

Beyond HIPAA: Ethics in the e-Health Arena

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As the area of online, interactive healthcare communications continues to expand, healthcare organizations must be concerned about securing individual privacy and fostering strong ethical behavior. What are the ethical principles relevant to e-health? How should healthcare organizations develop and promote ethics guidelines and codes of conduct for websites and electronic patient information?

The American healthcare system is undergoing a reform in which technology—and especially the Internet—is playing a major role. While HIPAA's privacy and security rules have paved the way for e-health applications by easing some concerns about patient privacy and the security of electronic health information, HIPAA offers a floor, rather than a ceiling, for health privacy. The legislation does not apply to health information and services offered through the Internet by nonhealthcare professionals, and it is silent on other extralegal ramifications of e-health, such as the quality of health information online and the biases that may be introduced by the commercialization of e-health. These issues must be addressed to build trust in e-health and ensure its success.

THE GOAL: BUILD TRUST

Trust is fundamental to healthcare. Patients rely on healthcare providers to keep their personal information confidential, to provide accurate and appropriate information about their conditions and possible treatments, and to recommend the therapy they believe to be in the patient's best interest.

But trust can be particularly difficult to achieve in the anonymous, virtual environment of the Internet where anyone who has access to a computer, an online connection, and modest technical skill is able to set up a website offering health information, products, or services, regardless of his or her qualifications. Trust was especially in short supply during the heyday of the Internet “dot-com boom” era (1995 through 2000) when many entrepreneurs established commercial, for-profit health information websites. This early phase of the Internet was likened to the Wild West—a land without formal laws in which you ventured at your peril. It was left up to consumers themselves to determine what they were dealing with.

THE E-HEALTH CODE OF ETHICS

In response to ever-growing public scrutiny of the Internet health arena, several organizations have championed e-health ethics initiatives. These include

- Health On the Net (HON), *Code of Conduct* (www.hon.ch/HONcode/Conduct.html);
- American Medical Association, *Guidelines for Medical and Health Information Sites on the Internet*;
- Health Internet Ethics (Hi-Ethics), *Ethical Principles for Offering Internet Health Services to Consumers* (www.hiethics.org/Principles/index.asp);

- Internet Healthcare Coalition, *e-Health Code of Ethics* (www.ihealthcoalition.org/ethics/ethics.html); and
- URAC, “Health Web Site Standards” (www.urac.org/documents/HealthWebSitev1-0Standards040122.pdf).

The goals of these initiatives and organizations are to draft ethical guidelines for creating credible and trustworthy health information and services on the Internet. There has been much cross-fertilization among these groups in terms of shared members and documents. The resulting guidelines, codes, and standards, therefore, share much in common.

The *e-Health Code of Ethics*, developed by the nonprofit, non-aligned Internet Healthcare Coalition, was created by the largest and most diverse group of stakeholders, including members of all the organizations mentioned above. The coalition based its initiative and the resulting *e-Health Code of Ethics* on collaboration and consensus among a broad mix of stakeholders, including traditional healthcare organizations, commercial Internet health information publishers, regulatory organizations, and most important, individual consumers. The coalition’s *e-Health Code of Ethics* aims to help healthcare managers and executives operationalize e-health ethical leadership within their organizations. The code provides what I call the “eight commandments” of e-health ethics. As such, it offers the moral and ethical framework

e-Health Code of Ethics: An Executive Summary

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 and 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

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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.

that other groups can interpret to satisfy the individual, practical needs of different kinds of stakeholders (see box).

TIPS FOR E-HEALTH DEVELOPERS AND EXECUTIVES

Healthcare executives at the highest levels can ensure that proper ethical standards are adopted to govern their e-health applications by keeping the following in mind:

- Remember that adopting any of the codes mentioned above is a step forward from no code at all. All of the codes contain sound advice on how to conduct business on the Internet. It is critical that healthcare executives educate consumers about ethical practices and how to distinguish e-health services based on ethical principles from those that are not.
- Website developers and e-health executives should practice “ethical due diligence” with regard to choosing their business partners and sites to which they link. Your trusted reputation

is often transferred to your partners. Don't let this trust be betrayed by partners who do not comply with the same high ethical standards that you do.

- It is important to train key employees in ethical standards. Often, mistakes are made by well-intentioned employees who are ignorant of the issues and who do not know how to identify and resolve ethical dilemmas. Ensure that key employees and managers are familiar with the ethical issues for creating trustworthy health sites.
- For now, adopting an ethics code is voluntary. Organizations that adopt a code should perform a critical self-assessment of their websites to ensure they comply with the code. Participating in URAC's fee-based Web Site Accreditation program may help you formalize this process and identify critical gaps between ethical standards and actual practice.
- If you do adopt a code, be sure to promote it to consumers and patients who use your e-health services. This can be a competitive advantage, but more important, you can use the code to teach users how to find credible health information and services through other websites they are likely to visit.

Meeting the e-health challenges ahead calls for innovative management and a new focus on ethical issues. Healthcare providers, payers, and consumers share a responsibility to ensure the value and integrity of e-health by exercising judgment in creating and using the technology according to the highest possible ethical standards.

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