



Web Review

Healthcare Consumer Information on the Web

By Mike Moralis

The Baby Boom generation has a demonstrated track record in North America of challenging authority and shaping society, and its members are demanding consumers. As they age, they are becoming increasingly concerned about health. At the same time, the Internet has the potential to shift the balance of power between consumers and providers, at least in terms of access to information.

The consumer healthcare-activist movement is more advanced in the United States than anywhere else, and both Web sites and on-line discussion groups are common tools. There is less evidence of such a movement in Canada on the World Wide Web, although the development of such a movement concerns policy-makers and professionals across the country. While the push to increase the accountability of the healthcare system to consumers through report cards and other mechanisms is commendable, it does not appear to be driven by a grassroots consumer activist movement – at least, not so far in Canada.

The collective power and influence of healthcare consumers is magnified in the U.S., because of market forces that, at least as yet, are not replicated in Canada. In the simplest terms, consumers increasingly see themselves as customers and want to get their money's worth for insurance or out-of-pocket expenditures. Canadian users of healthcare services have so far been relatively silent in terms of a web presence, perhaps because they are less concerned than their counterparts to the south about

getting value for their healthcare dollars, which are predominantly paid through taxes. When Canadian healthcare consumers do band together, it is generally along disease-specific lines. Canadian healthcare consumer information on the Web to date is mainly aimed at managing consumer utilization.

1. CONSUMERS' ASSOCIATION OF CANADA (CAC)

<http://www.consumerreports.org>

The Consumers' Association of Canada (CAC) evolved from a coalition of women's organizations during WWII. Its mission is to inform and educate consumers and lobby on their behalf. Its efforts are diffused because the interests of consumers are scattered. The CAC says healthcare consumers have the right to:

- be informed;
- to participate in decision-making affecting their health;
- be respected as an individual with a major responsibility for their own health care; and
- equal access to health care regardless of the individual's economic status, sex, age, creed, ethnic origin and location.

The CAC's interest in health is not evident on the Web. Based in Ottawa with provincial chapters, the national organization doesn't even have a home page, although some provincial offices do. This contrasts with its U.S. counterpart, the non-profit Consumers Union, which publishes the magazine *Consumer Reports*. For the nominal fee of \$2.95 (U.S.), anyone can get a month's access to

Consumer Reports Online, which includes an archive of more than 60 health-related feature articles. These range from comparative reports ranking the "best" Health Maintenance Organizations to reports on diseases, conditions and treatments.

2. CONSUMER WORLD

<http://www.consumerworld.org>

Consumer World is the Web site of Edgar Dworsky, who says he is a consumer advocate and educator, as well as an attorney. He offers about 60 links, aimed at providing U.S.-based consumers with a variety of information to help them make informed decisions. Consumers can check a physician's board certification, compare health plans, look at various hospital report cards and check out the latest medical breakthroughs. One link offers access to live or televised cosmetic surgery procedures via the Internet.

3. TORONTO REFERENCE LIBRARY'S CONSUMER HEALTH INFORMATION SERVICE (CHIS)

<http://www.mtrl.toronto.on.ca/centres/chis/index.html>

The Toronto Reference Library's Consumer Health Information Service (CHIS) is funded by the Ontario Ministry of Health. The CHIS has a special collection of various physical resources including news clippings, pamphlets, brochures and books that can be viewed at the library. The service also offers limited telephone consultations and will prepare information packages for people outside the local calling area.

The key electronic resource consists of one of the best compilations anywhere of electronic databases and links to more than 300 health-related Internet sites, mostly in the U.S. and Canada. They are arranged according to topics that are not restricted to diseases, but include three separate sites, one Canadian, for rare disorders. It indicates which sites are Canadian, and even notes whether they are bilingual. The resource also includes links to sites that assist in web site evaluation, as well 15-20 general search engines and about 20 medical search engines.

4. U.S. NATIONAL LIBRARY OF MEDICINE

<http://www.nlm.nih.gov>

The U.S. National Library of Medicine is the largest biomedical library in the world, with extensive resources on everything from medical history to biotechnology. In addition to news, its web site offers access to numerous databases including the Visible Human Project, an on-line human anatomy resource. It also provides search capabilities through MEDLINE and MEDLINEplus. Resources accessible through MEDLINEplus include medical dictionaries, health topics with links to information for consumers, links to catalogues and clearinghouses of health information, resources available from various arms of the federal government such consumer-health information from the National Institutes of Health, and directories of U.S. hospitals and doctors.

5. MEDICONSLT.COM

<http://www.mediconsult.com>

Mediconsult.com is a leading provider of patient-focused health information via the Internet. It offers free access to consumer information about more than 65 medical conditions contained in a searchable database. The web site features educational material, journal articles, on-line support groups and interactive e-mail with medical specialists. One partnership is a link with CenterWatch, which provides an interna-

tional listing of about 5,000 clinical trials enrolling patients. Mediconsult.com, headed by Canadian Ian Sutcliffe, has grown rapidly over the past two years. Recent developments include a relationship with the Ontario Hospital Association that has seen the fledgling development of YourHospitalAtHome, in which content developed by Mediconsult.com can be incorporated into an individual hospital's web site for a fee. In December 1998 Mediconsult.com acquired all rights to the Pharmaceutical Information Network (PharmInfoNet) and its award-winning Web site, www.pharminfo.com, which provides direct-to-consumer marketing. As a result, Mediconsult.com now claims the highest traffic of any healthcare web sites.

6. INTELIHEALTH

<http://www.intelihealth.com>

Intelihealth is a joint venture of Aetna U.S. Healthcare and the Johns Hopkins University Hospital and Health System. The web site provides access to a wide spectrum of health information aimed at both consumers and providers. One of the key content providers is the U.S. National Health Council, the not-for-profit umbrella for more than 100 agencies, associations and foundations focused on specific diseases and conditions. Another information stream comes from the U.S. National Institutes of Health, an umbrella organization for scientists and researchers. The Web site offers comprehensive, well-organized information including Intelihealth newsletters, access to consumer and medical journals and drug databases.

7. HEALTHWORLD ONLINE

<http://www.healthy.net>

HealthWorld Online is an attempt to bridge the conventional, provider-driven medical culture and the more consumer-driven culture of alternative medicine. The web site bills itself as "the only Internet health network that integrates both alternative and conventional health information into a synergistic whole,"

Check Them Out!



offering links to both. Its emphasis is “self-managed care” with a focus on health rather than on illness or on increasing efficiency and cost-effectiveness – although these motives are not mutually exclusive. The web site is a good central source of information about traditional medicine, and alternative and complementary therapies.

8. MAYO CLINIC HEALTH OASIS

<http://www.mayohealth.org>

When it comes to basic consumer information about illness and disease, one of the most comprehensive sites is the award-winning Mayo Clinic Health Oasis, the web site of the Mayo Foundation for Medical Education and Research. Updated daily, it has extensive, up-to-date information about diseases, ailments and conditions, but there are also many extras. The consumer-oriented web site is searchable, and offers a wide range of online resources including a glossary of medical

terminology with an audio pronunciation guide. One feature of the library section is a guide called How Your Body Works. Another feature is the guide to medical tests and procedures. The Mayo Clinic offers a free weekly e-mail bulletin, and there is also a product showcase for various publications available through the site.

9. HEALTH FAMILIES USA


<http://www.familiesusa.org>

Health Families USA is a Washington-based non-profit, non-partisan organization with a 15-year track record of lobbying for “high-quality, affordable health and long-term care” for Americans at the national, state and local levels. Understandably, there’s a strong emphasis on the national Medicare and Medicaid programs. In addition to advocacy and policy analysis, Families USA is also a clearinghouse of information for consumers. The web site offers access to a newsletter and a variety of

other publications, as well as a listserv for discussions. The resources site has about 65 links divided into five categories: research and advocacy organizations; child health sites; senior issues groups; managed care sites; and government agencies.

10. SOCIETY FOR HEALTHCARE CONSUMER ADVOCACY

<http://www.shca-aha.org>

The Society for Healthcare Consumer Advocacy of the U.S. dates back to the National Society for Patient Representation, founded in 1972. Affiliated with the American Hospital Association (AHA), the mission of the SHCA is to “lead the advancement of healthcare consumer advocacy by supporting the role of professionals who represent and advocate for consumers across the healthcare continuum.” The web site includes a link to the AHA’s Patient Bill of Rights and about 30 other sites, mostly for professional associations. 

Conferences

Developing and Implementing Performance Measurement in Healthcare

February 18-19, 1999
Toronto, ON
Contact: *The Canadian Institute*
Tel: 416 927-0718

Medical Call Centers: Legal Issues

March 12-13, 1999
Pensacola Beach, Florida
Contact: *Sheri Watson*
Tel: 1 888-242-5240 or 850 469-5758
Email: *SWatson@bhcpns.org*

Joint National Conference on Quality

Presented by: Canadian Council on Health Services Accreditation, Canadian College of Health Services Executives and The CQI Network.
March 15-16, 1999
Toronto, ON
Contact: *Suzette Besner, CCHSE*
Tel: 613 235-7218, ext 26 or 1 800 363-9056, ext. 26
Email: *sbesner@cchse.org*

Telemedicine and Distributed Medical Intelligence Conference: Leadership for Next Century Medicine.

March 16-18, 1999
Steamboat Springs, Colorado
Contact: *Telemedicine Center,*
Tel: 252 816-2695
training@sparky.med.ecu.edu
<http://www.telemedtech.com>.

4th Annual HEALNet Conference

March 28 -30, 1999
Calgary, AB
Contact: 613 241-9333
Fax: 613 565-2173
Email: *gpi@intranet.ca*

Partnering in Healthcare Conference

April 7 - 8, 1999
Toronto, ON
Contact: *The Canadian Institute*
Tel: 416 927-0718

Creative Financing Options in Healthcare Conference

April 9, 1999
Toronto, ON
Contact: *The Canadian Institute*
Tel: 416 927-0718

15th World Congress on Occupational Safety and Health

April 12-16, 1999
Sao Paulo, Brazil
Contact: *15th World Congress on Occupational Safety and Health Secretaria, Rua Capote Valente, 710, 05409 Sao Paulo Sp, Brasil.*

Health Services Research Awareness Day

Queen's University
April 29, 1999
Kingston, ON
Contact: *Queen's Health Policy Unit,*
Tel: 613 545-6387

Catholic Health Association of Canada 1999 Convention

"Living with Integrity: Ethics as the Soul of Health Care"
May 15-17, 1999
Saskatoon, SK
Contact: Tel. 613 731-7148
Fax: 613 731-7797

World Symposium for Central Service Personnel Infection Control, O.R.

May 16-20, 1999
Orlando, Florida
Contact: *Nancy Chobin*
Tel: 908 730-8902
Fax: 908 730-6025
Email: *nchobin@worldnet.att.net*

12th Annual CHEPS Health Policy Conference

Treatment Decision-Making in the Clinical Encounter
May 19 - 21, 1999
Hamilton, ON
Contact: *Keith Monrose, Conference Coordinator, Centre for Health Economics and Policy Analysis, McMaster University*
Tel: 905 525-9140 ext. 23198
Fax: 905 546-5211
Email: *monrosek@fhs.mcmaster.ca*