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To cite this article: Jivesh Sharma, Kristi Dover & Ellen Magnis (1999) Harnessing the Internet for Cancer Care, Oncology Issues, 14:5, 14-15, DOI: [10.1080/10463356.1999.11905085](https://doi.org/10.1080/10463356.1999.11905085)

To link to this article: <https://doi.org/10.1080/10463356.1999.11905085>



Published online: 17 Oct 2017.



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Harnessing the Internet for Cancer Care

by Jivesh Sharma, M.D., and Kristi Dover, Pharm.D., and Ellen Magnis, M.B.A.

The Internet is the fastest growing medium in history, gaining fifty million users in a five-year period. Television took thirteen years and radio thirty-eight to achieve the same usage rate. By 2002, it is estimated that half of the U.S. population will be on the Internet.¹ Web surfers are twice as likely to have high incomes, college degrees, and management positions than the overall population. It is therefore no surprise that businesses are turning to the Internet in record numbers in an effort to reach this attractive target market.

Health, along with sports and entertainment, ranks highly among the types of information people seek online.² Internet users seeking health information, dubbed "Health Med Retrievers," are more likely to be women. The 50-plus population seeks more health information than any other age group, closely followed by 30- to 49-year-olds. These web surfers are searching for specific information at physicians' web sites as well as more general information pertaining to fitness, stress, diseases, injuries, prescription drugs, diet supplements, support groups, and health insurance.³

Because of the vast amount of information available on the Internet,

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national health portals are emerging, such as www.Onhealth.com, www.AHN.com (America's Health Network), Medscape.com, and www.DrKoop.com. These portals target the consumer population and consolidate information into a navigable format. Other portals have a regional focus, such as www.TexasHealthGuide.com.

According to the president of AHN.com, the most popular area of the AHN site is the "Diseases and Conditions" area, with cancer second only to alternative medicine in popularity.⁴

PROFESSIONAL TOOLS

A powerful way to improve the delivery of oncology services is through the communication of current, comprehensive, and accurate information among researchers, patients, and care providers. There are several on-line resources and web-based tools to assist oncology professionals in their day-to-day practice. Oncolink (<http://www.oncolink.upenn.edu>) is an example of a tremendously successful oncology Internet site. Oncolink was founded in 1994 by University of Pennsylvania cancer specialists with a mission to help patients with cancer, families, health care professionals, and the general public find accurate, cancer-related information at no charge. Between March 1994 and June 1999, Oncolink recorded more than 130 million transactions from more than four million unique addresses.⁵

Practicing oncology clinicians also have an unprecedented number of on-line resources to draw upon to support patient care. Disease-related information, access to clinical trials, information about grants, literature searches, journals, and professional organizations are all

part of a growing pool of on-line resources. Additional examples include:

■ NCI's CancerNet (<http://wwwwic.nci.nih.gov>). Using this site, a clinician can easily access a full spectrum of information by disease site, ranging from prevention to treatment.

■ PDQ [Physician Data Query] (<http://wwwwic.nci.nih.gov/pdq.htm>). This service provides peer-reviewed treatment summaries. Health care professionals can search national PDQ clinical trials (<http://wwwwic.nci.nih.gov/prot/protrsch.shtml>) by multiple criteria, including diagnosis, phase, modality, drug, and location. The results of the search provide basic information regarding the study overview (including eligibility criteria) and the contact information for the principal investigators.

■ NCI's Cancerlit (<http://cnetdb.nci.nih.gov/cancerlit.shtml>) is a database of more than 1.4 million records of cancer literature that is updated monthly. It is a truly functional tool designed to support day-to-day patient care and continuing education.

■ The *Journal Of Clinical Oncology* (<http://www.jco.org>) provides searchable abstracts and tables of contents.

■ Professional organization web sites, such as the American Society of Clinical Oncology (www.asco.org) and the American College of Radiology (www.acr.org), now offer clinical practice guidelines, CME, regulator watch updates, and on-line journal clubs.

Clearly, the pool of resources will continue to grow. Adding web-based resources to work flow is both an affordable and efficient reality for clinicians.

CHANNELING INFORMATION

The Internet has sparked an information revolution. No one is barred from publishing or accessing information. Yet, accessibility is both the strength and weakness of the Internet. Since there is no FDA equivalent to oversee scrutiny of Internet content, one can anticipate that for every bona fide site, there will be others promoting information of questionable value. Unsophisticated users, especially those coping with life-threatening health problems, are vulnerable to grasping at straws of hope. Thus, it is important that information seekers be directed to reliable sites.

Many oncologists find that communication is more effective and efficient when speaking with a patient who has become more informed about his or her disease. University and NCI-based web sites, as well as on-line support groups, such as those at the Association of Cancer Online Resources (www.acor.org), often provide excellent general information for patients. Frequently the result is a patient-physician dialogue focused more on the specific issues of the individual patient's case. However, discussions can become far more complicated when the patient's interpretation of available information differs from that of the physician. As one gynecologic-oncologist discovered, a patient may be so adamant about her understanding of the information that she may insist upon third or fourth opinions.⁶

Alternative medicine may offer hope and potential for many patients with cancer. It is well-known that patients often associate terms like "natural," "herbal," and "plant extract" with the idea of a medicinal treatment that is more effective and less toxic than conventional medications. The vulnerability of oncology patients reinforces the need for accurate and unbiased information about these substances. It is worth noting that much of the alternative medicine information on the Internet is provided by merchants in pursuit of a sale. The quality of information viewed by patients often depends on the integrity of the organization selling the product. Some sites have been criticized for providing

incomplete or inconsistent information about the safety of their products.⁷

A physician practice web site can be a valuable tool for directing patients to credible information. This task is accomplished by providing a hyperlink from a practice web site to trusted sites such as the American Cancer Society (www.cancer.org).

In addition to helping patients navigate the breadth of information, some cancer care facilities use the Internet for marketing purposes. However, developing an initial marketing-oriented web site is merely a first step. The true functionality of the web channel lies in the ability to communicate asynchronously (when it is most convenient for both parties). It is possible to exchange basic business information via this channel in a manner that lowers access barriers for patients and partners, while allowing for improved handling of requests in the office environment. The potential gains provide an opportunity for office workflow redesign, improving access and efficiency while lowering costs. Ultimately this web channel is ideally suited for disease management, supporting wellness through information and access.

The widespread availability of Internet access has revolutionized the way many cooperative research groups operate. For example, the Southwest Oncology Group, or SWOG (www.swog.org), launched its site in 1994. Prior to that time, SWOG mailed more than two million pieces of paper each month. Now, the majority of protocols, updates, consents, and policies can be downloaded. The site also has an electronic form for reporting research-associated adverse drug reactions. Data are transmitted via e-mail directly to support personnel for immediate follow-up the next business day. These techniques yield more rapid and less expensive communication with the 273 web-enabled SWOG sites.⁸ Although an obvious decrease in photocopying, postage, and man-hours has been observed, the net savings after technology investment and support have not been formally evaluated.

Because of the challenges associated with the communication of

medical information, the government is developing encryption guidelines and standards as called for by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). There are clearly some forms of information that are appropriate for communication by e-mail and some that are not. The American Medical Informatics Association published the first guidelines for communication of health information using e-mail: (<http://www.amia.org/pubs/pospaper/positio2.htm>).

There have been dramatic advances in the presence of oncology-related resources on the Internet. These trends will continue and we will see the further maturation of virtual communities as mainstream America goes on-line. These communities will use Internet tools to access support for wellness, disease management, research, and treatment. Care provider organizations will continue to build virtual front desks and ultimately the lowest cost practice of all...the virtual cancer care practice. ■

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