ETHICS SURVEY OF CONSUMER ATTITUDES ABOUT HEALTH WEB SITES

Sponsored by
California HealthCare Foundation
and **Internet Healthcare Coalition**

Conducted by **Cyber Dialogue**
in cooperation with
the **Institute for the Future**

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cyber dialogue
customer relationships
through digital media™

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METHODOLOGY

The California Health Care Foundation commissioned Cyber Dialogue to conduct a survey to measure U.S. online adults' concerns regarding the ethical conduct of healthcare Web sites and services on the Internet. To meet this objective, Cyber Dialogue surveyed via the Internet a nationally representative sample of 1009 U.S. online adults age 18 or older. The survey was conducted January 10-17, 2000. All respondents are members of Cyber Dialogue's database of online users. Quotas were established to interview 750 respondents who currently seek health and medical information online and 250 who do not. Respondents were sampled and weighted, based on Cyber Dialogue's American Internet User Survey, to reflect nationally known norms for online adults in terms of age, gender, household income, ethnicity, health status, Internet tenure and whether they use the Internet for health or medical information.

INTRODUCTION

Health. Privacy. Technology.

Each topic on its own has played a central role on the national stage for decades, and each maintains its prominence at the start of the new millennium. With the advent of wider access to the Internet, and the growing promise (or, as portions of this white paper may indicate, the growing threat) that the convergence of healthcare information, personal information, and Internet-based collection and distribution of both has wrought, the issue of personal privacy as it relates to health matters has never been more important. The dramatic revolution that has resulted from the array of healthcare-related consumer, connectivity and ecommerce Web sites poses a series of complicated ethical and legal questions — most of which bewilder the consumer, few of which have been addressed adequately by the institutions upon which the consumer depends for security. The data reported in Ethics Survey of Consumer Attitudes about Health Web Sites, collected from in-depth interviews of over 1,000 Internet users in the United States, 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. The California HealthCare Foundation and the Internet Healthcare Coalition have sponsored this groundbreaking study with the intention that it will spur such a discussion at the national level.

Table 1: Half of online users are concerned about the potential invasion of privacy of personal health information in the U.S

	Online Users
1 (Not At All Concerned)	16%
2	21%
3	29%
4	23%
5 (Very Concerned)	28%

Source: Cyber Dialogue, 2000

I. General Concerns About Privacy Permeate Society — The Internet Compounds Many of Those Fears

Americans using the Internet are concerned about protection of their privacy not only while online, but in their everyday lives and activities. When asked to answer "How concerned are you about the potential for invasion of your personal privacy in the U.S. today," on a scale from 1 ("not at all concerned") to 5 ("very concerned"), fully 61% of all respondents placed their level of concern at 4 or 5. Among seekers of health information on the Internet ("health seekers"), that figure rose to 66%.

Among populations that may perceive themselves as more vulnerable to breach of privacy — online health information seekers over 50, online health information seekers with household incomes under $50,000 per year, and online health information seekers of color — the ratio rose 72%, 71%, and 72% for each

Table 2: Internet users are concerned about privacy issues, both online and offline

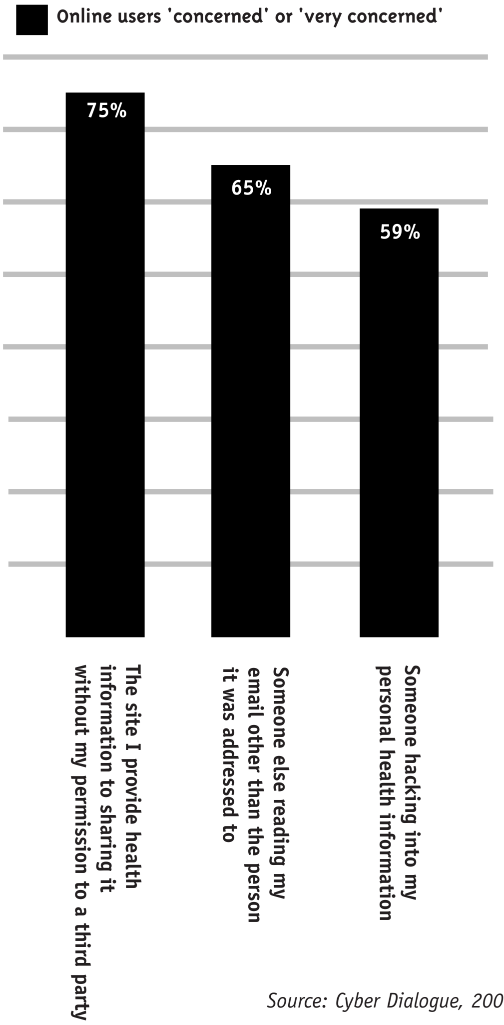
	Online Adults	Online Health Information Seekers	Non-Seekers
Concerned/Very Concerned about personal privacy in general	61%	66%	59%
Concern regarding personal privacy on Internet vs. personal privacy in general:			
More concerned about Internet	52%	49%	53%
Less concerned about Internet	8%	12%	6%
Neither more or less concerned	40%	39%	41%

Source: Cyber Dialogue, 2000

group respectively. These data show that the ongoing American debate about the scope and sanctity of our perceived right to privacy has extended into the Internet sphere. For example, Table 2 also shows the majority of respondents — 52% — are even more concerned about general invasion of privacy occurring via the Internet than through other means, with 49% of health seekers sharing that measure of concern. These numbers indicate unease about privacy even among individuals already comfortable using the Internet to access information and services for themselves and their families.

Table 3: Three Main Health Privacy Issues Concern Online Users

(Respondents rating 4 or 5, with 5 meaning 'very concerned')



Source: Cyber Dialogue, 2000

II. Half of Internet Users Concerned About Potential for Invasion of Privacy of Personal Health Information

When asked specifically about preserving the privacy of health information in the United States (whether online or offline), the survey found similar rates of concern.

When questioned about particular types of breaches of privacy, the vast majority of respondents rated themselves "concerned" or "very concerned" about the following three issues (see Table 3).

III. Balancing Privacy and Personalization

The current survey confirms earlier privacy studies conducted by Cyber Dialogue that have shown there is a range of personal information that individuals are willing to share with Internet sites, provided that information is:

- used to enhance the quality of their online experience, and
- not subject to unwarranted or undisclosed sharing or abuse

Comfort levels with revealing certain types of personal data as part of a site's registration process have grown as the Internet is used more widely. But, as Table 3 shows, disclosing personal health information still raises concerns, with just 18% of all respondents and 21% of health seekers willing to do so in return for a more personalized Web service. This figure compares with acceptance rates for disclosing email addresses, name, and gender, all of which reach well into the 80+% range. A person's favorite color (a fact sometimes used by Internet marketers to personalize banner advertisements to make them more attractive to individual users) is disclosed willingly by 72% of users; ethnicity by 66%, and address by 55%. Only credit card information is more closely guarded that health data: 10.5% of all respondents are willing to disclose their credit card numbers in exchange for personalized Web site service. This finding is consistent with previous Cyber Dialogue research from 1999 which found a similarly higher level of vigilance regarding credit card numbers as compared to other personal information:

	The Internet Poses a Risk to my Privacy	**The Internet Poses a Risk to my Credit Card Number**
Strongly Agree	9%	30%
Agree	33%	38%

Source: Cyber Dialogue, 1999

When the survey considered less sensitive information (such as products purchased online, or promotions to which a consumer responded), a majority of those surveyed were comfortable having these types of data points collected without their explicit consent. Opinion changes drastically, however, when users are asked whether it is acceptable for information gathered during the site registration process to be shared with other Web sites, companies or advertisers. For example, while 90% of those surveyed were willing to give their email address to a site, only 18% of respondents said it was acceptable for the site to share that information. Eighteen percent were willing to share health information to register, but just 3% were comfortable with that data being shared with a third party.

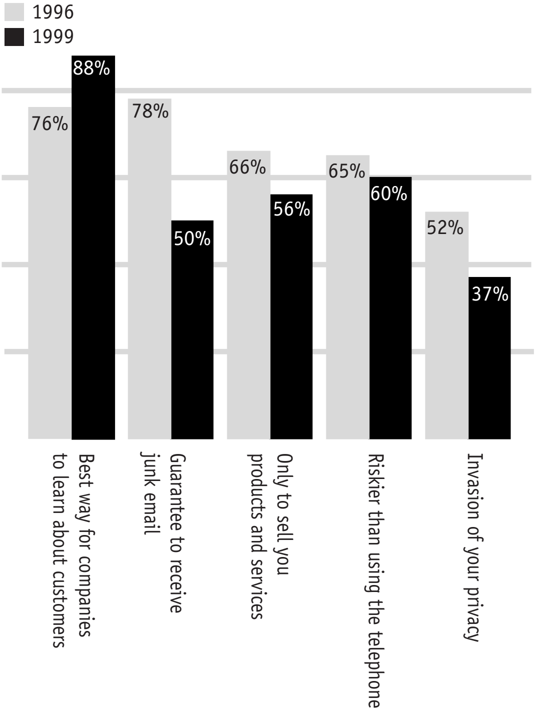
Interestingly, the tracking technology referred to as "cookies" (which places an electronic tag on an individual's Internet browser and tracks Web site visits) is well known, and seemingly well accepted by the vast majority of Internet users. Eighty-four percent of all Internet users (and 89% of health seekers) are aware of cookies, but only 4% of users set their browsers to reject all cookies automatically.

Table 4: "What information do you feel is okay for a Web site with which you have registered to also share with other Web sites, companies or advertisers?"

	Info. Willing to provide site for more personalized service	**Info. OK for Web sites to share with other sites, companies & advertisers**
Email address	90%	18%
Gender	87%	27%
Name	82%	15%
Favorite color	72%	22%
Ethnicity	61%	18%
Address	55%	8%
Employer	21%	2%
Health information	18%	3%
Credit card number	11%	0%
Promotions you respond to	50%	31%
What Ads you click on	28%	48%
Products you buy on the site	26%	55%

Source: Cyber Dialogue, 2000

Table 5: Submitting Personal Information Online Is...



Source: Cyber Dialogue 1996/9

Finally, among those Internet users who do not use the Internet to seek health information or services, "privacy/security concerns" are the second most inhibiting factor (with 17% citing such concerns), just below 'lack of need' for health information (34%). Eight percent cite concerns about the reliability of information as their primary inhibitor.

IV. Divergent Opinions About Specific Online Offerings

The Internet has the potential to provide a multitude of services to the healthcare consumer, from the timesaving (online health insurance claims processing) to the life saving (access to vital health information from any emergency room around the world). When Internet users were asked about this range of possibilities, as well as the desirability and the potential risks of each, they responded with the most divergent opinions found in this survey:

	Would Do	**Would Not Do Because of Concern**
Allow my doctors to have access to my personal medical record online	42%	40%
Access my personal medical record online	38%	40%
Have password-protected Internet access to my medical record in my doctor's office	47%	33%
Sign-up for or purchase health insurance online	37%	27%
Personalize a health information site by selecting information to have updated whenever you visit the site	37%	26%
Purchase or refill prescription drugs online	45%	25%
Seek advice online regarding a specific medical condition from other online patients	51%	18%
Use a secure Web site	48%	17%
Register at a health-related Web site	43%	16%
Participate in a health-related chat room	36%	15%
Purchase a health product other than a prescription	53%	12%
Access the latest disease-specific research or news	56%	3%

Source: Cyber Dialogue. 2000

In short, the very aspects of Internet-driven healthcare that hold the most promise for improving care delivery are the same aspects that raise the most concern among the public. 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, a fact that will resonate among the many Internet healthcare players planning to offer such services.

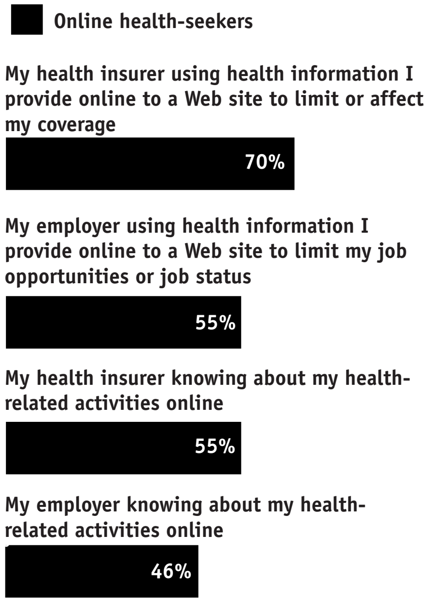
Online health seekers are also concerned that insurers could use private personal health data to limit or affect their insurance coverage, or that employers could use such information to limit job opportunities. In fact, many Internet users fear that the mere act of searching for general health-related information online may bring repercussions from insurers and employers.

V. Drivers of Increased Trust and Positive Opinion Change

Online users' fears about making personal health information available via the Internet can be assuaged, however. The survey found several measures that, if implemented, could have a distinctly positive impact on user's desire to release personal health information online. They include physician recommendation, published privacy statements pledging not to share information with advertisers, marketers and other sites, and individual control over the distribution of information (see Table 7).

Table 6: Online health seekers are concerned about health information they provide online being used by insurers to affect coverage and by employers to affect job opportunities

(Respondents rating 4 or 5, with 5 meaning 'very concerned')



Source: Cyber Dialogue, 2000

Table 7: Positive drivers of willingness to submit information online

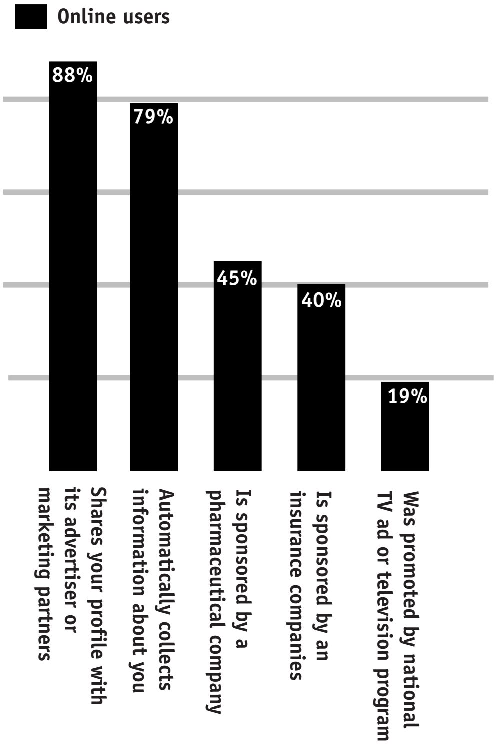
Online users

Is recommended by your doctor	80%
Has published a privacy policy statement that claims information you submit will not be shared with advertisers	79%
Gives you the opportunity to see who has access to your profile	78%
Allows you to make choices about the use of your information	78%
Has published a privacy policy that claims information you submit will not be shared with other sites or marketing partners	78%

Source: Cyber Dialogue, 2000

(These factors are, not surprisingly, similar to those that influence a person's likelihood to trust any given site's content. Research conducted by Cyber Dialogue in 1999 found that a doctor's recommendation of a particular health site's content led 74% of online health users to trust the information they found there.)

Table 8: Negative influencers of willingness to share health information online



Source: Cyber Dialogue, 2000

Table 9: Characteristics with no impact on willingness to submit health information online

Online users

Has seal of approval from trade group such as HON or TRUSTe	53%
Is sponsored by a non-profit organization	52%
Is sponsored by patient groups	50%
Is free of banner advertisements	50%
Is sponsored by a library or medical librarians	49%

Source: Cyber Dialogue, 2000

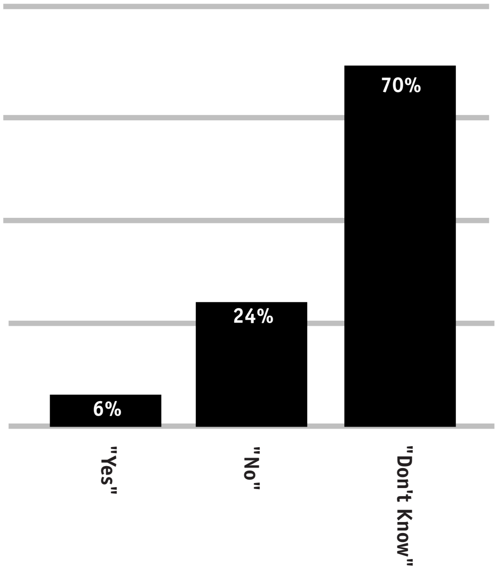
Conversely, there are a number of variables that can have a negative influence on consumers' willingness; most significantly, linkages that share information with a site's advertisers and marketing partners (see Table 8).

Finally, several factors, including:

- seals of approval from Internet trade groups such as HON and TRUSTe
- sponsorship by non-profit organizations
- presence of banner advertisements

have no impact — positive or negative — among the majority of respondents. The lack of influence of seemingly disparate factors may point to an increasingly sophisticated ability among online users to discern fact from hype. One fact is perfectly clear: Internet users respond favorably to clear, meaningful policies that protect the privacy of personal information. Privacy policies, with proper implementation and strict quality assurance, have the potential to allay consumer fears to a significant degree. Once such policies are developed, though, the public must be made more aware of their existence. Currently, only 14% of online health seekers 'always' read sites' privacy and ethics statements; 21% read them 'often', 36% read them 'sometimes'. Fully 29% 'rarely' or 'never' review the policies at all.

Table 10: "As Far As You Know, Are There Current State or Federal Laws That Protect the Privacy and Confidentiality of Personal Medical Information on the Internet?"
Among All Online Users



Source: Cyber Dialogue, 2000

Table 11: "Who Do You Think Should Be Responsible for Regulating Health Sites and the Way They Use Information Obtained from Visitors?"
Online users

Government	35%
Industry Associations	20%
Other	6%
Web sites should not be regulated	8%
Don't know	30%

Source: Cyber Dialogue, 2000

VI. Who Is Minding the Store? Who Should?

Despite the firmly held convictions of the majority of American Internet users about the importance of privacy, there is a paradoxical lack of understanding as to whether Internet privacy is protected (if at all), how it should be regulated (if at all), and who should be responsible for any oversight. When asked which types of sites are currently most trusted to keep personal health information private and secure, online health users cited institutes (such as the NIH or CDC) and medical associations (such as the AMA) highest, and Web portals and online drugstores lowest.

Table 12: "What is your level of trust that the site will keep your personal information private?"

(Respondents rating site 4 or 5, with 5 meaning 'high level of trust')

	Online Health Seekers
Institutes (NIH, etc.)	44%
Medical Associations (AMA, etc.)	42%
Hospitals (Mayo Clinic, etc.)	41%
Disease specific sites	32%
Medical-focused sites	32%
Not-for-profit groups	30%
Patient-run sites	24%
Health sections of major media sites (CNN, etc.)	20%
Online communities (iVillage, etc.)	14%
Pharmaceutical companies or products	14%
Portals (Yahoo, etc.)	14%
Online drugstores	12%

Source: Cyber Dialogue. 2000

Most significant about this finding is the fact that not one single type of site was trusted by a majority of respondents.

CONCLUSION

As is true with many studies of technological change, especially those fraught with significant personal implications for the average citizen, this survey perhaps raises more questions than it answers. Indeed, that was its intent. Nonetheless, certain findings of Ethics Survey of Consumer Attitudes about Health Web Sites are definitive and incontrovertible:

The American Internet user is confused and concerned about online health privacy in equal measure.

Safeguards for the privacy Americans expect (and indeed treasure) must be developed, but they first must be proposed and discussed in forums that include all stakeholders in the new Internet healthcare arena.

Any steps taken in this new medium must be as innovative as the medium itself.

ACKNOWLEDGEMENTS

Internet Healthcare Coalition

The Internet Healthcare Coalition is a nonprofit, non-partisan organization dedicated to identifying and promoting quality healthcare resources on the Internet. Founded in 1997 in response to issues raised by the Food and Drug Administration (FDA), the IHC represents a diverse group of professional and consumer organizations worldwide interested in healthcare and the Internet. The IHC's goal is to help healthcare consumers and professionals stay well informed about the evolving issues relating to the quality of Internet health resources and information.

The IHC can be found on the Web at http://www.ihealthcoalition.org

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Cyber Dialogue can be found on the Web at http://www.cyberdialogue.com

Survey Instrument Development

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