Hi-Ethics:

Tough Principles for Earning Consumer Trust

by Donald W. Kemper, MPH

Any realtor can tell you the top three rules of success in real estate: location, location, location. The top three rules for success on the health Internet have become equally clear: trust, trust, trust. If users don't trust a site, they won't come back. If doctors don't trust it, they won't send their patients there, and if regulators don't trust it, they will put it out of business. Without trust, the e-health industry cannot work.

Because of the importance of trust, 17 of the nation's largest, mostly commercial, for-profit health Web sites were moved to create Hi-Ethics (Health Internet Ethics) to earn the trust of health Internet users. This is not a public relations play or slight-of-hand move. Since the first meeting of Hi-Ethics in November 1999, the emphasis has been on "earning" trust. The result is a set of principles that are not only consistent with the aspirational e-Health Code of Ethics, developed by the Internet Healthcare Coalition, but are also designed with clear implementation guidelines and for the purpose of objective verification. This tough set of ethical principles has put forth the rules by which ethical health Web sites can play.

The Hi-Ethics principles give protection to both users and providers of health Web sites. Users benefit because the principles provide strong and verifiable rules to prevent privacy and commerce abuses. Web sites benefit because the same set of rules takes the guesswork out of what is and is not acceptable practice. The Hi-Ethics principles create an even playing field for all e-health organizations. Furthermore, Web sites benefit by pre-empting the press attacks and bureaucratic paperwork that might otherwise develop from uncoordinated interpretations of ethics in an unregulated space.

About Hi-Ethics

Hi-Ethics, Inc., is an association of major health Web sites as listed in Table 1. These companies represent many of the most popular U.S.-based consumer health Web sites. They include content companies, commerce companies, interaction companies, and many combinations of these business features. All but one of the original members are for-profit. (Healthwise is non-profit.)

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Don Kemper is CEO of Healthwise, a nonprofit company dedicated to helping people make better health decisions. Since 1975, he has passionately promoted medical self-care, shared decision-making, and patient empowerment. His Healthwise® Knowledgebase is an award winning Internet tool that translates evidence-based medicine into terms consumers can use in shared decision-making. Healthwise is the world's leading provider of prescription-strength health information. (www.healthwise.org)

Don Kemper is also Chairman of Hi-Ethics, Inc., a coalition of the most widely used Internet health sites and content providers that have united to create a detailed set of ethical principles for health Web sites. (www.hiethics.org)

While the business models of these companies differ dramatically, all share a fundamental need to earn the trust of consumers. In addition, all feel that their own Web sites will do best if the cloud of concern and distrust hovering over the e-health world could be lifted.

Hi-Ethics was incorporated as a non-profit company in November of 2000 and filed for 501(C)6 tax exempt status with the federal government. To achieve its goal of creating implementable and verifiable standards, Hi-Ethics engaged the staff-support services of Hogan and Hartson, a long-established and respected Washington, D.C. law firm. The Hogan team, led by former FTC Commissioner Christine Varney, contributed expert advice on writing the regulatory language needed to measure and verify compliance with the principles.

Each Hi-Ethics member was asked to contribute equally and substantially to provide the funding for the initial year of operation.

Table 1
Hi-Ethics Participants
August, 2001

Hi-Ethics Chairman: Donald W. Kemper

Healthwise, Incorporated
adam.com
allHealth.com/iVillage
America Online
drkoop.com
HealthCentral.com
HEALTHvision
Healthwise
InteliHealth
LaurusHealth.com
Medscape
PersonalMD
Veritas Medicine
WebMD
WellMed

The Hi-Ethics Principles

Officially, the Hi-Ethics principles are called the "Ethical Principles for Offering Internet Health Services to Consumers." The principles cover the five areas of privacy, commerce, information quality, professionalism, and disclosure. (See Appendix B to read complete principles, or visit www.hiethics.org.) Each ethics area is discussed below:

Privacy Principles

The first three principles set clear rules for protecting the privacy of health Web site users. These principles cover the following key points for the health Web sites of Hi-Ethics members:

- The Web site must have and display a privacy policy;
- It must disclose proposed uses of information and limit the uses of personalized health information to those that are in the best interest of the consumer;
- It must provide users with a meaningful choice regarding the proposed collection and use of personal information and require a specific "opt-in" before providing personal health information to any third party; and
- It must provide assurance of security procedures to protect against unintended access to personal information.

Commerce Principles

Principles four, five, and six focus on protecting the user from unethical commerce. The basic concepts of openness and transparency were followed to assure that health Internet users were not misled into services, products, or behaviors not in their own best interest. Disclosure was used

here, rather than restrictions, so as not to unduly constrain the business models of Hi-Ethics' member sites. Key Hi-Ethics rules include the following:

◆ Disclosure of ownership and financial sponsorship;

◆ Clear distinction between content and advertising;

◆ Clear disclosure of sponsor involvement in content;

◆ Clear disclosure of how the site earns revenue from consumer use;

◆ Clear disclosure of whether information or ads are targeted based on user's content selection; and

◆ Restrictions on promotional offers.

Quality Principles

Principles seven, eight, and nine focus on the quality of health information presented on health Web sites. The writers of the principles attempted to accommodate the health Web user's competing needs for high quality, evidence-based information, as well as for unrestricted access to differing points of view and alternative medicine approaches. The key points of these principles, summarized below, provide for full disclosure of quality factors without imposing restrictions on what is allowable. Hi-Ethics Web sites will offer:

◆ Only therapeutic benefit claims with reasonable support and no knowingly false information;

◆ Disclosure of sponsor support of, and involvement with, content;

◆ Disclosure of the author or source of third party content;

◆ Disclosure of authors for content claim to be based on research or clinical experience;

◆ Disclosure of editorial policy and author credentials;

◆ Disclosure of the date of creation or updates for all self-created content; and

◆ A conflict of interest policy for affiliations and the financial relationships of authors.

Consumer concern about the quality of information is second only to concern over privacy. Sixty-five percent of health site users feel confident in the quality of Internet health information while only 42% are confident in the privacy and confidentiality of health Internet services (*Ethical Issues Awareness of eHealth Site Users vs. Developers*, Harris Interactive and the Internet Healthcare Coalition, 2000). Another survey indicates that 36 percent of consumers are frustrated with content credibility while 41 percent are concerned enough with privacy that they would not submit personal information to a commercial site (Jupiter Research, 2001).

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While the Hi-Ethics quality principles provide a sound foundation of protection for consumers, they do not assure that only the best, evidence-based medical information is provided on the sites. To do that would have been overly restrictive on such valuable features as self-help group chat rooms or patient bulletin boards.

The principles do provide a solid foundation for preventing most unethical and commercially biased efforts to influence consumer behavior. More importantly, the principles will require the disclosure of information that the consumer can use to assess the quality of information. Yes, consumers deserve access to evidence-based, up-to-date, and expert-reviewed

information. With the Hi-Ethics disclosure requirements in place, they will be able to determine if they are getting it. (See Prescription-Strength Information bar.)

Professionalism Principles

Hi-Ethics encourages health care professionals to apply and follow the ethical standards of their respective professions whenever possible. However, these professional codes do not always apply to every interaction between a consumer and a professional. While Hi-Ethics expects that the principles governing professional activities on the Internet will evolve dramatically over the next few years, its initial principles 10 and 11 do highlight the following points:

- Conspicuous and appropriate information will be available for consumers to understand when they are and are not in an interaction with a health professional that is covered by the ethical standards of the profession.
- Health Web sites will be designed to enable health care professionals to adhere to professional ethical principles in the online environment.
- Credentials and qualifications of persons responsible for health care services will be available.

Disclosure and Feedback Principles

The final three Hi-Ethics principles cover issues of transparency, limitations, and feedback including the following:

- Disclosure of risks, responsibilities, and reasonable expectations;
- Disclosure of when a user moves into areas of greater or lesser risk;
- Disclosure of any limitations of the health Web site as a source of health care services; and

- Ease of consumer feedback or complaint submission.

Hi-Ethics has also provided a comprehensive glossary of terms used within the principles to remove the risk of multiple interpretations of their intent. To further the goal of consistent use of terminology, Hi-Ethics has initiated a joint project with the Internet Healthcare Coalition, the American Medical Association, and the Health on the Net Foundation (HON) to develop a common vocabulary.

Compliance, Verification and Accountability

It is clear that an ethical code relying solely on self-evaluation will not be treated as serious industry self-regulation. Therefore, Hi-Ethics has set about to create a compliance, verification, and accountability program with "teeth." Any Web site that wishes to claim that it meets the Hi-Ethics principles will have to subject itself to the scrutiny of an independent review.

In Spring 2001, Hi-Ethics announced that it had selected the URAC accreditation process as the mechanism by which Hi-Ethics members will demonstrate compliance with the 14 Hi-Ethics Principles. URAC is a non-profit health accreditation organization. Its standards for the accreditation of health Web sites are based on the Hi-Ethics Principles, and Hi-Ethics members were active participants in the development of the URAC standards. By working with URAC, Hi-Ethics will promote accountability for all health Web sites. By meeting the URAC standards, Hi-Ethics members will demonstrate their commitment as leaders in the promotion of health Internet quality and consumer trust.

A Global System of Codes

Hi-Ethics is committed to working with the AMA, Internet Healthcare Coalition, URAC, HON, and others to create a system of health Internet ethical codes that use common terminology and that inter-relate to one another. While the ethical foundation of all of these codes is consistent, and although many of the code elements are nearly identical, the varying needs of different health Web site types may continue to require a variety of seal or certification programs. Hi-Ethics intends to work cooperatively both nationally and internationally to assure that the evolving system of codes is both understandable to the public and efficiently implementable for the Web sites. ■

Prescription-Strength Information

Health consumers are demanding the same quality of information that is available to their doctors. They want information that is good enough to bet their lives and their health on. Too much of the health Internet is covered with inch-deep, mile-wide content. Such content gives a little information on every health problem, but it offers little help in making serious, and often complex, medical decisions. For these consumers, a Web site that doesn't help them make a better decision simply doesn't help. To meet the needs of the consumer, Web sites must offer prescription-strength information.

Prescription-strength information is:
♦ Evidence-based
♦ Reviewed by experts
♦ Referenced
♦ Decision-focused

Evidence-based

Evidence-based medicine is founded on the study of randomized clinical trials and other objective research. Only when theories and opinions are tested and confirmed by high quality, objective research can physicians determine which treatments are best for which conditions. The evidence-base of medical science is expanding every year. Unfortunately, there is often a delay in getting new evidence-based findings into practice quickly. Doctors, like any other group, are sometimes averse to making changes in how they practice medicine.

But patients need not wait for their doctors to give them the best information about diagnostic and treatment options. Consumers know that, and increasingly, are demanding the best and most current information directly from hospital and health plan Web sites, as well as general health portals. One element of prescription-strength information is that it must be evidence-based.

Reviewed by experts

Internet users should check to see that recognized experts in appropriate medical specialty areas review the health information. A good Web site will indicate to the consumer when and by whom each piece of health information has been reviewed. Reviewer credentials should include board certification and academic appointments at the nation's leading medical schools or other measures of credibility.

Referenced

Prescription-strength information should be referenced to dated source materials so that consumers can tell both the age and authentification of the results. The names and credentials of the authors should be listed.

Decision-focused

To be most helpful, prescription-strength information should be organized around key medical decisions. Shared decision-making between patient and professional, results in the best health decisions and the best medical outcomes. When prescription-strength information is presented in ways to help doctors and patients work together to make better decisions, huge benefits result.

**Hi-Ethics: Ethical Principles for
Offering Internet Services to Consumers**

Questions and Answers

What is Hi-Ethics?
Hi-Ethics, Inc., or Health Internet Ethics, is a coalition of the most widely used Internet health sites and content providers that united to create a detailed set of ethical principles for health Web sites. Our goal is to earn consumer trust and confidence.

What are the Hi-Ethics principles?
The document is entitled "Hi-Ethics: Ethical Principles for Offering Internet Services to Consumers." It is a 14-point set of principles that the member organizations will follow in order to help consumers confidently realize the fullest benefits of the Internet to improve their health and that of their families. These principles set high standards for consumer protection, including privacy, security, quality of information, fairness of transactions, and professional conduct.

Why was Hi-Ethics formed?
Hi-Ethics was formed in November of 1999 to address privacy, advertising, and content quality issues for Internet health consumers. While the Internet presents enormous opportunities to empower consumers to take charge of their health and well-being, there are so many Web sites offering health information and services that consumers may have trouble distinguishing reliable Web sites from unreliable Web sites. Hi-Ethics member companies have set standards to help operators of health Web sites offer quality services and to help consumers use the Internet to its greatest potential.

How were the Hi-Ethics principles developed?
Executives from Hi-Ethics member companies met frequently between November 1999 and May 2000 to develop the first version of the principles. In January 2000, the companies enlisted the help of attorneys from Hogan & Hartson LLP, a Washington, D.C. law firm with extensive experience in health and Internet privacy and regulatory issues. Members drew on each company's own policies and practices and compared them with ethical standards from medical, publishing and other fields. The goal was to establish principles broad enough to apply to a wide variety of health Internet businesses but also specific enough to really help consumers. The principles were launched in May of 2000. Hi-Ethics is currently working with other organizations to develop a second, updated version of the principles.

Why develop industry standards now instead of waiting for government regulation?
Hi-Ethics is in favor of the most ethical provision of health services over the Internet. Members share a common goal with government policy makers, and that is to provide consumers with a secure and trustworthy health Internet environment. Hi-Ethics members can swiftly adopt industry standards and bring their benefits to consumers in a shorter timeframe than government regulations. These industry standards have been developed by health Internet experts who actually have the power to implement them. This allows the industry itself to find innovative solutions that encourage business growth while at the same time help consumers to achieve the fullest potential of the Internet.

How will these principles be verified and the companies kept accountable for adhering to them?
Hi-Ethics, Inc. has signed an agreement with URAC whereby Hi-Ethics members can verify compliance with the principles. By applying for URAC Health Web Site Accreditation--the standards of which are based on the Hi-Ethics principles--the companies can certify compliance with the Hi-Ethics principles.

How will consumers know a Hi-Ethics site when they see one?
Hi-Ethics members will display the URAC accreditation seal, which will signify that a site has met rigorous quality standards based on the Hi-Ethics principles. In addition to displaying the URAC accreditation seal, all members of Hi-Ethics, Inc., are listed on the Hi-Ethics Web site, www.hiethics.org.

Will Hi-Ethics expand its membership?
The members of Hi-Ethics, Inc. are eager to have other health Web sites endorse the Hi-Ethics principles and participate in the development of a second version of the principles. A process for joining the effort is outlined at www.hiethics.org.

How can one get more information?
Visit the Hi-Ethics Web site at www.hiethics.org.