

A comprehensive review of selected cancer websites

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Abstract

With increasing availability of information on the Internet, it makes sense for health care professionals to use this resource to expand the range of resources available to both themselves and to clients. This paper was designed to provide health care professionals with a starting point from which to gather further website oncology resources. An established template for evaluating websites is described and criteria regarding the accuracy of information, site design, and navigation are examined. While the initial phase of this paper evaluated numerous sites, only the top five as noted by the author are presented here.

Individuals have various needs that arise during the different stages of their cancer. DeGrasse and Hugo (1996) cite the Ontario Cancer Treatment and Research Foundation definition for the Supportive Care Framework which addresses the following needs: physical, emotional, informational, psychosocial, spiritual, and practical. Each of these areas is important in determining how the individual copes with his or her diagnosis. Searching for information is a commonly used coping mechanism once an individual is diagnosed with cancer. Furthermore, the patient controls the amount and technical degree of information that he or she seeks (DeGrasse & Hugo).

Increasing numbers of patients and families are using the Internet as a means of gathering information and support. Professionals are then often faced with questions about information obtained this way. With the explosion of resources available via the Internet, including the number of website links to cancer information, it makes sense for health care professionals to utilize this information to expand their knowledge base.

It can be quite overwhelming for health care professionals and patients to access information about a particular type of cancer, treatments, clinical trials, research data, or statistics. A general scan of different search engines such as Altavista, Yahoo, and Excite! can turn up millions of hits. Altavista logs more than 3.5 million sites reporting

information on cancer. Yahoo reports 92 categories and 2,385 sites for cancer. Excite! logs more than 372,000 sites on cancer. There are many different focus areas for cancer information.

Grahn and Swenson (1998) state that, "the Internet is one of the newest, fastest-growing, and most visible examples of changes in technology, communication, and marketing" (p.231). There are many aspects of the Internet from which the health care professional/patient/families can look for information, such as websites, newsgroups, e-mail lists, and cancer-related chat rooms. This paper, however, will specifically look at websites for cancer.

This paper evaluates five cancer websites chosen by the author for their comprehensiveness and wide range of reliable, relevant information. The websites were evaluated using two main categories: types of information provided and categorical review of web design. For patients and health care workers searching for information, there are many sites that look at general and specific information about cancer. These sites provide information about defining cancer, as well as how to treat specific cancers using chemotherapy, radiation, and/or surgery. Some sites break down the cancers by body site/system. Other sites examine some of the complementary and alternative interventions that have been demonstrated to work in conjunction with standard cancer treatments. Several of the sites provide definitions of specific terms used, particularly if the site is aimed at the general public.

Joel Goldwein and Ivor Benjamin, editors-in-chief of OncoLink (a service of the University of Pennsylvania Cancer Center), provide a valuable template to evaluate cancer websites. OncoLink uses the following categories for the evaluation criteria: 1) accuracy of information, 2) availability of editorial staff, 3) qualifications of editorial staff, 4) freshness of content, 5) disclosure of conflicts of interests, 6) price of information, 7) confidentiality, 8) reputation, 9) look and feel, and 10) navigation and searching. The editors define each aspect of what they expect to find in each website for cancer. This OncoLink resource was the template used for reviewing the following five websites.

American Cancer Society (ACS) (<http://www.cancer.org>)

The American Cancer Society is a national voluntary organization. This website examines the various education, resources, actions, research, advocacy, and care which the ACS provides. Information is available in English and Spanish.

1. The information posted here is properly referenced with peer-reviewed material (journals, texts, periodicals).
2. E-mail contact is made available through this website. The site asks for e-mail, name, address, phone number, and type of information requested. It also states that due to the volume of e-mail requests or comments, responses may take up to 10 days. However, a 1-800 number is provided if immediate response is required.
3. The editorial staff collect information for review of education, resource, and research materials for this website. Positions include a) a medical editor who is a board-certified physician in oncology medicine with a minimum of five years clinical experience, computer literate, and comfortable with the Internet; b) a project manager for web community who has a bachelor's degree in humanities, marketing, or management, and has a background in health care or non-profit groups; c) a web developer who has a bachelor's degree or equivalent in education and two years experience in developing, managing, and marketing of Internet sites; and d) a web master who has a bachelor's degree in computer science plus three years experience with networked computers, one year in a web master role, or equivalent combination in education and experience.
4. The American Cancer Society is updated daily with new information as it becomes available. The index page includes the ACS News Today, which has daily news and information.
5. No disclosure of conflicts noted.
6. The information provided on this site is free to access. There is a link to free brochures and information provided by the American Cancer Society. The ACS also has a bookstore where specific books or journals on cancer can be bought, either by phone (credit card orders only), cheque or money order (by mail), or on-line via a secured site (credit card orders only) via a partnership with <http://www.atnazon.com/>
7. If buying products from the bookstore, a secured website is provided so that credit card purchases are encrypted for security. As well, donations to the ACS via the web are possible through a secured website. E-mail requests to the ACS are examined in confidence, as specific patient information may be requested before further advice or suggestions are given.

8. Resources are provided by researchers and clinicians in oncology who work toward improving the provision of cancer information from the American Cancer Society.
9. This website is well laid out and requested information is quite easy to locate. Toolbars allow you to locate the information quickly. There are few graphics on the main site, so downloading of information is quick.
10. If the user is unable to immediately locate specific information, an internal search engine is available to find that material. The site also provides a comprehensive resources list so the user can check out other resources, both internal to the site as well as external links.

Canadian Cancer Society (CCS)

(<http://www.cancer.ca/>)

This site provides information about the different aspects of cancer, from signs and symptoms to treatment and resources, as well as cancer statistics for Canada. It also looks at Canadian research in oncology, as well as services provided by the Canadian Cancer Society. The CCS is a voluntary agency. Information is provided in English and French.

1. Information provided falls in accordance with the American Cancer Society website.
2. Questions or concerns regarding the site can be directed to Darla McKay at webadmin@cancer.ca
3. Darla McKay is a web administrator for the Canadian Cancer Society and the National Cancer Institute of Canada.
4. There are no dates of when information is posted or updated.
5. No disclosure of conflicts noted, though there are many sponsors of the Canadian Cancer Society as it is a voluntary agency which relies on donations, both private and

corporate. This website lists the sponsors of the CCS.

6. Information provided on this site is free of charge to the user.
7. The Canadian Cancer Society notes on the website that users should submit private information to their Cancer Information Service by phone (1-888-939-3333), Monday to Friday, 9am-6pm, while general information requests can be sent via e-mail to info@cis.cancer.ca. Donations can be made at local offices of the CCS, rather than on-line donations.
8. The Canadian Cancer Society has been in existence since 1937 and is associated with the Canadian Medical Association's National Study Committee on Cancer Research in Canada.
9. This site does not have very many graphics, thus making it quick to download material. The look is clean and free of cluttered information. The information is laid out in a well-designed format. The on-line pamphlets are clear and well designed. The data are up-to-date in accordance with current data available.

10. This site is quite easy to navigate. Download time is quick. Links connect to the appropriate pages. There is no search engine available on the site, however, if you require further information the site does provide links to the American Cancer Society - <http://www.cancer.org> and the National Cancer Institute (USA) - <http://www.nci.nih.gov>

CancerGuide: Steve Dunn's Cancer Information Page

(<http://www.cancerguide.org>)

Steve Dunn's guide to cancer information is designed to help people find both information on cancer and resources. He offers a guide on how to research cancer information, as well as providing some links to medical sources of

data.

1. Though the information is well researched, Mr. Dunn is not a physician or medical expert. He has spent a lot of time doing research for his own cancer experience and has chosen to share this information with others.
2. Steve Dunn - steve.dunn@cancerguide.org. Mr. Dunn is a cancer survivor who teaches information on cancer clinical trials.
4. Content on each page of this site is updated as new materials become available. For the most accurate information, he refers the user to other sources, such as CancerNet, as well as links to oncology books.
5. No disclosure of conflicts noted.
6. The information on this site is free to the user.
7. Mr. Dunn provides a link where people can include their stories about their own experiences with cancer. This area does require information about the user, however, it is voluntary as the user does not have to include his or her own experiences. There are a few guidelines that Mr. Dunn sets out for including stories, which are available via a link in his site (Dunn, 1999).
8. Mr. Dunn specifies that he is not a physician and requests that any individual questioning their health/illness consult their physician, though the material may assist the user in the types of questions to be asked.
9. The site is text only with the exception of a few diagrams. The information is well presented and in a format that can easily be understood by the user. The information is quick to download and a site map assists the user to find information.
10. The links within and from this site work easily. There is no search engine on this site.

CANO is on the web!!!

In search of CANO's web pages? Here's how to find us:

- go to the Canadian Oncology Society's (COS) website, found at www.cos.ca
- when the COS home page appears, click on the number 5 in lower portion of left-hand side of screen; this will take you to the next screen
- on the left-hand side of the new screen, click on "Affiliated Societies"
- members of COS will appear. Scroll down until you find CANO
- click on CANO's name
- you will arrive at CANO's home page where the philosophy, mission, and goals and objectives are easily viewed
- CANO's home page also allows you to obtain a membership form and/or obtain access to CANO's secure web pages
- if you want to obtain a membership form or learn more about membership benefits, click on "Membership Application and Benefits" • to access CANO's secure web pages, click on "CANO members"
- follow directions to obtain your password
- once you have your password, your journey through CANO's web pages will begin!!

Have fun learning more about CANO! Don't forget - your comments are important to us. Please let us know how we are doing by e-mailing the web pages working group at r3kchapman@health.nb.ca.

CancerNet (A service of the National Cancer Institute [NCI]) (<http://cancernet.nci.nih.gov>)

This site provides a comprehensive gathering of cancer information in order to provide resources to patients, friends and families, and health care providers. Research data, statistics, available treatments, clinical trials, signs and symptoms, specific cancers information, as well as supports and resources are highlighted.

1. The information on this site is **compiled** by the National Cancer Institute's office of cancer information, communication, and education (OCICE). Most of the information comes from the NCI's comprehensive database, physician data query (PDQ), whose editorial board is comprised of physicians specializing in cancer.
2. There are several contacts available. The director of the office of cancer information, communication, and education can be reached at directorgicic.nci.nih.gov. The CancerNet staff can be reached at cancernetstaff@mail.nih.gov.
3. Board-certified physicians and specialists in the many types of oncology and related specialties make up the editorial staff.
4. Content is routinely updated on a monthly basis, though new updates are added when available to provide the most up-to-date information.
5. No disclosure of conflicts noted.
6. Information provided free for use by the user, however, there is a licensing agreement

Useful resources

- AltaVista search engine
<http://dir.altavista.com/>
- Amazon On-Line
<http://www.amazon.com>
- American Cancer Society
<http://www.cancer.org>
- Canadian Cancer Society
<http://www.cancer.ca>
- CancerGuide: Steve Dunn's Cancer Information Page
<http://www.cancerguide.org/>
- CancerNet (a service of the National Cancer Institute)
<http://cancernet.nci.nih.gov>
- Excite! search engine
<http://search.excite.com/>
- National Cancer Institute (USA)
<http://www.nci.nih.gov>
- OncoLink (a service of the University of Pennsylvania)
<http://oncolink.upenn.edu>
- Yahoo search engine
<http://ca.search.yahoo.com/>

to universities, commercial, and non-profit organizations.

7. CancerNet respects the privacy of its users. Data about the number of users, domain name or IP address, date and time page was accessed, type of browser used, operating system, and whether or not CancerNet was linked from another site are collected for statistic& reference. E-mail addresses are logged only so that responses can be made to queries. No data are collected that can identify an individual user.
8. As mentioned, this site is managed by the National Cancer Institute, the largest of 17 specializations of the National Institutes of Health. It provides accurate, current information to patients, the public, and health care providers.
9. This website is very well designed and laid out. The topics are broken down by category: types of cancer, treatment options, clinical trials, genetics, causes, risk factors and prevention, testing for cancer, coping with cancer, support resources, cancer literature, and PDQ. There are not many graphics, so the page is quick to download.
10. The Intranet and Internet ~ connect quickly and are easily located. If the user is unable to directly find something on the site, the site provides a "frequently asked questions" (FAQ) area for new users and a search engine for Intranet data.

OncoLink - University of Pennsylvania Cancer Center (<http://oncolink.upenn.edu>)

OncoLink provides a detailed site of hypertext links to information concerning all aspects of cancer in order to improve education, research, and knowledge about cancer to patients, family, caregivers, and health care professionals.

1. The available information has been properly referenced with authors and dates. The information comes from reliable sources within the health care profession.
2. Both postal and e-mail addresses are provided, as well as phonelfax numbers. E-mail: editors@oncolink.upenn.edu
3. Ivor Benjamin, MD, is a gynecologic oncologist at the University of Pennsylvania Cancer Center (UPCC) (ibenjamin@mail.obgyn.upenn.edu). Joel W. Goldwein, MD, is a

References

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radiation oncologist at UPCC (goldwein@crt.upenn.edu). James Metz, MD, is a radiation oncologist and Maggie Hampshire, RN, BSN, OCN, is an oncology clinical nurse, both at UPCC.

4. Site is updated daily with new information, tips, resources, research, and clinical trial information. Included at the top of the page is a "What's New" section.
5. No disclosure of conflicts noted.
8. OncoLink is designed by and based from the University of Pennsylvania Cancer Center.
9. The information is neatly presented, clearly understandable, and has interesting and relevant graphics. The site is well organized and easy to use. The information can be understood by patients, family members, and health care professionals.
10. Easy to find your way around the website through links provided. Links are functioning properly. The site search engine is powered by Altavista.

These cancer websites are recommended by the author of this paper as being the top five web resources for cancer information for health care professionals, patients, and family members. They provide the most comprehensive collection of information regarding the varied aspects of cancer, clinical treatments, resources, supports, and research data. A pamphlet (available in English and French) to complement this paper is currently being used as a patient cancer website resource tool for the Region 3 Hospital Corporation in New Brunswick.

About the author

At the time this article was written, Lynn Stapleton was a third year nursing student at the University of New Brunswick's Fredericton campus.

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