



Ethics Survey of Consumer Attitudes about Health Web Sites

Sponsored by California HealthCare Foundation & Internet Healthcare Coalition

EXECUTIVE SUMMARY

The *Ethics Survey of Consumer Attitudes about Health Web Sites* demonstrates that the average American Internet user is:

- Concerned about the privacy of online health information
- Suspicious of the ethics of many Internet health Web sites
- Uncertain whether personal health data are protected by law, and
- Confused about who should regulate Internet health information, or if it should be regulated at all

I. Internet users overwhelmingly do not want their health information shared with anyone else without their consent. Eighty-eight percent of respondents said they would not be willing to submit information if it were to be shared with advertisers or marketers. In fact, they are more concerned about a site sharing information with advertisers than they are about someone hacking into the site and gaining access to their information. There is also a high level of concern about access to personal health information by insurers and employers who might use that information against them.

II. Online medical record keeping, even if access is restricted to an individual and his or her physician, is perceived as the greatest threat to individual privacy on the Internet. These numbers are particularly significant given that these are some of the major services that healthcare companies are trying to expand online.

III. Physicians may hold the key to overcoming consumer's fears. Internet health consumers are most likely to trust their physicians, medical institutes and associations to maintain the privacy of their personal health information. They trust pharmaceutical companies, Web portals and online drugstores the least. Consumers are more willing to provide information to (and trust the content of) a site that has been recommended by their doctor, or if there is a privacy statement on the site stating that information will not be shared. Paradoxically, while seventy-eight percent of respondents say a privacy statement on a site is a positive influence on their likelihood to use that site, fully two-thirds of all respondents say they "sometimes, rarely, or never" read those privacy statements, nor do they check to see who sponsors the sites that they're using. These data indicate that meaningful privacy policies can have a positive impact on willingness to engage in online health activities. But despite their concern, the majority of

Internet users have not yet taken an active role in educating themselves about online security issues.

IV. People don't know if their privacy is legally protected (a fact mirrored by polls showing most people believe there is a Federal law that protects medical records). Further, Internet users are sharply divided over who, if anyone, bears responsibility for regulating health information and services on the Internet.

V. Seventeen percent of Internet users will not even search for health information online because of privacy concerns. Despite the real risks to privacy posed by the Internet, this statistic hints at a level of concern that may be unwarranted -- simply searching for information, without registering or providing other personal information, could be an anonymous activity. This fear may be an impediment to the adoption of services that may provide significant benefits to consumers in the future.