

Ethical Issues for Internet Healthcare: The eHealth Code of Ethics

The First National HIPAA Summit

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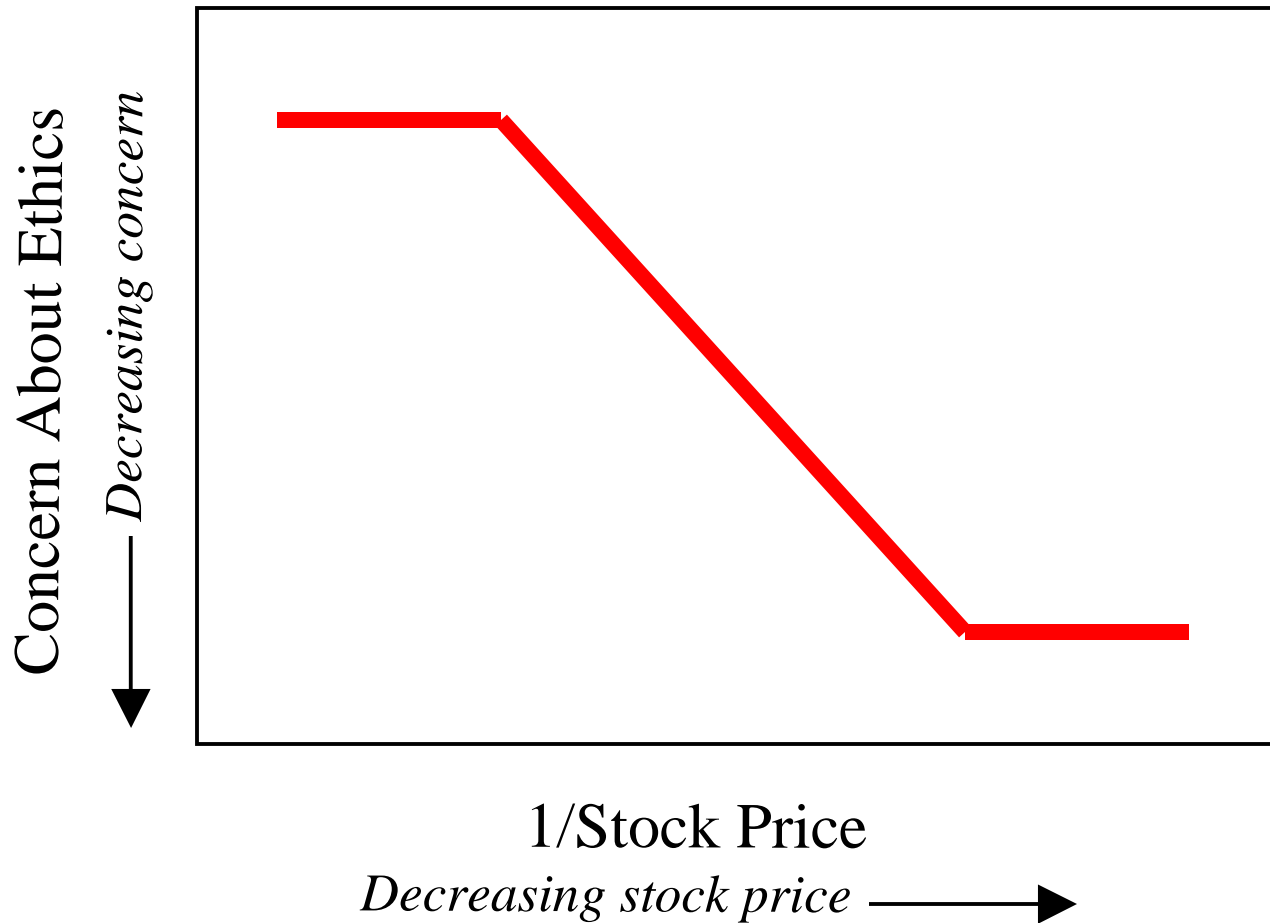
Internet Healthcare Coalition (www.ihealthcoalition.org)



Code of Ethics: Why Now?

- Critical mass and exponential growth
- “New”/“non-health” participants
- Questionable practices
- Bad press
- Legislation/regulation concerns

Mack's Law of Dotcom Diminishing Concern



Ethics Standards and Guidelines

Ethics standards and guidelines for Internet health sites are being developed and promoted by several organizations and quasi-government agencies.

- Internet Healthcare Coalition
- Hi-Ethics Alliance
- AMA
- HON
- Other (e.g., medCERTAIN)



Common Goals

- Focus on ethics guidelines, codes of conduct for web sites
- Education of consumer and content providers
- Self-regulation
- Compliant with the eHealth Code of Ethics



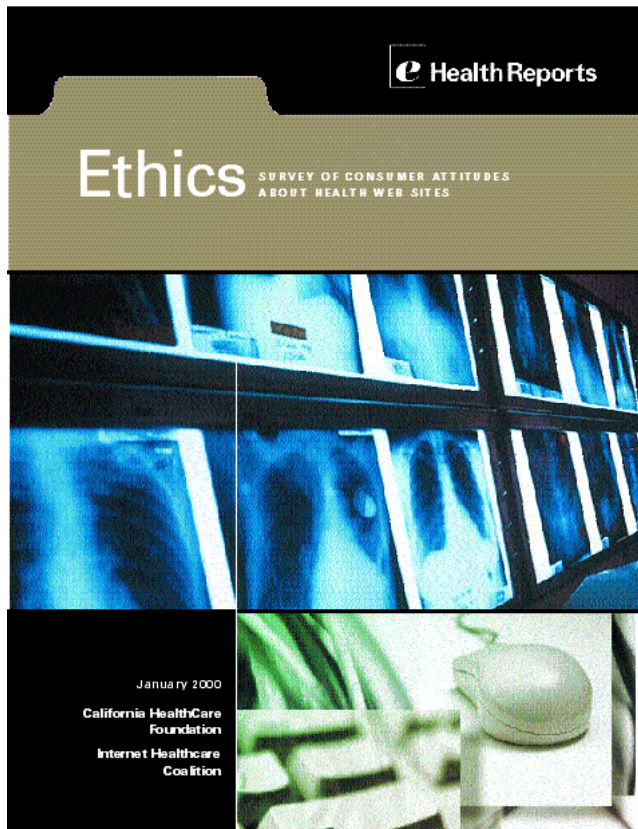
Internet Healthcare Coalition

- 501c3 Non-profit formed in 1997
- International and broad-based membership
- Educational Mission
- Projects include:
 - eHealth Code of Ethics
 - eHealth ethics books, focus groups, surveys, workshops
 - Health fraud on the Internet
 - Tips for consumers
 - Annual conference



The mission of the Internet Healthcare Coalition is
quality healthcare resources on the Internet.

Ethics/Privacy Survey



- January 2000 Survey of consumer attitudes about health web sites
- Sponsored by Internet Healthcare Coalition and the California Healthcare Foundation
- Conducted by Cyber Dialogue
- Basis for Coalition's eHealth Ethics Initiative and eHealth Ethics Summit

A new survey is being conducted by Harris Interactive and Internet Healthcare Coalition.



Some Survey Results

- 66% of online health seekers are concerned about privacy (more concerned if over 50, low income, non-white; ~72%)
- Only 21% of health seekers willing to trade privacy for personalization
- Online medical record keeping perceived as greatest threat
- Seals of approval have no impact on attitude
- Government and medical associations most trusted sources

Conclusions

“The data ... point to the urgent need for a thoughtful, thorough and fair discussion of ways to secure individual privacy, foster strong ethical behavior, and harness the incredible power of the Internet to improve the quality of healthcare for all Americans.

By necessity, this discussion must include all concerned parties: traditional healthcare organizations (insurance companies, pharmaceutical manufacturers, hospitals, etc.), Internet health players, appropriate regulatory organizations, and, most importantly, the individual consumer.”



eHealth Ethics Initiative

The Internet Healthcare Coalition aims to develop and promote ethical principles relevant to the fast expanding area of online, interactive healthcare communications, through the consensus of industry, academic, government, patients, and consumer leaders. This ongoing agenda is the **eHealth Ethics Initiative**.

GOALS

- Develop an international ehealth code of ethics
- Educate site developers, users, and the medical community
- Work with other organizations to implement and enforce the code through voluntary programs



Internet Healthcare Coalition's Approach to Ethics Guidelines

- Consensus by open discussion
- Broad membership and participation
- Guidelines for entire Internet health arena
- Ongoing initiative
- Educational focus

eHealth Ethics Summit

- Date - January 31, February 1 & 2, 2000
- Host - Pan American Health Organization
- Sponsor & Organizer - Internet Healthcare Coalition
- Purpose - Begin the development of an international eHealth Code of Ethics
- Over 60 representatives: for-profit dotcoms, patient groups, academic institutions, government, medical ethicists, international organizations, etc.



eHealth Code of Ethics

“...The goal of the "eHealth 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.”

eHealth Code of Ethics: Principles

- **Candor**
 - Disclose information that if known by consumers would likely affect consumers' 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.

eHealth Code of Ethics: Principles

- **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 Health Care**
 - Respect fundamental ethical obligations to patients and clients.
 - Inform and educate patients and clients about the limitations of online health care.

eHealth Code of Ethics: Principles

- **Accountability**
 - Provide meaningful opportunity for users to give feedback to the site.
- **Responsible Partnering**
 - Ensure that organizations and sites with which they affiliate are trustworthy.

eHealth Code of Ethics: Implementation

- Align with implementation organizations
- Define the Need
 - Focus groups
 - Surveys
- Educate the Stakeholders
 - Book
 - Conference
 - Training workshops

Internet Healthcare Coalition Partners

- URAC
 - a leading health care accreditation organization
 - issued over 1,600 accreditation certificates to more than 500 managed care programs doing business in all 50 states
- Center for Ethics in Health Care
 - corporate ethics training
- Others
 - California Healthcare Foundation, Harris Interactive, Hi-Ethics, NMHA



eHealth Issues Focus Groups

- Co-sponsored by URAC and Internet Healthcare Coalition
- June 28, 29, 30; Washington, D.C.
- Stakeholders
 - consumers, healthcare providers, and ehealth businesses
- Goals
 - URAC: health care web site accreditation program
 - COALITION: information for developing workshops and other educational programs
- Results will be announced at the Coalition's annual meeting



Focus Group Questions

- What does the word “quality” mean in an e-health context?
- What is the role of health care providers in the e-health community?
- What are the elements of good online practice required to build consumer trust?
- Should e-healthcare personnel be trained to deal with ethical decisions?
- Can accreditation be a useful tool in promoting quality healthcare information on the Internet?
- What might be the elements of an effective health web site accreditation program?

The New Frontier: Exploring eHealth Ethics

- Co-published by URAC and the Internet Healthcare Coalition
- Explore the ethical challenges created by the convergence of health care and the Internet
- Available December, 2000



Ethics Training

- Developed by the Internet Healthcare Coalition
- Distinguished faculty
- Based upon the eHealth Code of Ethics
- Delivered on-site and virtually via web conferencing

Purpose of Ethics Training

- Certify People, Not Sites
 - The New “CEO” - The Chief Ethics Officer
- For Executives
 - define and shape a leadership role in fostering ethical climate and behavior
- For Management
 - to encourage management to model ethical behavior
- For Employees
 - to help employees understand and meet organizational expectations
 - help employees achieve “critical distance”



Training Objectives

- Review the eHealth Code of Ethics
- Discuss ethical decision-making in the context of online healthcare business decisions
- Discuss how to recognize and respond to ethical concerns and dilemmas through case studies

The Ethical eHealth Employee

- Ethics training gives employees “leverage” by giving them tools for critical thinking
- Gives employees a “voice” against dishonest or self-serving managers
- Ethically-trained employees bring their culture to their next employer and spread good ethical practices rather than bad practices

Coalition's Annual Conference

- **Quality Healthcare Information on the 'Net 2000:
Establishing Trust, Ensuring Privacy, Enabling e-Commerce**
- When: October 3 & 4, 2000
- Where: Las Vegas Hilton, Las Vegas, NV
- Program
 - Keynote Speakers – George Lundberg, Mark Samuelson, Lee Peeler, Ahmad Risk
 - Concurrent Tracks:
 - Track A: Establishing Trust
 - Track B: Ensuring Privacy
 - Track C: Enabling Ethical, Profitable E-Commerce
 - Track D: Empowering Patients/Healthcare Consumers
 - **Power Panel: eHealth Codes of Ethics: Compliance in the Real World (AMA, HON, Hi-Ethics, Internet Healthcare Coalition, URAC, etc.)**



Ethical Due Diligence

- Be sure that you and your online partners adhere to the eHealth Code of Ethics or guidelines consistent with the Code
- State your policy on your site and link to the eHealth Code of Ethics
- Sign up your ehealth employees and managers for Coalition ethics workshops

URLs

- Internet Healthcare Coalition
 - www.ihealthcoalition.org
- URAC
 - www.urac.org
- eHealth Code of Ethics
 - www.ihealthcoalition.org/ethics/ehcode.html
- Quality Health Information on the Net 2000 Conference
 - www.ihealthcoalition.org/community/program2000.html

