

## **HOW THE PUBLIC VIEWS HEALTH PRIVACY: SURVEY FINDINGS FROM 1978 TO 2005.**

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### **EXECUTIVE SUMMARY**

- Surveys show consumers rate personal health information and financial information the two most sensitive types of consumer personal information
  - Persons with chronic and especially genetically-based health conditions express sharp concerns about circulation and use of their health status to deny them important consumer opportunities and benefits
  - Consumers also express concerns about privacy and security in the current move to greater collection and use of medical records electronically
  - While 80% of online consumers go to health sites for information, they express high concerns about privacy and security in their surfing
  - Because of their privacy concerns, many consumers using health information web sites do not share their personal data, and take full advantage of these sites
  - Consumers also express fears that their health information might be accessed or used improperly to commit identity thefts
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### **• Personal health information and financial information rated the two most sensitive types of consumer personal information**

Surveys from 1992-93 to recently that ask consumers to rate the sensitivity of various types of personal information uniformly find that health information and financial information are rated as the two most sensitive bodies of consumer personal data. These are the ones that respondents say would most trouble them if this information was released without their knowledge or permission, or if not regulated by law, and especially if captured when the consumer is online. In fact, 85% said that protecting the confidentiality of people's medical records is absolutely essential or very important in national healthcare reform. They put this priority even ahead of providing health insurance for those who do not have it. (See Survey Bibliography for references.)

The 1993 Harris Equifax Health Information Privacy Survey found that 25% of the public scored high in general privacy concern, 18% scored low and 57% scored medium. When measured specifically for medical privacy concern, 48% – representing 89 million Americans – fell into the high concern position. This 23 percentage-point difference is an indication of how strongly the public felt about health privacy in 1993. Twelve years later, the public still feels strongly about health privacy, if not more so.

**• Public trust in doctors is high, but low in hospitals, clinics and other healthcare organizations**

Surveys dating as far back as 1978 show that trust in doctors is high among patients. The 1993 found that 87% of the public believes their health providers keep their medical information confidential. Hospitals, clinics and other healthcare organizations, however, do not fare as well with the public. In the 1978 Dimensions of Privacy Survey, 24% of respondents said hospitals ask for too much information, compared to 11% of doctors. When asked if hospitals should be doing more to protect the confidentiality of personal information, 23% said yes, compared with 17% who said doctors should be doing more.

The 1993 Harris-Westin survey found that the public is concerned about how medical information is circulating beyond direct care. Forty-one percent are worried that medical claims information submitted under an employer health plan may be seen by their employer and used to affect their job opportunities; and 60% believes it is not acceptable for medical information about them to be provided, without their individual approval, by pharmacists to direct marketers who want to mail offers to new medications. Almost two of three Americans (64%) don't want medical researchers to use their records for studies, even if the individual is never identified personally, unless researchers first get the individual's consent.

The June 2004 Customer Respect Group study found that healthcare and pharmaceutical firms still do not have the full trust of the public. The survey found that many of these firms with online presence share customer data with business partners without permission (12%) while others share data with affiliates (24%). Further, 65% do not provide clear opt-in/opt-out policies so that users do not feel they have control over how medical and health products are marketed to them.

**• Persons with chronic and especially genetically-based health conditions are worried about circulation and use of their health status to deny them important consumer opportunities and benefits**

Consumers with serious health conditions say they are worried about discrimination by insurance companies because of a disease they are living with, or a disease to which they may be genetically predisposed. And if their employer requires the information because they self-insure their employees, many consumers say they are at risk for discrimination.

According to a 2002 survey by the National Human Genome Research Institute of the National Institutes of Health, 85% of respondents believed that if life insurance companies had access to genetic testing results, they would refuse to issue policies or

would charge higher premiums. Only 27% said that companies would agree to sell the policy at the regular rate if they had access to that information; and just 20% said that genetic information would result in issuing policies at a lower price. More than 90% of those in the 35-64 age group believed insurance companies would, in fact, refuse to sell a life insurance policy.

About 61% of respondents said life insurance companies should not be allowed to use either the results of genetic tests or other genetic information. A slight majority said that companies should be able to use genetic information from existing medical records, but they should not be allowed to require applicants to take a genetic test. Just 15.4% agreed that companies should be permitted to require all applicants to take a genetic test.

A 2002 *Privacy & American Business* workplace privacy survey found that 24% of employees are concerned that their employer collects or uses medical or health condition information about them and is using it to make limiting or adverse personnel decisions or to affect their health insurance benefits.

- **Consumers are moving to keep their own medical records electronically**

A July 2004 Harris Interactive survey on keeping health records found that 42% of consumers keep personal or family health records, and 13% of those are keeping their health records electronically. Forty percent of those who do not currently keep medical records at all say they recognize the value of doing this and are likely to do so in the future.

- **Consumers express concerns about privacy and security in the move to greater collection and use of medical records electronically**

When asked about the trend toward the healthcare system moving to keep medical records electronically, 68% of consumers felt this raised threats to their privacy and 66% said they would be concerned about security breaches, according to the July 2004 Harris Interactive survey on keeping health records.

Concern over electronic medical records is not a new phenomenon among Americans. The 1993 Harris-Westin found that 70% of respondents were worried about the extensive use of computers in a national healthcare system to manage and monitor healthcare operations. Strong majorities feel that such computer use is causing mistakes to be made in charges (75%); mistakes in medical conditions to be put into patient records (60%); and medical information to be given to people who aren't supposed to see it (64%). Three of four Americans (75%) said they were concerned "that a computerized healthcare information system will come to be used for many non-healthcare purposes," with 38% of the public saying it is *very* concerned about this.

- **While 80% of online consumers go to health sites for information, they express high concerns about privacy and security**

A 2002 Harris Poll found that 80% of consumers going online – representing 110 million U.S. adults – use the Internet to look for healthcare information. However, a 2001 Pew Internet and American Life Project survey found that 89% of online health information seekers are worried that Internet companies might sell or give away their information. Another 85% fear that if insurance companies find out what online information they accessed, the company might change their coverage.

Furthermore, although the number of online health information seekers is high, surfers are still concerned about protecting their personal data. According to a California HealthCare Foundation survey, 6.3 million consumers not going to health web sites say they avoid them due to concerns about privacy and security.

- **Because of their privacy concerns, many consumers using health information web sites do not share their personal data, and take full advantage of these sites**

The 2001 Pew Internet and American Life Project survey found that 80% of respondents said that it is important to them to be able to access health information anonymously. Because this is not usually possible, most users do not share personal information at such health web sites. Just 21% say they have given their email address at such sites. Only 17% have provided their name and other identifying information, while just 9% have participated in an online support group about a health condition. This is in comparison to 54% of all Internet users who have shared personal information at other kinds of web sites.

- **Consumers also express fears that health information might be accessed or used improperly to commit identity theft**

Theft of personal data, including identifying information in health records, ranks very high on the list of privacy concerns among consumers. A 2003 *Privacy & American Business* ID theft survey found that 33.4 million Americans – 16% of the U.S. adult population – had already been victims of ID theft. Recent news accounts of identity theft episodes have shown that ID thieves can “hit the jackpot” with individual health information. Hospital records with personal identifiers in them have been obtained by ID thieves and used to commit sizeable ID thefts. A recent Seattle, Washington court case shows how one man stole personally identifiable health information of a cancer patient and racked up over \$9,000 in credit card debt.

Many recent surveys cite insider information theft (customer data stolen by an employee) and improper safeguarding of information as the cause of identity theft. Even 12 years ago, the public was concerned about how companies secured their information. The 1993 Harris-Westin survey found that 83% of the public says it is important that the information-processing companies hired by government agencies, employers and insurers to review individual medical records for analyzing treatments, results and costs should have “detailed privacy and confidentiality policies.” In fact, 94% of the public feels that such organizations should be selected “on the basis of a proven record of protecting the confidentiality and security of the personal records they handle.”

- For a summary of the 2005 survey, “How the Public Sees Health Records and an EMR Program,” visit [www.pandab.org](http://www.pandab.org).

## SURVEY BIBLIOGRAPHY

### Health Privacy Surveys: 1993-2004

1. ***“The Dimensions of Privacy,”*** Louis Harris & Associates and Dr. Alan Westin; 1,511 U.S. adults; 1978.
2. ***“Information Sensitivity Survey,”*** Louis Harris & Associates and Privacy & American Business; 1000 respondents’ 1993.
3. ***“Health Information Privacy Survey, 1993,”*** Louis Harris & Associates and Dr. Alan F. Westin, for Equifax Inc.; 1,000 adults of the national public; 1993.
4. ***“Workplace Health and Privacy Issues: A Survey of Private Sector Employees and Leaders,”*** Louis Harris & Associates and Dr. Alan F. Westin, for the Educational Film Center; national public sample of 1,000 employees working in private-sector companies with 15 or more employees and 300 Human Resources executives; 1993.
5. ***“Medical Privacy and Confidentiality Survey,”*** Princeton Survey Research Associates for The California Healthcare Foundation; conducted via telephone of 1,000 U.S. adults nationally and 1,100 adults in California; 1999.
6. ***“Most Americans Shun Using Internet for Personal Health Information,”*** Gallup for MedicAlert Foundation; conducted via telephone of 1,000 U.S. adults; 2000.
7. ***“Ethics Survey of Consumer Attitudes About Health Websites,”*** Cyber Dialogue for the California Healthcare Foundation and the Internet Healthcare Coalition; conducted online of 1,009 U.S. online adults, 2000.
8. ***“Public Attitudes Towards Medical Privacy,”*** Gallup for the Institute of Health Freedom; conducted via telephone of 1,000 U.S. adults; 2000.
9. ***“Generation Rx.com: How Young People Use the Internet for Health Information,”*** International Communications Research, for Kaiser Family Foundation; 1,209 U.S. respondents aged 15-24 years; 2001.
10. ***“Cyberchondriacs Update,”*** Harris Interactive, 707 U.S. adults online conducted via telephone; 2002.
11. ***“Genetic Testing,”*** Telesurveys Research Associates of Houston, for the National Human Genome Research Institute of the National Institutes of Health; 2,108 respondents interviewed via telephone; 2002.

12. ***“Assessing Public Attitudes Regarding Genetic Privacy in Oregon: Statewide Telephone Survey,”*** conducted by David, Hibbitts, and McCaig, Inc. for GeneForum, via telephone of adult 500 Oregonians; 2002.
13. ***“If Genetic Tests Were Available for Diseases Which Could Be Treated or Prevented, Many People Would Pay to Have Them,”*** Harris Interactive; conducted via telephone of 1,013 respondents; 2002.
14. ***“Keeping Electronic Personal or Family Health Records,”*** Harris Interactive; conducted online of 2,242 U.S. adult respondents; 2004.
15. ***“2004 Online Customer Respect Study of Pharmaceutical and Healthcare Firms,”*** The Customer Respect Group; 78 healthcare and pharmaceutical firms examines; 2004.
16. ***“How the Public Sees Health Records and an EMR Program,”*** Harris Interactive and Dr. Alan F. Westin for the Program on Information Technology, Health Records and Privacy, of the Center for Social & Legal Research; 1,012 U.S. adults; 2005.