



National Consumer Health Privacy Survey 2005

November 2005

SINCE THE CALIFORNIA HEALTHCARE Foundation (CHCF) last surveyed consumers in 1999 about how they view, manage, and safeguard their personal health information, landmark legislation (HIPAA) has been signed into law that gives consumers important new rights and protections. HIPAA also created new obligations for health care institutions, intended to hold them accountable. After President Bush last year pledged to strengthen the nation's health information network to improve medical care, CHCF decided to commission a follow-up study. The study's objective: to inform and strengthen the nation's health information technology effort by assessing the impact of such factors as health care information technology, HIPAA privacy notices, and the effect of recent privacy breaches on consumers' attitudes and behaviors. Surveying 1,000 consumers nationally and 1,000 more in California, the study found that:

- **Consumers remain concerned about the privacy of their personal health information.** Sixty-seven percent of national respondents are "somewhat" or "very concerned" about the privacy of their personal medical records. Furthermore, 73 percent of racial and ethnic minority respondents and 67 percent of those with chronic illnesses expressed concern.
- **Recent privacy breaches have raised the level of concern.** Twenty-four percent of national respondents report awareness of specific incidents in which personal information was compromised; that figure is 29 percent among those with college educations. Of those, 66 percent report they are even more concerned about their personal medical records as a result.
- **Employee concern about misuse of medical claim information rose dramatically.** Some 52 percent of respondents said they were "very concerned" or "somewhat concerned" that insurance claims information might be used by an employer to limit their job opportunities—a 44 percent increase in concern from the 1999 study.
- **Consumers are unfamiliar with HIPAA protections.** Although two thirds of national respondents say they are aware of federal protections for their personal medical records, and 59 percent recall receiving a privacy notice, only 27 percent believe they have more rights than they had before receiving the notice.
- **Privacy-protective behaviors persist.** One out of eight consumers has put their health at risk by engaging in such behaviors as: avoiding their regular doctor, asking their doctor to fudge a diagnosis, paying for a test because they didn't want to submit a claim, or avoiding a test altogether. Chronically ill, younger, and racial and ethnic minority respondents are more likely than average to practice one or more of these risky behaviors.
- **Consumers will share their personal medical information.** Just over half of respondents believe they have a duty to share their personal

medical information to advance health care, and 98 percent will do so willingly with their doctor. Sixty percent would share their personal medical information with doctors not directly involved in their care in exchange for better coordination of their medical treatment.

The survey's findings suggest that consumers continue to have serious misgivings about the security of their personal health information. Without strong safeguards, reliable privacy protection, and vigilant enforcement of privacy laws, public support for the national effort to develop a health care network could be in jeopardy. Advocates must raise awareness of consumers' lawful rights and demand compliance from health care institutions, while consumers must act on their willingness to share their medical information for both personal and societal benefits. Industry must enhance communication of HIPAA policies and practices and redouble efforts to secure personal medical information. And policy makers must be vigilant in advocating and funding the continued implementation of health care IT in ways that honor consumers' concerns and values.

Background and Methodology

In 1999, the California HealthCare Foundation conducted a National Consumer Health Privacy Survey that became a national benchmark of consumer attitudes and behaviors about privacy and health information. This survey showed that consumers' privacy concerns were not abated by information technology used by doctors and hospitals, and that some consumers practiced behaviors that put their health at risk due to these concerns. Given the implementation of HIPAA regulations and a changing technology environment, CHCF worked with Forrester Research to field a custom survey in 2005 that updated key findings from the 1999 study and investigated new consumer health privacy issues that have emerged since the initial study.

Project Overview

Forrester's prior research on consumer attitudes toward health privacy illustrated that consumers have acute concerns about the privacy of their health information, but, at the same time, 75 percent of consumers will share medical data if it will help a doctor during an emergency.¹ This 2005 National Consumer Health Privacy Survey builds on that premise, as well as findings from CHCF's past National Privacy Survey, to unveil the impact of HIPAA Privacy Rules and the heightened electronic environment on consumers' attitudes towards and behaviors around personal health information.

This deeper understanding of consumers' attitudes toward and management of their own personal health information allows CHCF to discuss implications for consumers, industry stakeholders, and policymakers — and to put forth analysis and high-level recommendations that will inform and strengthen the national health information technology (HIT) agenda.

CHCF based this primary research project on initial hypotheses about consumers. These research hypotheses were culled from a panel discussion with industry stakeholders and consumer representatives on critical and timely issues regarding consumer health privacy, as well as CHCF's findings from its prior study.

Research Methodology

For this project, Forrester Research collaborated closely with CHCF to develop the survey instrument and field the primary research. Forrester surveyed 2,100 U.S. adults aged 18 and older. This final sample included 1,000 national respondents — residents of the continental United States — and an additional 1,000 oversampled California residents. In addition, Forrester oversampled approximately 100 consumers living with

1. See the December 2003 Forrester Report, "The X Internet and Consumer Privacy."

HIV or substance abuse conditions. The survey was conducted by telephone in English and Spanish during the summer of 2005.

Forrester weighted the respondents of the datasets by a number of demographic parameters (i.e., age, gender, income, race, and Hispanic ethnicity) to be representative of their respective populations. Respondents within the national sample were weighted to national population averages, while respondents within the California sample were weighted separately to California averages. For results based on samples of this size (i.e., 1,000 national and 1,000 California respondents), there is a 95 percent confidence that the results have a statistical precision of approximately plus or minus 3 percent of what they would have been if the entire adult population of the continental U.S. or all California residents had been polled.

Key Findings

Forrester analyzed consumers' survey responses about health care privacy attitudes and behaviors—looking at entire populations, both in California and nationally—and comparing differences between smaller, more defined segments of consumers, where applicable and statistically relevant. Some of the key findings from this analysis include:

Consumers Are Concerned About Personal Health Information Privacy

Despite HIPAA's federally mandated privacy protection, consumers continue to be anxious about the privacy of their personal health information. Nationally, two-thirds of consumers said they were “very concerned” (36 percent) or “somewhat concerned” (31 percent) about the privacy of their personal medical records. Upon closer examination, the data also revealed differences in concern levels among specific consumer segments. In particular, 73 percent of respondents belonging to an ethnic minority said they were “very” or “somewhat” concerned about

their personal health information (PHI)—compared to 62 percent of Caucasian respondents. Two-thirds of consumers living with a medical condition were “very” or “somewhat” concerned, tracking closely with the national average. However, adults who have not been diagnosed with a medical condition show lower concern levels about their PHI (62 percent).

Recent incidents in which the privacy of personal information has been compromised fuel consumers' continuing concern about PHI privacy. Twenty-four percent of respondents nationally were aware of such privacy breaches, with college educated respondents among those most aware of such events (29 percent). Among consumers aware of privacy-related incidents, two-thirds said such events increased their concern about the privacy of their own medical records—with 42 percent saying that, in light of recent events, they are “significantly more concerned” about PHI privacy.

Consumers Are Unaware of Their Privacy Rights

While 67 percent of respondents nationally are aware of the existence of federal laws that protect the privacy and confidentiality of personal medical records, awareness levels do vary within specific consumer segments. Among the college-educated, there is increased awareness of federal regulations; 75 percent say that they believe federally mandated privacy protection is in place. In contrast, among ethnic minority consumers, only 60 percent were aware of privacy protective federal laws.

At 52 percent, these ethnic minority groups were also less likely than the average national respondent to recall receiving a notice from a health plan or provider notifying them of PHI-related privacy rights. Of the 59 percent of national respondents overall who stated that they recalled receiving a notice from a plan or provider, only 27 percent felt the new rights outlined in the notice gave them more rights than they thought they had.

Despite consumers' professed awareness of HIPAA regulations, respondents' concerns about possible employer misuse of medical information have dramatically increased. In CHCF's 1999 study, 36 percent of respondents were "very concerned" or "somewhat concerned" that insurance claims information might be used by an employer to limit job opportunities. The comparable figure in the 2005 study was 52 percent of respondents expressing concern about misuse of claims data, with racial and ethnic minorities expressing the highest level of concern (61 percent).

Consumers' Privacy-Protective Behaviors Continue

Thirteen percent of national respondents said they had engaged in behaviors intended to protect the privacy of their PHI. These behaviors included: asking a physician to forego reporting a health problem or to report a less serious diagnosis; avoiding their regular physician for certain health conditions; avoiding diagnostic tests due to anxiety over information privacy; or paying out of pocket for procedures to avoid submitting a claim. The youngest respondents — those under age 45 — were the most likely (17 percent) to have engaged in privacy-protective behaviors.

These protective behaviors were most common among those diagnosed with a disease. Fifteen percent of those with a disease diagnosis had engaged in a protective behavior. In fact, at 6 percent, respondents with a diagnosed disease are twice as likely as healthy consumers to ask a physician to obfuscate their diagnosis. When investigating respondents' likelihood to pay out-of-pocket for a test or procedure rather than submit a claim, disease differences come to the fore. While on average, 5 percent of consumers diagnosed with a disease have personally paid for a procedure, 11 percent of Californian residents living with cancer, 9 percent of arthritics, 9 percent of obese consumers, and 9 percent of diabetics have done so.

Consumers Are Willing to Exchange PHI for Specific Benefits

Not surprisingly, nearly all respondents were willing to share their PHI with physicians involved in their care. In contrast, only 30 percent of respondents were willing to share PHI with health professionals not directly involved in their care. At 27 percent, even fewer respondents say they are willing to share their PHI with drug companies; just one in five respondents are open to sharing PHI with government agencies.

For 59 percent of respondents, this willingness to share personal information with employers, the government, and others could be bolstered if they received some personal benefit in return. For example, 60 percent of consumers living with a medical condition — and averse to sharing PHI with doctors not involved in their care — say they would reconsider this position if it meant they had access to better coordinated medical treatment.

Nearly two of three respondents recognized that computerization could potentially reduce medical errors, a key goal of efforts to implement electronic medical records. However, in a seemingly contradictory finding, 66 percent of respondents felt their paper medical records are "very secure" or "somewhat secure," contrasted with 58 percent of those who felt their records are more secure in an electronic format.

Implications and Recommendations for Stakeholders

Consumers. Despite new federal protections, consumers are still anxious about the privacy of their personal health information and misinformed about their rights under HIPAA. Consumer concerns about privacy cause some to put their health at risk by engaging in privacy protective ways, while those who are misinformed or unaware of their rights can neither take action to protect their own information nor demand higher levels of information privacy protection from health industry stakeholders. Consumers and their advocates should gain a deeper understanding of privacy rights—and act on them by only selecting providers or health insurers that actively support personal privacy rights, or by insisting that adequate security measures be present in any new ehealth initiatives put forth by industry.

Industry. Providers' and health plans' efforts to educate consumers about HIPAA regulations and protections have fallen short. Consequently, the health care industry has missed an opportunity to reassure a concerned public about the health care privacy safeguards that are in place. Health care organizations should simplify and enhance their communications to consumers about organizational measures taken to increase the privacy and security of consumers' PHI—understanding that the resulting consumer loyalty will exceed the costs of taking on this educational burden. Employers should bolster internal practices to maintain information privacy, and, like health plans, should ensure they communicate this adherence to privacy regulations to employees.

Policymakers. Public messages that link information technology, privacy, and resulting health benefits are not reaching consumers effectively—particularly the chronically ill, aging consumers, ethnic minority groups, and the less educated segments of the U.S. population. As a result, the health IT agenda is at risk for lack of consumer appreciation of its primary intent and full potential. Political advocates should recognize that privacy issues are not a hurdle. Instead, privacy concerns among consumers are an opportunity to build consumer confidence and broaden support for the health IT agenda. Political entities should speed the spread of health IT with increased funding and political support—and address privacy issues by broadening the scope of federal protections and more vigorously enforce current federal laws.

AUTHORS

Lynne “Sam” Bishop, with Bradford J. Holmes and Christopher M. Kelley, Forrester Research, Inc.

FOR MORE INFORMATION, CONTACT:

California HealthCare Foundation
476 Ninth Street
Oakland, CA 94607
tel: 510.238.1040
fax: 510.238.1388
www.chcf.org