

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.

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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?²

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 approval⁹ are usually based on checklists of desirable attributes of quality or some other feature of the information. However, most checklists are unstandardised³ 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 work¹¹ 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

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publication screened and acknowledging that material may contain useful information despite falling short of quality criteria.¹² Such initiatives will enable the user to supplement information found by using professionally developed databases and to build a set of core skills that can be applied in the dynamic context in which health information is available. These strategies will help users of all types of information. (They cannot, however, address the persisting inequalities of access to internet resources.¹⁵)

Concerns about the quantity of available information and how it is delivered and accessed are valid, but these are separate from the issue of quality and should not deflect attention from the standards that need to apply across all information types and media.¹⁴ Future initiatives focusing on core standards and transferable skills will equip users, providers, and producers of health information to deal with rapidly developing new technologies, and the increasingly dynamic context in which health information is available.

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The quality of health information on the internet

As for any other medium it varies widely; regulation is not the answer

This week's theme issue attempts to provide a framework for thinking about the quality of health information on the internet—a source of anxiety almost since its first appearance.

Five years ago Impicciatore and colleagues reviewed website advice on managing fever in children and concluded that it varied widely in terms of accuracy, completeness, and consistency.¹ Pick any medical problem today, and the chances are you'll find the same. With at least 80 studies reporting similar findings (G Eysenbach, personal communication), we need no more convincing that the quality of information on the web varies as widely as it does in other media.

In 1997 Gagliardi and Jadad identified 47 instruments for measuring healthcare quality on the internet. Four years later, they found another 51—all of them unvalidated (p 569).² Generating yet more unproved instruments looks like another activity that researchers could usefully stop. However, the proliferation of tools for assessing quality continues unabated, fuelled by anxieties about patient harm. As our international roundup shows (pp 566-7), countries now seem poised to get in on the act, although little beyond urban myths exists to justify the level of their concerns.³

Health information on the internet ranges from personal accounts of illnesses and patient discussion groups to peer reviewed journal articles and clinical decision support tools. Defining a single quality standard for such a disparate collection of resources is challenging. Furthermore, different users may have different criteria for quality. Patients and caregivers

may want simple explanations and reassurance, whereas healthcare professionals may want data from clinical trials.

Criteria for determining quality can be organised by their applicability to various dimensions of online health information, such as content, type, and intended audience. For standards pertaining only to content we can use traditional metrics, such as the levels of evidence and strength of recommendations.⁴ The type of information also affects which measures are applicable. Medical knowledge can be evaluated by scientific standards, whereas literary or journalistic criteria may be more appropriate for personal narratives. And the intended audience influences the measures of quality that are applicable to a particular type of content. Consumer health information should be written at a comprehensible reading level; often patients want pragmatic information, such as how long their illness will prevent them from working, before scientific details.⁵

Shepperd and Charnock argue against “exceptionalism” for medical information on the internet and support standards of quality that apply across media (p 556).⁶ While this approach may be appropriate for many aspects of electronic health resources, some features warrant special consideration. The interface to online information can be distinguished from the content, and the criteria for quality of an interface depend on the communication technology used. Principles for good web design differ from those for creation of high quality handheld applications. Furthermore, our concepts of quality change as the technology evolves.