

Assessing, Controlling, and Assuring the Quality of Medical Information on the Internet

Caveant Lector et Viewor—Let the Reader and Viewer Beware

Health care professionals and patients alike should view with equal parts delight and concern the exponential growth of the Internet (the Net), and especially its graphical, user-friendly subset, the World Wide Web (the Web), as a medical information delivery tool.^{1,2} Delight because the Internet hosts a large number of high-quality medical resources and poses seemingly endless opportunities to inform, teach, and connect professionals and patients alike. Concern because the fulfillment of that promise remains discouragingly distant. Technical glitches aside, when it comes to medical information, the Internet too often resembles a cocktail conversation rather than a tool for effective health care communication and decision making.

See also p 1258.

The problem is not too little information but too much, vast chunks of it incomplete, misleading, or inaccurate, and not only in the medical arena.^{3,4} The Net—and especially the Web—has the potential to become the world's largest vanity press. It is a medium in which anyone with a computer can serve simultaneously as author, editor, and publisher and can fill any or all of these roles anonymously if he or she so chooses. In such an environment, novices and savvy Internet users alike can have trouble distinguishing the wheat from the chaff, the useful from the harmful.

This should not be terribly surprising. After all, the Internet is a new and exciting communications medium and, therefore, highly attractive to those whose agendas range from the sublime to the ridiculous.⁵ At first glance, science and snake oil may not always look all that different on the Net. Those seeking to promote informed, intelligent discussion often sit byte by byte with those whose sole purpose is to advance a political point of view or make a fast buck. And naive viewers may be lulled by technological brilliance into placing more value on the content than it deserves, simply because they get it from the Net.

In fact, effective use of technology can be an important indicator of quality—and especially utility—in communicating medical information on the Net. The best digital destinations will employ designs and tools that facilitate navigation through large quantities of information, provide appropriate mechanisms for feedback and interactivity, monitor and maintain the links they've chosen to provide to other sites, and generally commit the resources needed to maintain a useful presence in an increasingly crowded electronic landscape.

But the bedrock on which these technical tools rest is content. And in this regard, the basic issues involved in presenting information on the Internet have changed little since Gutenberg first pulled the lever on his printing press. In the case of traditional print publishing, of course, the rules of engagement have been worked out over 5 centuries. There are standards by which to judge the quality of editorial content, to differentiate author from shill, editorial from advertising, education from promotion, evidence from opinion, science from hype. Those who follow these conventions develop a respected brand identity, establish a level of trust with their readers, and serve as a forum for the kind of informed, intelligent discourse that advances the scientific process and benefits the public health.⁶

Not everyone in the print world plays by these well-established rules. More than a few presses produce little more than empty pages. Nor are the rules under which even the best-known and most-trusted purveyors of medical information function by any means final or foolproof. But at least they provide a base, tested by lengthy experience, on which to operate.

The same set of quality moorings that helps users of medical information navigate in print should apply in the digital world. We believe the time has come to discuss vigorously how such a set of basic quality standards can be developed and applied in an electronic context. Such standards are built on the foundation of accountability—that an identifiable person or group of people stands behind what is being “published” on the Web and in Internet discussion forums. These principles amount to a framework for critical thinking, allowing consumers and professionals alike to reasonably judge whether what they are reading is credible, reasonable, or useful and to make measured, informed decisions about how to apply this information in the real world.

Mr Silberg is Editorial Director, New Media Office, Scientific Information and Multimedia Group (e-mail: Bill_Silberg@ama-assn.org); Dr Lundberg is Editor, *JAMA* (e-mail: George_Lundberg@ama-assn.org); and Dr Musacchio is Vice President of Information Resources and Chief Information Officer (e-mail: Robert_Musacchio@ama-assn.org), American Medical Association, Chicago, Ill.

The core standards that can help to achieve these goals are not complicated:

- **Authorship:** Authors and contributors, their affiliations, and relevant credentials should be provided.
- **Attribution:** References and sources for all content should be listed clearly, and all relevant copyright information noted.
- **Disclosure:** Web site "ownership" should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest. This includes arrangements in which links to other sites are posted as a result of financial considerations. Similar standards should hold in discussion forums.
- **Currency:** Dates that content was posted and updated should be indicated.

Web sites and other Internet-based sources of medical information that fail to meet at least these basic standards should be considered suspect. The best will be those where such quality protocols are part of a broader, well-established editorial process. We encourage content providers to outline and post that process for all users to see (listing the factors by which they produce or select content) and to identify staff, reviewers, and advisory boards.

The benchmarks we propose certainly are no guarantee of quality in and of themselves. Nor is the only valuable information to be found on the Internet produced by "traditional" sources, such as journals, professional societies, universities, libraries, and government agencies. Medically oriented communities of interest—both professional and nonprofessional—thrive in the digital world. There is much to be gleaned and likely gained from these sources.⁷

But all who surf the Net also must be wary in evaluating such information, applying the same stringent criteria of context, relevance, and utility as we hope they would in weighing any other resource. And, needless to say, it should be made clear to users that the information presented in a Net discussion group or on any medically oriented Web site is designed to be part of—not substitute for—the relationship between patient and professional that is central to the health care decision-making process. The Net should facilitate, not serve as a barrier to, care of high quality.⁸

Efforts to better assess the quality of medical information on the Net are under way in several quarters. For example, the Geneva-based Health on the Net Foundation has established a 6-point code of conduct for sites providing health information.⁹ The US Food and Drug Administration, which now regulates pharmaceutical advertising and promotion in the traditional print and broadcast media, is now looking at how (or whether) to apply such regulations on the Internet.¹⁰ The US Department of Health and Human Services, meanwhile, is looking at how to best promote quality in consumer health information networks (Mary Jo Deering, PhD, director, Health Communication and Telehealth, US Department of Health and Human Services, Washington, DC, oral communication, March 12, 1997).

Industry groups have begun discussing ways to craft voluntary guidelines, believing self-restraint could head off more stringent government regulation (John Mack, president, Vir-Sci Corp, Levittown, Pa, written communication, March 7, 1997). Some health care information technology groups also are looking to draft guidelines with input from major professional organizations (Helga Rippen, MD, PhD, MPH, director, Health Information Technology Institute, Mitretek Systems Inc, oral communication, January 24, 1997). In addition, Web site index and review services increasingly offer evaluations of sites by topic area (examples of such sites include Medical Matrix [<http://www.slackinc.com/matrix/>], Six Senses [<http://www.echo-strategies.com/sixsenses/>], and Physicians Choice [<http://www.mdchoice.com/>]). We suggest that criteria similar to those that we propose for Web sites be applied to Web site reviewers as well and are pleased to see that some already apply such standards.

We applaud the current discussions about quality and hope that they will lead quickly to widespread agreement on a set of core standards that information producers can choose to follow. We are not, however, calling for a single or centralized review process, institution, or agency, except to any extent that appropriate laws or regulations might require. We believe such an approach is neither desirable or realistic, since the Internet is a decentralized, global medium. Nor are we calling for punitive action against those who do not follow such standards. Professionals and the public alike are hungry for quality information, will over time recognize efforts to provide it, and will show their appreciation by pointing their Web browsers to sites that do so.

We also hope our proposal will not be taken as an exercise in arrogance or an attempt to protect traditional publishing's "turf" in the new digital world order. Web "publishers" of all stripes—ourselves included—should be free to post whatever they like and live with the consequences. Let a thousand flowers bloom. We just want those cruising the information superhighway to be able to tell them from the weeds.

William M. Silberg
George D. Lundberg, MD
Robert A. Musacchio, PhD

1. Lundberg GD, for the JAMA Review Group. One multimedia medical world. *JAMA*. 1995;274:655.

2. Kassirer J. The next transformation in the delivery of health care. *N Engl J Med*. 1995;332:52-54.

3. Achenbach J. Reality check: you can't believe everything you read, but you'd better believe this. *Washington Post*. December 4, 1996:C1.

4. Medical help on the Internet. *Consumer Rep*. 1997;62:27-31.

5. Lundberg GD. Providing reliable medical information to the public—caveat lector. *JAMA*. 1989;262:945-946.

6. Guarding the guardians: research on editorial peer review: selected proceedings from the First International Congress on Peer Review in Biomedical Publication. *JAMA*. 1990;263:1317-1441.

7. Ferguson T. *Health Online*. Reading, Mass: Addison-Wesley Publishing Co; 1996:201-236.

8. Widman L, Tong D. Requests for medical advice from patients and families to health care providers who publish on the World Wide Web. *Arch Intern Med*. 1997; 157:209-212.

9. Health on the Net Foundation, <http://www.hon.ch>. Accessed March 20, 1997.

10. Public hearings, Food and Drug Administration and the Internet, Advertising and Promotion of Medical Products; October 16-17, 1996; Silver Spring, Md. Hearing transcript available (<http://www.fda.gov/opacom/morechoices/transcript1096/fdainet.html>). Accessed March 18, 1997.