canadians reportedly used the Internet recently (and this number is rising), many still do not know how to use information technology or access health information on the Net.

Because of these considerations, policies on public access to health information need to focus on more than just *delivery technologies*. They also need to consider the most appropriate *format* for communicating this information.

ISSUE # 3: HOW DO YOU ENSURE THAT THE FORMAT HEALTH INFORMATION IS PROVIDED IN, WILL BE USEFUL TO PEOPLE?

The way information is "packaged" influences how "digestible" it will be. As Canadians told the National Forum, providing different levels of health information in different formats such as audio (for people with literacy or visual impairments), video, computer and print is vital, to effectively reach consumers.

For homeless Canadians, improving access to information may mean improving linkages with outreach programs, hostels, psychiatric institutions and the police.

Increasing health information directed at children would be an investment in Canada's future.

Posters, pamphlets, fact sheets, 1-800 numbers, working with consumer and health organizations to support their demonstration projects or launch consumer information campaigns - all are useful ways for governments to reach the broader public.

Whatever the format used to present health information, it is obvious that people *process information* in different ways. Some may find a *personal testimonial* to a health product or service far more comprehensible and convincing than a review of extensive medical information on a clinical trial.

On the CHN site, search functions make it easy for people to find information. Likewise, CHN has strict guidelines about how people "take in" information. They ensure their health information is presented in "plain language". Another handy feature, "Frequently Asked Questions", takes large chunks of complex information and breaks it into manageable, *user-friendly* "bites".

Another challenge that stakeholders who provide electronic health information must meet is the need to *constantly update* information - so that users can trust its reliability. The Canadian Health Network, for example, has a full-time Web administrator. Information is catalogued in a highly evolved "metadatabase", with a sophisticated search engine that allows easy retrieval. CHN is constantly adding new resources to its site, and its affiliates regularly update the information they provide.

ISSUE #4: HOW DO YOU BUILD PARTNERSHIPS WITH PROVIDERS - WHO ARE INTERACTING DIRECTLY WITH THE PUBLIC - SO THEY CAN HELP SHAPE THE INFORMATION THAT IS MADE AVAILABLE TO THE PEOPLE WHO COME TO SEE THEM?

Health intermediaries and consumer organizations - in addition to family and friends - play an invaluable role in situations when an individual is under stress, or requires support or help. In such instances, electronic health information would be a poor replacement for the personal contact they can provide.

Because these providers are working on the "front lines", they need to be up to speed on the latest developments in health information and the newest forms of treatment, in order to counsel their clients effectively.

They need to be able to answer the question: "Would this be useful for me?" and to advise clients on the best course of action or the full range of options available to them, including alternate medicines or alternative forms of treatment.

People's needs for health information vary widely, depending on their particular situation and condition. Ultimately, a *combination* of several of the methods we have outlined for providing information to the public is often what works best.

Summary

Health Canada's efforts to make health information available to the public *electronically* represent a giant leap forward. The Internet is a key tool that provincial, territorial and federal governments, and community groups, are using to put accurate, up-to-date health information in the hands of Canadians.

The federal *Government On-Line* (GOL) project, which began a few years ago to "connect" the government to citizens, is leading the way electronically by linking health information and services in the federal, provincial, territorial and private arenas and providing improved health information to Canadians.

The long-term vision is a health portal which will give Canadians efficient and effective, "single-window" access to authoritative, integrated health information and services, regardless of who they are or where they live.

It will enable them to become knowledgeable about health issues, to take responsibility for their own well-being and to participate fully in health care decisions, resulting in the best possible health information and health care for all health consumers in Canada.

It is therefore essential for us to ensure that the decisions we make with regard to health information for the Canadian public continue to move us towards that goal. The health information initiatives that we, at the federal government, have begun with our provincial and territorial partners are important building blocks in making this vision a reality.

