Saturday 9 March 2002

BMJ

From patients to end users

Quality of online patient networks needs more attention than quality of online health information

BMJ 2002;324:555–6

P+

Guidelines for patients who want to use the web appear on bmj.com

Some doctors still tremble in their boots when patients bring in printouts from the internet. If they refuse to read them, their patients may take offence. But if they attempt to review and discuss them, they may precipitate long, inconclusive discussions. And since many internet aware patients bring in information which their doctors know nothing about,[1] such discussions can sometimes be embarrassing. Consequently, some doctors have gone so far as to warn their patients, "Whatever you do, don't go on the internet."

Some studies seem to confirm the wisdom of such advice. A recent literature search turned up 100 studies that attempted to rate the accuracy and completeness of health information on the world wide web. Ratings ranged from about 15% to 85% (Eysenbach G. personal communication). Some doctors have understandably concluded that the healthcare information on the net is not to be trusted.

Our recent surveys at the Pew Internet and American Life Project offer a strikingly different perspective.[2,3] Of adults from the United States who had gone online for health information, 92% said that the last time they went online they found what they were looking for; 81% said they learned something new; 88% said the information they found improved the way they took care of their health. Of those who found health information online, 94% said that it was either "very easy" or "somewhat easy" to do so. And of the 37% who discussed the results of their searches with a health professional, only a tiny minority said that their health professional disagreed with the information they found online.

In explaining this notable difference of opinion between providers and patients, we must remember that it is only systems without their own inherent intelligence that require perfect input to operate effectively. Suppose that we were to subject a dozen randomly chosen printed sources such as textbooks, articles from magazines, newspaper stories, patient handouts to a similar evaluation and found a similar level of variability in quality and completeness. Would we be justified in concluding that healthcare information in printed form is so undependable and unreliable that we should warn our patients against it? I think not. And before we conclude that the information on the net is inadequate, incomplete, and generally scary, we might try comparing it with what the typical doctor tells the typical patient in the typical 10 minute office visit. Medical services provided online should not be held to a higher standard than similar services provided in person.

The internet and "medical end users"

A net savvy person in the immediate kinship group does most of the searching. Forty three per cent of online health searchers said that the last time they went online they were searching for materials related to their own health concerns—but a surprising 54% were searching on behalf of someone else—a child, parent, another relative, or friend.[4]

When a new illness is diagnosed in a "wired" family, patients or caretakers reach out electronically to inform friends and family. Many recipients respond with messages of support, information, and advice. Interchanges within these private, patient centred networks serve to help end users sort good information from bad information.

When end users with a new diagnosis go online to research their condition, they frequently seek and receive the help of online support communities as well as online helpers—knowledgeable and experienced internet users with the same condition. Some online helpers have set up websites to help others with similar concerns.[4,5]

Experienced online end users frequently communicate with online health professionals on sites like www.drgreene.com, www.drweil.com, and www.drdrew.com. They can also check up on their own doctors,[6] get informal second opinions online, and find referrals to the best treatment centres.

Online patients do agree with their doctors on one point—that much of what passes for online health information is not to be trusted. Of those with internet access, 82% say that they are concerned about getting online health information from an unreliable source.[4] Where professionals and patients differ is in their views of these patients' ability to tell the good from the bad.

The patients that I and my colleagues have studied have proved themselves so unexpectedly capable in this regard that we have been forced to ask ourselves whether we can, in good conscience, continue to use the term "patient" in describing them. They are by no means patients in the usual sense—a person under a doctor's care, an invalid, a sufferer or victim, someone who bears pain and misfortune with fortitude and calm. We are beginning to substitute the term "medical end user" whenever this seems appropriate.

The medical end users we study do much more than just visit a single website and make snap decisions based on what they find. They typically use a search engine to find and review a number of different sites that target their specific concerns.[2 3] And they frequently find or form sophisticated online and offline networks, which can help them deal with the task of interpreting complex medical information (see box).

These person to person interactions provide patients with a valuable source of quality control. As one online self helper recently commented: "Doc, out here on the internet we patients have our own system of peer review."

We believe that the 21st century will be the age of the net empowered medical end user and that the patient driven online support networks of today will evolve into more robust and capable medical guidance systems that will allow end users to direct and control an ever growing portion of their own medical care. Doctors who continue to believe that their patients are inherently incapable of navigating the plentiful health resources of the internet will find their net savvy patients leaving them for other doctors. By contrast, those wise and caring doctors who realise that we may have just as much to learn from our patients as they have from us should do very well indeed.

Tom Ferguson *senior research fellow*

Online Health, Pew Internet and American Life Project, 1100
Connecticut Avenue, Washington DC 20036-4116, USA
(doctom@doctom.com)

---

1 Wilson SM. Impact of the internet on primary care staff in Glasgow. *J Med Internet Res* 1999;1(2):e7. http://www.jmir.org/1999/2/e7/ (accessed 28 February 2002).
2 Fox S, Lee R. The online health revolution: how the web helps Americans take better care of themselves. The Pew Internet and American Life Project, Washington, DC, 26 November 2000. www.pewinternet.org/reports/toc.asp?Report=26 (accessed 28 February 2002).
3 www.pewinternet.org/reports/index.asp. (accessed 28 February 2002).
4 Ferguson T. Online patient-helpers and physicians working together: a new partnership for high quality health care. *BMJ* 2000;321:1129-32.
5 Ferguson T."God bless my CML support group." The Ferguson Report, No. 8, January 2002. www.fergusonreport.com/articles/fr00803.htm (accessed 28 February 2002).
6 Stone E, Heinold, JW, Ewing, LM, Schoenbaum, SC, Accessing physician information on the internet. www.cmwf.org/programs/quality/stone_mdinternet_bn_503.asp (accessed 28 February 2002).

Against internet exceptionalism

There's nothing radically different about information on the web

The sheer novelty of the internet continues to colour discussions of it. Attention paid to online health information invariably focuses on how it differs from what has gone before rather than how it has remained the same. Certainly, the internet provides swift access to large amounts of information that previously required determined tracking. Users can communicate rapidly through email, chat rooms, and other internet forums. And it is remarkably easy to publish and disseminate information, with little accountability.[1] But are these enough to justify the belief that information retrieved via the internet differs radically from what has gone before, requiring an exceptional response?

The combination of rapid access and wide dissemination makes it easy to understand the appeal of initiatives aimed at limiting access to misleading or inaccurate information on health. Allowing users to judge at a glance the quality of such information by the use of labels has been widely debated.[2 3] However, the exact purpose of controlling the quality of health information on the internet remains unclear.[4] Health information in other media has not received the same degree of attention, even though the public is exposed to misleading and inaccurate information from a variety of sources.[5 6]

What has changed is the rapidly increasing consumer involvement in decisions about health care. Patients and their relatives are now accessing ever more information from ever more diverse sources, with health professionals having little or no time to help them manage what they have found.[7] Yet good quality information is seen as a key component in increasing consumer choice and participation. As well as being accurate and up to date, information is expected to provide detailed explanations of likely outcomes with and without treatment, with any areas of uncertainty dealt with honestly.[8] Determining whether treatment information reaches these standards rests largely on an analysis of its content.

Suggested strategies aimed at ensuring public access to high quality health information online include kitemarks or seals of approval and the creation of databases of information that have been quality assured in some way. Kitemarks or seals of approval[9] are usually based on checklists of desirable attributes of quality or some other feature of the information. However, most checklists are unstandardised[3] and inaccessible to the public and so are an opaque way of conveying quality to the user. Screened databases require huge resources and may be impractical in terms of the volume of available health information and the resources needed for staff training and updating. Neither system takes into account the range of information available (both on the internet and in other media), the preferences of users, or the desirability of going down this route.

An alternative is to take a "non-exceptionalist" approach to online health information. Many of the issues arising from the internet that cause concern are common to all types of information, with readability and accuracy of content causing the most anxiety. Solutions to these concerns are seldom restricted to a single method of delivering information.[10]

A non-exceptionalist strategy should aim to help producers of health information publish high quality websites using explicit guidelines that take into account previous work[11] and to provide users and providers with transferable skills. These standards and skills should be based on an understanding of search strategies that can be employed to retrieve high quality information (regardless of type) and how content can be appraised for quality. Providers of databases or bibliographies of health information can aid this process by highlighting the strengths and weaknesses of each

BMJ 2002;324:556–7