IHC Eyes E-health Code of Ethics

Save to myBoK

by Donald D. Asmonga

The privacy of personal information on the Internet is a hot topic nationwide. Is an e-health code of ethics in order? AHIMA and several other organizations are offering guidance this spring to the industry's first attempt at one.

Together with the American Medical Informatics Association (AMIA) and the Center for Healthcare Information Management (CHIM), AHIMA is part of the Coalition for Health Information Policy (CHIP). In April, CHIP submitted comments to a proposed draft code of ethics for e-health developed by the Internet Healthcare Coalition (IHC).

Nationally, a number of parties recognize the need to address the content, quality, security, and privacy of personal health information used, maintained, or transmitted on the Internet. The IHC has aggressively pursued information standards for the Web and aims to bring together industry, academia, government, patients, and consumer leaders to develop and promote ethical principles relevant to the rapidly expanding arena of online, interactive healthcare communications.

IHC convened an e-Health Ethics Summit earlier this year and developed a draft code of ethics. Upon the release of the draft, the IHC solicited comments from the public. A final, revised code was scheduled for publication in May.

CHIP submitted comments to the IHC to help strengthen the draft code of ethics. The comments are based on the developing and existing e-health policies of the CHIP member organizations. The general comment follows:

"AHIMA, AMIA, and CHIM represent a broad array of professionals who are involved in the development, use, management, and security of health information systems. Because we believe that the enormous potential of computer and communications technologies to improve healthcare delivery, quality, and access, while also reducing costs, cannot be realized unless individuals, and the broader society, are confident that safeguards are in place to protect the confidentiality of personal health information, both as individual associations and as part of CHIP, we applaud the IHC for its efforts to shape a consensus code of ethics that will foster an environment of honesty and trust between the developers and users of Internet healthcare sites. While the initial IHC draft represents a good start, clearly the 'devil is in the details.' We are particularly concerned about the issues of noncompliance with the code and consumer recourse regarding violations of an ethical code for the Internet. Particularly in light of the California Healthcare Foundation study of privacy policies and practices, we ask that the steering group discuss possible approaches to the monitoring or auditing of sites that purport to subscribe to the consensus code, and to consider mechanisms that might be used to 'enforce' compliance."

CHIP also offered specific suggestions to improve the language of the draft code of ethics by addressing specific issues of candor and trustworthiness; quality; informed consent, privacy and confidentiality; and best commercial practices. The specific sections CHIP addressed are shown below, with CHIP comments in bold. The complete draft code of ethics can be viewed at www.ihealthcoalition.org.

In the long run, it is doubtful that a code of ethics will be sufficient to protect individual activity and privacy on the Web. Privacy already permeates the public policy agenda at the federal and state level. Can a legislative effort be far behind? As these efforts continue, AHIMA and CHIP will continue to provide expert advice and assistance to those involved with addressing health information policy issues.

IHC Draft Code of E-health Ethics

Earlier this year, the Internet Healthcare Coalition (IHC) released a draft code of ethics for e-health. At press time, a final report was scheduled for release in May. This excerpt highlights the comments of the Coalition for Health Information Policy (CHIP), a collective that includes AHIMA, in bold type. To view the complete draft, go to the IHC Web site at www.ihealthcoalition.org.

Vision Statement

The Internet is changing how people receive health information and healthcare. All who use the Internet for health-related purposes must join together to create an environment of trusted relationships to assure high-quality information and services, protect privacy, and enhance the value of the Internet for both consumers and providers of health information, products, and services. The goal of the "e-Health Code of Ethics" is to ensure that all people worldwide can confidently, and without risk, realize the full benefits of the Internet to improve their health.

Introduction

Health information has the potential both to improve health and to do harm. All people who use the Internet for health-related purposes must be able to trust that the sites they visit adhere to the highest ethical standards and that the information provided is credible.

Because health and healthcare are critically important to people, the organizations and individuals that provide health information on the Internet have special, strong obligations to be trustworthy, provide high-quality content, protect users' privacy, and adhere to standards of best practices for online commerce and online professional services in healthcare.

Principle 1: Candor and Trustworthiness

Content

People who use the Internet for health-related purposes must have sufficient information to make fully informed decisions about the integrity of content and the potential for bias. Thus, organizations and individuals offering health information, products, or services on the Internet have an obligation to:

1. prominently, clearly, and accurately indicate
   a. ownership of the site or service
   b. the purpose of the site or service
   c. how to contact the owner and the party responsible for the site or service
   d. any relationship, financial or other, **including, for instance, disclosure of co-owners, partners, significant stockholders, or those with co-branding or profit-sharing arrangements** that a reasonable person would believe might influence the user's perception of the information, products, or services offered
2. clearly distinguish advertising from educational or scientific content

Risk

People may not realize that personal information may be collected when they use the Internet. And they may not understand that declining to provide personal data may affect the information or services they receive. Thus, organizations and individuals offering health information, products, or services on the Internet have an obligation to:

1. alert users to the potential risks to the privacy of personal information on the Internet (for example, that third parties may be collecting information without the site's knowledge)
2. provide clear, complete, and accurate information regarding:
   a. what information is being collected and by whom
   b. to what uses information will be put
   c. the possibility that information will be distributed to/acquired by third parties
   d. the choices available to the individual regarding use and distribution

   e. steps to data quality and access
3. state the organization's commitment to data security **including a description of measures used to detect and prevent unauthorized collection of personal information by third parties**
4. clearly disclose the consequences, if any, of refusing to provide personal information
5. clearly describe the accountability mechanism used by the organization or site and how to contact the responsible party

Principle 2: Quality

Obligation to Provide High-quality Information

1. High-quality health information:
    a. uses language that is culturally appropriate for intended users
    b. presents information in language that is easy to read
    c. presents information in formats that accommodate the needs of special populations (for example, large type for users who are visually impaired)
2. High-quality health information should:
    a. be rigorously and fairly evaluated
    b. be consistent with the best available evidence
    c. distinguish "experience-based" information from information that has been formally evaluated scientifically
    d. present all reasonable sides of controversial issues
3. High-quality health information should clearly display:
    a. publication date and version number (if appropriate)
    b. date last reviewed
    c. date when substantive changes were last made
    d. **authorship or attribution, including relevant affiliations**

User Evaluation

People who use the Internet for health-related purposes need to be able to judge the credibility of content. Thus organizations and individuals offering health information, products, or services on the Internet have an obligation to

1. clearly and accurately
    a. disclose the sources of information
    b. disclose how the site evaluates information, **and ensures information accuracy, timeliness, verifiability and reliability**
    c. indicate when there have been substantive changes in the information
2. provide tools for feedback from users about the quality of content and usability of the site

Principle 3: Informed Consent, Privacy and Confidentiality

Informed Consent

To make prudent decisions about whether to provide personal information online, especially information about their health status, people need to know what information is being gathered and why. Thus, organizations and individuals providing health information, products, or services on the Internet have an obligation to:

1. prominently and clearly describe:
    a. what information is being gathered
    b. how that information will be used (for example, for individual health care, **that is, to permit the delivery of 'personalized' or tailored health information research, or commercial purposes including the use of personal information to deliver 'personalized' or targeted advertising based on demographics, health concerns or interests, or other information provided by the individual)**
    c. with whom information will be shared
    d. how/where information will be stored and for how long it will be stored
2. verify that users have given their voluntary informed consent to collect and use personal information in the ways described

Principle 4: Best Commercial Practices

Transparency

People who use the Internet for health-related purposes need to be assured that commercial health or medical sites are trustworthy. They have a right to expect that material presented as scientific or educational in nature is accurate, timely, and objective, and to be assured that they will be able to choose, consent, and control when and how they actively engage in a commercial relationship." **We suggest that the word "actively" be deleted, to clarify that whenever the Internet visitor's actions contribute to a commercial relationship, whether actively or passively, that they will be aware of that.**

Thus, organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to:

1. prominently, clearly, and accurately identify the business and/or site sponsors
2. clearly distinguish content intended to promote or sell a product, service, or organization from educational or scientific content
3. clearly disclose any financial or other incentives for providers who develop or present content
4. **clearly identify when information is being collected, either by the site itself or another party, and prominently display applicable 'opt-out' or 'opt-in' policies in language that is easily understood and implemented.**

Privacy

We suggest adding: Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet should provide maximum opportunity for consumers to exercise control over the use of their personal information.

At a minimum, consumers should be offered the option to 'opt-out' of the sharing of identifiable or linkable information between a site and any of its business partners, and such a choice should be easy to understand and to effect.

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