

What's a body to do?

"There is an amazing amount of useful information on the Web, but it is getting harder and harder to find. As one researcher puts it, the retrieval job is worse than looking for a needle in a haystack; it's like looking for a specific needle in a needle stack." (Hubert L Dreyfus, *"On the Internet"* Routledge, <http://www.routledge.com>, 2001)

I began the March issue of *CyberSpace* by asserting that we know very little about whether online information is now—or ultimately—capable of helping us improve the quality and safety of health care. I thought I should say a bit more on this topic and point readers to some relevant resources in the process.

There is a "chicken and egg" aspect to this debate. Which questions do we wish to address? Are we concerned more about the usefulness of online information in terms of its specific quality and safety content? Or the quality of online health information in terms of its ease of navigation and facilitation of end user networking and decision making? Or patient harms that may arise from uncritical reliance on incorrect online information or the misuse of correct information? Or the now little discussed lack of online access for vulnerable minority and ethnic population groups who arguably could benefit most from culturally sensitive consumer health information online?

The work of Gunther Eysenbach represents one prominent line of inquiry. In a June 2001 paper in the *Journal of Medical Internet Research* ("Evidence-based patient choice and consumer health informatics in the Internet age", <http://www.jmir.org/2001/2/e19/index.htm>), Eysenbach and Jadad highlight "the gap between the ideal and the real" in assuring meaningful consumer access to any kind of useful health information online. They write:

"Ideally (as long as they wish), all consumers should be able to access valid and relevant information about their health status. They should be able to judge the advantages and disadvantages of all possible courses of action, according to their values, beliefs, preferences, and their personal circumstances. In reality, we are far from this ideal state, as many barriers prevent consumers from accessing the information they need, when they need it, where they need it, and in the amount and format in which they need it." The main barriers to access cited by the authors include "health care providers who adopt the role of main purveyors of knowledge", "lack of easy to access sources of high quality relevant information", "low health literacy", "limited access to the Internet", "unlimited access to poorly organized information", and "few mechanisms to control the quality of the information".

Not long ago, government policymakers professed great concern over the so called "digital divide" separating the wealthier and more educated members of developed societies and the poorer less educated members of those societies and the rest of the global population. Clarence Irving, a former commerce undersecretary, recently resurrected this issue in the US where most African- and Hispanic-Americans have no Internet access at all. Irving asked rhetorically: "We're a nation online?" (<http://www.newsbytes.com/news/02/176000.html>).

Without better evidence we don't know whether, how, and for whom Internet access matters for health service outcomes. Sally Wyatt of the Amsterdam School of Communications Research puts it like this: *"Will the greater availability of health information via the Internet lead to the emergence of more informed patients, better able to assess the risks and benefits of alternative treatments for themselves? Or, will the over-abundance of information lead to confusion and anxiety as lay users do not have the expertise to interpret and evaluate the appropriateness of the information?"* (<http://home.pscw.uva.nl/lleydesdorff/sts/Apr02/swyatt.htm>).

End users unite For now, the minority of savvy "end users" of online health information (Tom Ferguson's term,

<http://bmj.com/cgi/content/full/324/7337/555>) are busy learning what to trust and what to verify. Ferguson and the *BMJ* editors accompanied his editorial cited above with a handy reference guide (<http://bmj.com/cgi/content/full/324/7337/555/DC1>) full of simple commonsense maxims—"Don't search alone", "Tell your doctor what you have found online". The growing consensus appears to be that medical consumers must be encouraged, even formally trained, to take the lead in forming new kinds of partnerships with health professionals that include critical assessment and proactive use of relevant materials gleaned from the web.

Researchers, meanwhile, are busy developing formal aids to patient-professional decision making under conditions of uncertainty. As Edwards, Elwyn, and Mulley note in their recent *BMJ* article on explaining risks, *"Information often highlights uncertainties, including collective professional uncertainty, which we address with more and better research; individual professional uncertainty, which we address with professional education and support for decisions; and stochastic uncertainty (the irreducible element of chance), which we address with effective risk communication about the harms and benefits of different options for treatment or care"* (<http://bmj.com/cgi/content/full/324/7341/827>).

Related sites

TalkingQuality ▶ In the US three government agencies jointly launched TalkingQuality.gov in April 2002 (<http://www.talkingquality.gov/>). The site is "designed to help benefit managers, consumer advocates, and state officials communicate with their audiences about health care quality" (<http://ahrq.gov/news/press/pr2002/tqwebpr.htm>).

Hi Quality ▶ In the UK the Centre for Health Information Quality (C-HI-Q) launched Hi Quality in March 2002 (<http://www.hiquality.org.uk/>). The site provides guidance on health information quality standards to both consumers and producers of online health materials.

Listening to readers

In Issue 1 of *CyberSpace* (which appeared in the March issue of *QSHC*) we asked readers to send us links to useful online information. No one responded. After Issue 2 appeared on our website (<http://www.qualityhealthcare.com>), four people responded: a government official notifying us that her agency's web site was to be revamped; a researcher saying that his report had been posted; a professional acquaintance asking us to look at a site she is affiliated with; and a commercial vendor seeking to tout its online patient safety materials. These communications were very helpful. We need many more in future.

CyberSpace is a reader-focused, content-driven service. We aim primarily to provide annotated links to online research reports, policy documents, book chapters, proceedings or transcripts of past meetings, programme information on upcoming meetings, etc, related to quality and safety in health care. Ideally, the content cited should be freely accessible—that is, not encumbered by subscription fees or one-off charges. It should also be useful—meaning that it is reasonably likely to aid the promotion of safe and effective practice at one or more levels of the healthcare system.

This seems an ambitious—perhaps impossible—task. While health and medical information in all formats mushrooms, formerly free online materials rapidly vanish under proprietary cover. For example, by the time we can cite an excellent (and initially free) online article from a quality US newspaper, the article link has

changed into an invitation to purchase the article from the archive (after only one or two weeks). Retrieving an online article from a medical care or health policy journal without a personal subscription or access to a university library or other well resourced information service is a frustrating proposition for most people, especially patients and families. Frustrating, too, is the knowledge that much of the best information about improving the quality and safety of health care will never be published, and much of what is will never be used.

Calling once more QSHC is making all issues of CyberSpace freely available to anyone with Internet access. This policy, planned to continue after the journal reverts to subscription only online access, facilitates reader interaction with the service and the site as a whole. The ultimate success of this project, however, will depend on the commitment of writers, authors, researchers, publishers, policymakers, practitioners, patients, and public agencies to circulate useful information about health care quality and safety in accessible, readable, and affordable online formats. If you have published such information or discovered it through your own research, please let us know about it so that we may, in turn, share the best of it with as many others as possible.

Broken links CyberSpace verifies that featured links (URLs) are working at the time of publication. However, sites change their content frequently; resources are moved, deleted, or go private; servers crash; and we sometimes make mistakes. So please let us know about any broken or otherwise incorrect links you encounter in this issue. Thank you for your assistance.

About the author Adam L Scheffler is an independent journalist, policy researcher, and social worker based in Chicago. He has provided conference organizing, project management, editorial services, and consulting services to the National Patient Safety Foundation (<http://www.npsf.org/>) since 1998. His work as project manager for the "Annenberg II" patient safety conference in 1998 and editor of the proceedings from that meeting in 1999 was supported by a grant to the NPSF from the US Veterans Health Administration (http://www.va.gov/health_benefits/).

A L Scheffler

Chicago, Illinois, USA
a-scheffler-1@alumni.uchicago.edu

BMJ JOURNALS FREE TO THE DEVELOPING WORLD

Now free for the 100 poorest countries

The BMJ Publishing Group has for more than a year provided free access to the electronic version of its 23 specialist journals including QSHC to anybody in the 50 poorest countries in the world.^{1,2} Now free access is being extended to over 100 of the world's poorest countries which between them include most of the world's population. Free access is also available to *Clinical Evidence*, an evidence based compendium of answers to commonly asked clinical questions.³

The BMJ Publishing Group is not alone in providing free access to those in the developing world. This initiative follows the switching on of the World Health Organization initiative which provides institutions in the developing world with free or very low cost access to the publications of many of the big commercial publishers.⁴ The WHO initiative is being extended to include more publishers, and the Royal College of Psychiatrists has announced that it will be providing free access to its journals for those in the developing world.

Publishers can afford these initiatives because, although journals are expensive to produce, the cost of providing electronic access to one more individual is effectively zero. In contrast, the cost of printing and shipping a paper journal is substantial. Some cynics wonder if providing free electronic access to those in the developing world might be an empty gesture as internet access is limited. Access, however, is skyrocketing in the developing world, particularly with the spread of technology that avoids the necessity for wires in the ground. What's more, there is no point in spending money to get access if you can't then afford to access material. Making material free should fuel a virtuous circle of increasing access.

Healthcare workers in the developing world have for years had the problem of very limited access to the latest information.^{1,5,6} Ironically, they might quickly have the problem of healthcare workers in the developed world of being overwhelmed with material of low quality and limited relevance. Providing free access to material is only one part of what is needed to improve the use of health information in the developing world. Initiatives are also necessary among those in the developing world to increase their own capacity to distil, package, present, and disseminate not only the material originating from the rich world, but also their own material. Publishers and editors from the rich world should be able to help.

The final aim of these initiatives is not to send a flood of material from the rich to the poor world but for those in the developing world to become equal participants in the global discourse on health. We all stand to gain. We hope you will contribute to the debate via the rapid responses feature on our website (www.qualityhealthcare.com).

- ▲ 1 **Godlee F**, Horton R, Smith R. Global information flow. *BMJ* 2000;**321**:776-7.
- ▲ 2 **Williamson A**, Moss F. Getting journals rapidly to developing countries: opportunities through the internet. *Qual Health Care* 2001;**10**:133-4.
- ▲ 3 **Barton S**. Using clinical evidence. *BMJ* 2001;**322**:503-4.
- ▲ 4 **Kmietowicz Z**. Deal allows developing countries free access to journals. *BMJ* 2001;**323**:65.
- ▲ 5 **Pakenham-Walsh N**, Priestley C, Smith R. Meeting the information needs of health workers in developing countries. *BMJ* 1997;**314**:90.
- ▲ 6 **Kale R**. Health information for the developing world. *BMJ* 1994;**309**:939-42.