

# Developing E-Health Standards for Web Sites

Save to myBoK

*by Carol Ann Quinsey, RHIA*

Healthcare consumers are increasingly turning to the Internet for information about services critical to their health. An estimated 80 percent of adult American Internet users (approximately 93 million people) have searched the Internet for information on at least one of 16 major health topics.<sup>1</sup> Some people are even storing their personal health information (PHI) on the Internet. From these numbers it can be speculated that on any given day more individuals are using the Internet for medical advice than are actually visiting health professionals.

The reasons healthcare Web sites are developed are as numerous as the sites themselves. Some sites are sponsored by health plans or providers, endorse specific products or services, are developed by individuals with a personal story about a specific condition, or offer the opportunity to build and maintain PHI on the Internet.

But much of the information found on the Web is unknown in terms of quality and security. There is no guarantee that any e-health Web site is reliable. So what's being done to protect consumers and their PHI on the Internet?

During AHIMA's 2003 National Convention, speaker Christopher Ducanes, JD, LLM, vice president, chief privacy officer, and general counsel for HEALTHVISION, Inc., gave an overview of what the laws say and what some organizations are doing to develop health Web site standards.

## Meeting Consumer Needs

Typical online health consumers are middle-aged with a higher than average household income, very engaged in understanding their healthcare status, and actively seeking health information for themselves, their parents, or their children, Ducanes said. This group of consumers wants to be well informed about their medical conditions and the options available for treatment.

In the past few years, several well-publicized privacy and PHI breaches have heightened concerns about the privacy and security of health information on e-health Web sites. Visitors to these sites should be concerned about whether their information will be kept private and what the site's sponsors do with personal information, he said.

## What the Laws Say

Comfortingly, a number of regulations pertain to e-health on the Internet, Ducanes said. To the extent that Web sites are maintained by HIPAA covered entities, the privacy and security rules apply. However, many Web sites offering health information or storage of personal health records are not maintained by HIPAA covered entities.

While the Gramm Leach Bliley Act is primarily aimed at financial institutions, some e-health Web sites may be afforded protection by the law. Notably, insurance company sites must be compliant with the act because patients submit health information to them.

The Children's Online Privacy Protection Act (COPPA), which went into effect in April 2000, applies to the online collection of personal information from children under the age of 13. COPPA specifies the content and placement of privacy notices, how to seek verifiable consent from parents, and when it is permissible to disclose children's information to third parties or to the public. Web site content is given serious consideration in COPPA, including subject matter, visual and audio content on the site, the age of models on the site, and language.

The EU Safe Harbor Directive, developed by the US Department of Commerce with the European Commission, went into effect in October 1998. Many provisions of the directive are similar to HIPAA. US Web site developers must comply with the directive for all personal information collected, not just health information.

The directive requires Web sites to notify individuals about the purposes for which they collect information, how individuals may make inquiries, and the circumstances under which information will be disclosed to third parties. Individuals must also be given the opportunity to choose whether their information may be disclosed to third parties.

In addition to various state privacy laws, the Federal Trade Commission Act applies to e-health Web sites. The commission is permitted to act in the interests of consumers to prevent “deceptive and unfair acts or practices.”

## Seals of Approval

Several voluntary organizations are working to promote the adoption of codes of ethics to govern the behavior of members. These organizations are trying to achieve an ethical ideal and get Web developers to comply, Ducanes said. Three voluntary organizations offer “seals of approval” for compliance with their standards: the Health on the Net Foundation, Hi-Ethics, and the American Accreditation Healthcare Commission. Though they are important, these voluntary efforts do not have the force of regulations.

The US Department of Health and Human Services announced in October 2003 new guidelines to improve Web-based communications.<sup>2</sup> In partnership with the National Cancer Institute (NCI), this resource was issued to help government, academic, commercial, and other groups make decisions about Web site design and usability based on research rather than personal opinions. NCI solicited experts from across government, industry, and academia to contribute to the development of the guidelines. The complete set of guidelines is available at <http://usability.gov/pdfs/guidelines.html>.

## Notes

1. Fox, Susannah, and Deborah Fellows. “Internet Health Resources.” Pew Internet and American Life Project, July 16, 2003. Available online at [www.pewinternet.org/reports/toc.asp?Report=95](http://www.pewinternet.org/reports/toc.asp?Report=95).
2. US Department of Health and Human Services. “HHS Announces Availability of New Guidelines to Improve Web-based Communication.” Press release, October 27, 2003.

*Carol Ann Quinsey ([carol.quinsey@ahima.org](mailto:carol.quinsey@ahima.org)) is an HIM practice manager at AHIMA.*

---

**Article citation:**

Quinsey, Carol Ann. "Developing E-Health Standards for Web Sites." *Journal of AHIMA* 75, no.1 (January 2004): 56-57.

---

Driving the Power of Knowledge

Copyright 2022 by The American Health Information Management Association. All Rights Reserved.