Regulating health information on the internet: international initiatives

"Buyer beware" remains US policy towards information on the net

Fred Charatan Florida

In the United States, no federal or state laws regulate the content of health websites on the internet. But guidelines drawn up by certain groups of healthcare experts try to ensure the integrity of health information on the internet. The most prominent of the expert groups are the Internet Health Coalition and the American Accreditation HealthCare Commission (URAC).

The Hi-Ethics code developed by the Internet Health Coalition calls for health websites to declare that they will:

- Clearly distinguish advertising from health information content
- Design their health websites to avoid confusion between advertising and health information content
- Clearly disclose significant relationships between commercial sponsors and health information content.

The American Accreditation HealthCare Commission runs a website accreditation programme, which it says "empowers consumers and business partners to identify health websites that follow rigorous standards for quality and accountability."

The Federal Communications Commission defends the absence of legislation, arguing that "the internet is dynamic precisely because it is not dominated by monopolies or governments."

Dr Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania Health Systems, summed up the attitude to the internet in the United States by saying: "In my view, the USA is doing almost nothing to help ensure the quality of healthcare information on the internet.

"While various private groups have tried to create websites that are aimed at gaining consumer trust by using either an affiliation with a trusted organisation [a university, a hospital, or a professional society] or by listing a peer review group, government policy has been to take a hands-off stance toward what is on the web.



Concerns over the website set up by Dr C Everett Koop (above) started the guidelines ball rolling in the United States

"In the USA, freedom of speech and the responsibility of users of the internet to find and evaluate information remain the dominant norms of quality control. In other words, 'caveat emptor' has been and remains the American policy vis-à-vis health information on the internet."

UK government aims to integrate health information on the internet

Lynn Eaton London

The UK government has gone a long way to ensuring that the information it puts on the internet is of a high quality and that the technology used makes it easy for everyone to access the information.

When it comes to the quality of health information on government related websites, the NHS Plan sets out its intention for patients to have "greater access to authoritative information about how they can care for themselves."

The government has subsequently set up the new "national knowledge service" to integrate health information on existing websites and to ensure that it is consistent and of high quality. This follows recommendations from Professor Ian Kennedy's report into children's heart surgery at the Bristol Royal Infirmary, which recommended that the public should receive guidance on which sources of information about health and health care on the internet were reliable and of good quality. It also recommended that a kite marking system should be developed.

Although NHS Direct Online has monitored non-government websites linked to its site in the past and is currently developing a rating system (see p 568), this is the only government kite marking of any kind so far—and even that is in its earliest stages.

None the less, Bob Gann, chief executive of NHS Direct, said that the UK government's policy on website quality is considered to be one of the more rigorous ones in the world.

The government has also issued general guidance on the design and management of its sites.

Weblinks www.e-envoy.gov.uk/ webguidelines.htm

www.doh.gov.uk/ipu/whatnew/ itevent/tables/ nationalknowledgeservice.htm

WHO calls for a health domain name to help consumers

Phyllida Brown Exeter

The California based body that oversees the creation of "top level" internet domains such as .com and .org is coming under renewed pressure to agree a new domain that would signal legitimate health information websites.

The Internet Corporation for Assigned Names and Numbers is being asked by the World Health Organization and others to set out a clear timetable for agreeing new domain names after rejecting a proposed "health" domain late 2000. The issue is likely to be discussed when the corporation's board meets this month.

The WHO, supported by consumer groups and others, believes that a health domain could be used to signal to users that certain sites meet standards of accuracy and safety. There are at least 10 000 sites that purport to offer health information on the web.

"Some sites are simply dangerous," said Dr Dzenowagis, chief scientist for the .health project at WHO's Geneva headquarters. Some sites, for example, advocate unproved treatments for diabetes, and others sell medicines with effectively no questions asked. "You could basically buy Viagra for your cat," she said. Health sites are also increasingly used by consumers in developing countries, whose access to other information may be limited.

The corporation rejected health from the list of proposed new domains in 2000 mainly because the plan needed more development, Dr Dzenowagis believes. "But the idea had a lot of support from the consumer unions, and it received a good press," she said. With health and medical sites proliferating, she said, "it is only a matter of time before health is created."

The WHO has no pretensions to control or regulate all health information on the web. "We don't want to, and even if we did, we couldn't do it," said Dr Dzenowagis. But by sponsoring a health domain that would be granted only to acceptable sites, WHO would enable users to narrow their searches.

Sceptics say that the web cannot be policed and that users are already sophisticated enough to recognise quackery. But, said Dr Dzenowagis, many sites provide just enough accurate information to appear trustworthy.

In addition to the WHO, several constituencies in the private and public sectors want the corporation to speed up its process for adding new top level domains. In particular, consumer groups are worried about "rogue" domain-name registrar companies that use a technology known as "alternative roots" to create the appearance of top level domains such as .doc. These confuse users and are costly to holders of legitimate domain names.