

Groups Offer E-health Ethics Smorgasboard

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by Donald D. Asmonga

E-health experts nationally are hard at work developing guidelines for this rapidly growing industry. Recently, three sets of guidelines were issued—by an advisory committee to the Federal Trade Commission, by the Internet Healthcare Coalition (IHC), and by a group of information sites and providers, Hi-Ethics.

These documents are consistent with the Clinton administration's 1997 Framework for Global Electronic Commerce, which established the following privacy principles for the administration to follow:

- encouraging private sector development and adoption of effective codes of conduct, rules, and technological solutions to protect privacy on the Internet
- developing recommendations on the appropriate role of government in privacy protection
- ensuring that means are developed to protect the privacy of children

The administration and many in Congress have consistently called on the industry to self-regulate to protect privacy. If the industry fails to make progress, the government likely would explore legislative and regulatory means to protect privacy of information. Protecting consumers is paramount; currently, the FTC can enforce regulations if a Web site harms an individual's privacy using unfair and deceptive trade practices.

FTC Addresses Online Access and Security

The FTC Advisory Committee on Online Access and Security produced its final report in May. The committee's charter directed the group to "consider the parameters of reasonable access to personal information and adequate security and present options for implementation of these information practices." The committee reviewed access and security in the context of fair information practices.

Online Access

This section of the report set out to define access and the difficult issues that accompany it. To address the breadth of this topic, the committee based its analysis on four primary questions:

- What is access?
- What is personal information?
- Who provides access?
- What is the cost of access?

Although not firmly defining "access," the committee outlined the parameters in which the questions should be discussed. For example, when addressing the definition of "personal information," the committee recommended using the following factors:

- "perfect versus imperfect" personal data
- the medium of collection: online versus offline
- the source of collection: individual versus third parties
- the method of collection: passive versus active
- the type of data: factual versus inferred and derived data

The report also examined the issues of access options and authentication.

Security

In addressing security, the report focused on three primary areas:

- competing considerations in computer security
- preliminary considerations for directing computer security
- notice and consumer education

The report offers several options for setting Web site security standards and describes the positions that proponents and opponents of each would take. In setting forth these options, the committee asked how security standards should be defined. The answers included:

1. rely on existing remedies
2. maintain a security program
3. rely on industry-specific security standards
4. case-by-case basis appropriate under the circumstances
5. required sliding scale of security standards

Primarily for options 2 and 4, the committee developed the following security recommendation:

- each commercial Web site should maintain a security program that applies to the personal data it holds
- the elements of a security program should be specified (e.g., risk assessment, planning and implementation, internal reviews, training, reassessment)
- the security program should be appropriate to the circumstances. This standard, which must be defined case by case, is sufficiently flexible to take into account changing security needs over time as well as the particular circumstances of the Web site—including the risks it faces, the costs of protection, and the data it must protect

Finally, the report cites a number of other items that the private sector and policy makers will need to discuss. These items include enforcement alternatives, advancing technologies, security incident data (industry sharing with the government), regulatory standards (extant and emerging), and non-commercial and government Web sites.

IHC Finalizes Code of Ethics

In the June *Journal of AHIMA*, "Capital Currents" discussed the Internet Healthcare Coalition's draft Code of Ethics with AHIMA's suggestions. The IHC published its final code in May. The vision statement of the code states that "the goal of the e-Health Code of Ethics is to ensure that people worldwide can confidently and with full understanding of known risks realize the potential of the Internet in managing their own health and the health of those in their care." To do this, the code provides eight general recommended principles:

- **candor:** Disclose information that if known by consumers would likely affect their understanding or use of the site or purchase or use of a product or service
- **honesty:** Be truthful, not deceptive
- **quality:** Provide health information that is accurate, easy to understand, and up to date. Provide the information users need to make their own judgments about the health information, products, or services provided by the site
- **informed consent:** Respect users' right to determine whether or how their personal data may be collected, used, or shared
- **privacy:** Respect the obligation to protect users' privacy
- **professionalism in online healthcare:** Respect fundamental ethical obligations to patients and clients. Inform and educate patients and clients about the limitations of online healthcare
- **responsible partnering:** Ensure that organizations and sites with which they affiliate are trustworthy
- **accountability:** Provide meaningful opportunity for users to give feedback to the site. Monitor a site's compliance with the IHC Code of Ethics

Hi-Ethics Offers Ethical Principles

Hi-Ethics, a coalition of healthcare sites, also released its Ethical Principles for Offering Internet Health Services to Consumers in May. The group aims to unite health Internet sites in support of high ethical standards for "privacy, security,

credibility, and reliability so that consumers can realize the fullest benefits of the Internet." The 20 coalition members include America Online, Healtheon/WebMD, HEALTHvision, drkoop.com, and Mediconsult/Physicians' Online. Hi-Ethics members pledge to meet the following goals:

- providing Internet health services that reflect high quality and ethical standards
- providing health information that is trustworthy and up to date
- keeping personal information private and secure and employing special precautions for any personal health information
- empowering consumers to distinguish online health services that follow our principles from those that do not

The general ethical principles of Hi-Ethics are listed below:

- **privacy policies**: Their members will adopt a privacy policy that is easy for consumers to find, read, and understand. Their policies will provide users with reasonable notice of their information practices; a positive commitment from them to use security procedures to protect personal information they collect from misuse; and, where appropriate, procedures for consumers to review and correct their personal information maintained by participating sites or to request that the sites delete the information
- **enhanced privacy protection** for health-related personal information
- **safeguarding consumer privacy** in relationships with third parties
- **disclosure of ownership** and financial sponsorship
- **identifying** advertising and health information content sponsored by third parties
- **promotional** offers, rebates, and free items or services will comply with existing federal and state laws
- **quality of health information content** will include no claims of therapeutic benefit without reasonable support
- **authorship and accountability**: Health information content that has been placed on a health Web site because of sponsorship or other support from a third party will be identified
- **disclosure of source and validation** for self-assessment tools
- **professionalism**
- **qualifications**: The credentials and qualifications of persons responsible for healthcare services delivered via their consumer health Web sites will be provided
- **transparency of interactions**, candor, and trustworthiness
- **disclosure of limitations**: Consumers will be advised any limitations of the health Web sites as a source of healthcare services.
- **mechanisms for consumer feedback**

The Hi-Ethics member companies state that they intend to comply fully with the principles by November 1, 2000.

Industry, policymakers, and the public are at the very beginning stages of investigating health concepts and issues. As evidenced by AHIMA's E-health Consumer Conference in Washington, DC, in May, these issues will continue to be of interest as they evolve. We will also continue monitoring and investigating these issues especially as they pertain to personal health records on the Web.

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