

# Consumer Health Informatics: The Medical Librarian's Role

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by Elaine Russo Martin, MA, MSLS

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*Growing consumer interest in health-related information has created a need for professionals to manage, provide, and interpret such material. In preparing for the new demands of the market, HIM professionals can learn from the example of medical librarians, who are already working to meet those needs.*

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Significant changes in healthcare, coupled with advances in technology, have sharpened interest in health information that can help consumers understand their own health problems and determine treatment options. What's more, research has shown that access to health information can lead consumers to attain better medical outcomes.<sup>1</sup>

Because they are trained in the identification, selection, organization, dissemination, and evaluation of information, medical librarians play important roles in helping consumers locate and choose the best information resources to meet their treatment needs. This article highlights the types of information resources needed by consumers, suggests some reliable sources of Internet-based medical information, identifies roles for medical librarians in providing quality health information to consumers, and presents some issues for further discussion for health information professionals who manage, provide, and interpret consumer health information.

## In Search of Information

Consumer health information needs to be distinguished from patient education information. Consumer health information tends to focus on prevention, wellness, and treatment options. The search for information is initiated by the consumer for themselves, friends, or family members. Patient information, on the other hand, encompasses medical instructions from a health professional regarding a treatment option or alternative treatments. Often, the purpose is to change behavior—for example, written instruction on how to take a drug. The information is initiated by the health professional rather than the patient.<sup>2</sup> This article focuses on consumer health information rather than patient education information.

In order to understand the information needs of consumers, it is important to identify who they are. Library use surveys show that although there is no "general consumer," they generally fall into some broad categories: women, the elderly, the chronically ill, and the disabled. Women remain the primary caregiver for their families. As the population ages and becomes sicker, use of the healthcare system by the elderly increases. The chronically ill patient includes the diabetic, the person with HIV/AIDS, cancer, or other long-term illness. The disabled include the blind, deaf, and physically handicapped. The latter two groups tend to be most knowledgeable about the kinds of information resources available to them and the least satisfied with what they find.<sup>3</sup>

Providers of consumer health information tend to fall into these broad categories: the news media, libraries (public and medical), associations, medical schools, hospitals, health professionals, lay persons, government agencies, drug companies, businesses, and most recently, the Internet or networked electronic information carriers. A number of "cyber communities"—online forums, discussion groups, mail listservs, and bulletin boards—also offer self-help information.<sup>4</sup> A recent magazine article stated there are as many as 12,000 medical Internet Web-based consumer health information sites.<sup>5</sup> While the number is growing daily, many of these sites are not considered reliable.

There are, however, several quality medical Web sites. These include general sites, subject specific sites, lists of lists, access to the National Library of Medicine's MEDLINE database, ask the expert sites, and alternative medicine sites. Table 1 suggests some sites often used by medical librarians answering consumer-related health questions.

*table 1—some sites of interest to consumers*

General sites	American Medical Association Healthfinder	<a href="http://www.ama-assn.org">http://www.ama-assn.org</a> <a href="http://www.healthfinder.gov">http://www.healthfinder.gov</a>
Subject specific sites	Oncolink Kid's Health Centers for Disease Control American Academy of Family Physicians	<a href="http://cancer.med.upenn.edu">http://cancer.med.upenn.edu</a> <a href="http://www.kidshealth.org">http://www.kidshealth.org</a> <a href="http://www.cdc.gov">http://www.cdc.gov</a> <a href="http://www.aafp.org">http://www.aafp.org</a>
Lists of Lists	HealthWeb MedWeb: Consumer Health Biomedical Internet Resources: Patient/Consumer Health Information	<a href="http://www.healthweb.org">http://www.healthweb.org</a> <a href="http://www.gen.emory.edu/MEDWEB.html">http://www.gen.emory.edu/MEDWEB.html</a> <a href="http://www.kumc.edu/service/dykes/RRPAGES/patient/phmpage.html">http://www.kumc.edu/service/dykes/RRPAGES/patient/phmpage.html</a>
Free MEDLINE	National Library of Medicine (PubMed and Internet Grateful Med)	<a href="http://www.nlm.nih.gov">http://www.nlm.nih.gov</a>
Ask the Expert	Netwellness	<a href="http://www.netwellness.org">http://www.netwellness.org</a>
Alternative Medicine	NIH Office of Alternative Medicine	<a href="http://altmed.od.nih.gov">http://altmed.od.nih.gov</a>

## The Roles of Medical Librarians

As the number of sources multiply and the demand by consumers for high-quality, reliable health information likewise increases, medical librarians find themselves in new and challenging roles. These roles include, but are not limited to, the following: teaching, quality filtering, organizing Internet resources, and partnering in order to provide access to more resources.

Although there are still those consumers who want the medical librarian to find the information for them, or just answer the question at hand, there are a number who would like to learn how to find the information themselves. Medical librarians teach formal and informal classes, in groups or one-on-one, on such topics as Internet basics, how to search Free MEDLINE using the National Library of Medicine's PubMed or Internet Grateful Med search systems, and finding health Internet resources on the Web. Tailoring the instruction to meet the consumer's need can be a challenge, since some consumers are very computer literate while others have never even used computers.

Traditionally, medical librarians answer consumer questions by opening a dictionary or other printed text to read a definition, or they quote word for word the usage information and warnings regarding a drug or treatment. They are always careful to cite the source and never interpret the information in any way. With the advent of the Internet, medical librarians have become more discerning about the information resources they give consumers. Some medical librarians are beginning to take a more active role in evaluating the information they give to consumers from the Internet. This includes developing a list of quality filtering criteria and measuring Web-based information sources against that criteria. Criteria may include content criteria such as authority of authorship, reputability of the Webmaster, publication date including date of origination and dates of revision, currency and accuracy of information cited, originality of information, purpose of the site (advocacy, sales, entertainment), and potential for bias. Technical criteria include link checkers in place, search interface design, use of graphics versus text, use of a search engine, and speed of access. Medical librarians are also investigating ways of interpreting the evidence presented in the literature, including carefully examining the study design and research methods and gaining a better understanding of the statistical concepts presented to support or disprove a particular treatment option.

Just as medical librarians have organized and classified printed materials in their libraries, they are involved in national and local efforts to "catalog" Internet resources. Activities may include collaborative projects like Healthweb, for which medical librarians from more than 20 institutions select and group resources according to defined categories within specific subject areas. Locally, librarians may group similar quality resources on their individual library's home page. Medical librarians realize that they are not the sole providers of consumer health information. In order to effectively provide accurate and timely information, medical librarians work in partnerships to share the responsibility for the delivery of health information. Some have formed partnerships with public libraries for the provision of full-text databases and core print collections to the public; others have collaborated with community-based clinics to provide Internet access and resources to underserved inner-city

populations.<sup>6,7,8</sup> In these partnerships, the medical librarian becomes an important link in the healthcare delivery triad of consumer, health professional, and online information.

## Implications for HIM Professionals

Recently the Joint Commission on Accreditation of Healthcare Organizations added a requirement that hospitals institute a systematic approach to providing information for patients and their families. Because of this requirement, many hospital librarians have begun offering some kind of consumer health information service. In 1996, the Medical Library Association also published a policy statement titled "The Librarian's Role in the Provision of Consumer Health Information and Patient Education." Although opportunities for medical librarians in this arena are still evolving, there is no question that consumers need and want access to timely, accurate medical information.

Medical librarians need to develop strong partnerships with all types of health information professionals to understand how best to provide this information, how to evaluate the information for quality, and how to share information across delivery systems—from the library to the bedside. HIM professionals have the background knowledge to assist in defining information system functionality and have the requisite knowledge of current clinical information systems. HIM professionals and medical librarians should work together to link clinical information systems to consumer health databases and design easy-to-use interfaces or single entry points to these resources in order to make the best information available that directly benefits consumers and their caregivers.

## Notes

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