



# nature medicine

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## Heading off a web of deceit

The pervasion of the Internet into all corners of society continues apace, and without doubt the Information Superhighway will irrevocably alter the practice and economics of medicine. Health care on the web is a complex affair encompassing many issues, some well established like health care information and e-pharmacy (see page 6), others just in their infancy—Internet-based clinical care, health care financing and administration, personal data management, public health surveillance, professional education and biomedical research initiatives. But a common thread is the real need for implementation of an ethical code to assure quality and commercial transparency, enabling consumers, patients and health professionals to ascertain content validity. How that quality assurance is best achieved is a matter of ongoing debate. Two disparate plans are currently proposed—self-regulation through voluntary codes versus top-down regulation by the World Health Organization (WHO).

That the Internet has become a primary source for health information is not in doubt. A 2000 report from the Pew Internet and American Life Project found that 55% of Americans with online access had obtained health information there and almost half of those said it directly affected their health care decisions. A survey in Glasgow, Scotland revealed that almost three-quarters of clinicians questioned had patients who supplemented their consultation with information from the Internet, and that 90% of these clinicians considered these patients to be more active participants in their treatment. Informed patients themselves can now locate and enroll in clinical studies and participate in experimental therapies. Such patient empowerment can only be encouraged.

But the advantages of the Internet come at a price. Direct enrollment of clin-

ical trials volunteers means that the traditional safeguard of referral by health professionals is bypassed, and pursuing erroneous advice obtained online can undermine the traditional physician-patient relationship and lead to the disregard of proven therapies.

The Pew survey also examined privacy issues, finding that almost 90% of those seeking online health information feared that Internet health companies would collect and share data about the medical sites they visit and report this information to health insurance companies. In a similar vein, 63% of those acquiring medical information online were opposed to keeping medical records there.

Recently the WHO formally proposed the establishment and regulation of a new restricted Internet domain, with addresses given the suffix '.health'. The Internet Corporation for Assigned Names and Numbers, the regulatory body that assigns Internet names, turned down this proposal (see [http://www.nature.com/nm/biomedical\\_news/who.html](http://www.nature.com/nm/biomedical_news/who.html)), noting that there was a basic ambiguity as to the ethical principles and quality standards to be employed. The WHO admits that their restrictions and the enforcement mechanisms associated with them are as yet undefined and plan to consult widely with all interested parties. However, some smaller community websites, such as virtual support groups and patient associations, have expressed concerns that an onerous certification process would in effect disqualify them and leave them on the margins of the web community. There are also fears that the involvement of a large bureaucracy like the WHO could wind up at either extreme—a tyrant or a toothless tiger if consensus is not reached.

The current Internet industry and public policy approach to these concerns is to foster voluntary codes of conduct and in-

dustry self-regulation, supplemented with legal enforcement of criminal activities, such as fraudulent trading and illegal sales of prescription drugs. The first such code was HONcode, introduced in 1996, and it defines a set of rules holding websites to basic ethical standards with particular regard to the source and purpose of data. But the adoption of voluntary codes has led to the creation of multiple standards, leading to a dilution of their credibility and hence value to consumers. Now an international collaboration among the overseers of five of the principal voluntary codes is aiming to harmonize these into a consensus code through consultation with members of the Internet industry, the medical profession, academia, government, the ethics community and consumers. But some industry insiders still think that a measure of legislation will be inevitable and necessary.

The Internet community has a record of stiff resistance to attempted government regulation but the current lack of quality assurance raises multiple concerns regarding privacy, confidentiality, professionalism, liability and responsible medical practice. The inherent dilemma of the Internet is that its anarchic nature fosters open debate without censorship while failing to ensure quality, a factor that seriously inhibits its potential. Regulation issues are very complex—compounded by the intersection of a global medium with state and national laws—but some form of health care regulation is required given the risks and the unique character of the medium itself.

The challenge now is to find an effective, practical solution that readily informs the most vulnerable party, the consumer. The law cannot and should not control everything—good judgment, professional ethics, common sense and wide consultation with all interested parties are paramount.