

MEDICAL PRIVACY AND CONFIDENTIALITY SURVEY

SUMMARY AND OVERVIEW

January 28, 1999

Americans are worried about the computerization of their medical records, and have reasons to be concerned about their medical privacy. However, these concerns are having only a limited effect on the way they interact with the health care system.

According to a new survey conducted by Princeton Survey Research Associates for the California HealthCare Foundation, most Americans trust private health insurance plans and government health programs less to keep personal medical information private and confidential than they trust private physicians and hospitals. Generally, most are concerned about their personal privacy and think it is more difficult to keep personal information private than in the past.

Computerization Seen as Greatest Threat to Privacy

Computerization of medical records is seen as the most serious threat to medical privacy. More than half of all U.S. adults (54%) and California residents (52%) say the shift from paper record keeping systems to electronic or computer-based systems makes it more difficult to keep personal medical information private and confidential. Most people consider electronic piracy—not disclosure of personal information by medical personnel, health plan officials, or other authorized users—as the bigger threat to privacy. Nationally, 55% say they worry more about computer hackers breaking into a system, while only 30% worry more about authorized users leaking information. In California, computer hackers are viewed as the number one threat by a margin of 58% to 28%.

Reluctance to Grant Access to Medical Records

While most people concede that persons other than their immediate providers should have access to their personal medical records, they display a strong preference to restrict access. When asked if they would grant access to various groups seeking permission, majorities say “no,” except in the cases of medical research studies conducted by government or academia.

Roughly six in 10 would not be inclined to grant access to a hospital offering preventive care programs (60% of national, 56% of California adults) or to an employer who was considering them for a new job (61% and 60%). Americans are least willing to allow drug companies to have access to their medical records for the purposes of marketing new drugs and other health care products (70% and 68%, respectively).

Good Feelings About Health Care Providers

Health care providers get a strong vote of confidence from the public. Solid majorities of adults nationally (60%) and in California (62%) say they trust doctors, hospitals, and other health professionals to keep personal information confidential all or most of the time. The confidence ratings earned by health care providers are superior to those received by banks (nationally 49% say they always or usually trust banks).

Little Confidence in Health Insurers

Public distrust of private and government health insurers to keep personal information confidential is pervasive. No more than about a third of U.S. adults say they trust health plans (35%) and government programs like Medicare (33%) to maintain confidentiality all or most of the time.

Few Believe Improper Disclosures

Most people don't believe their own medical privacy has ever been violated. When asked if they believe a health care provider, insurance plan, government agency, or employer has ever improperly disclosed personal medical information, one in five U.S. adults (18%) and California adults (20%) say "yes."

A comparison of the new survey results with those of a 1993 Louis Harris survey for Equifax shows no evidence that violations of medical privacy have become more common over the past five years. In fact, reports of improper disclosure by health insurance companies (15% vs. 8%), public health agencies (10% vs. 4%), and hospitals (11% vs. 6%) are down significantly, compared to the 1993 results.

Close to half the people affected by improper disclosure say it resulted in personal embarrassment or harm. In total, 7% of all U.S. adults and 9% of California adults say they have been personally embarrassed or harmed by a violation of their medical privacy. The segment of the population most likely to have been hurt are those who have used mental health services (13% of those in the U.S. as a whole and 14% in California).

Some Take Steps to Protect Medical Privacy

For the most part, Americans have not altered the way they interact with the health care system because of concerns about medical privacy. In total, 15% of national adults and 18% of California adults say they have done something out of the ordinary to keep personal medical information confidential. The steps people have taken to protect medical privacy include behaviors that may put their own health at risk or create financial hardships. These behaviors include: going to another doctor; paying out-of-pocket when insured to avoid disclosure; not seeking care to avoid disclosure to an employer; giving inaccurate or incomplete information on medical history; and, asking a doctor to not write down the health problem or record a less serious or embarrassing condition.

In both the nation as a whole and in California, those who have experienced a breach of medical privacy are about four times as likely as others to say they have taken one or more steps to protect themselves.

Conditional Support for Health Identifiers

In 1996, Congress passed legislation requiring the development of unique health identifiers (like a social security number) for all Americans. When told about the potential benefits as well as the risks in adopting a system of unique identifiers, 39% of the national survey respondents say they favor health identifiers while 52% are opposed. California respondents have a similar initial reaction—38% in favor, 50% opposed.

The survey results confirm that medical privacy concerns currently play an important role in limiting public support for unique health identifiers. Majorities of all U.S. adults (56%) and California adults (61%) say they are very concerned that “there will be no effective way to prevent unauthorized access to sensitive personal information.”

Survey Methodology

For this survey, Princeton Survey Research Associates interviewed a national sample of 1,000 adults, 18 years and older, in the continental United States and a separate sample of 1,100 adults in California. Interviewing was conducted by telephone between November 12 and December 22, 1998. For both the U.S. and California surveys, the overall margin of sampling error is plus or minus three percentage points for results based on the total sample. Results based on smaller subgroups are subject to a larger margin of error. In addition to sampling error, the practical difficulties of conducting surveys can also introduce error or bias to poll results. The survey topline is available on the California HealthCare Foundation’s Web site.

About the California HealthCare Foundation

The California HealthCare Foundation is a private independent philanthropy established in May 1996, as a result of the conversion of Blue Cross of California from a nonprofit health plan to WellPoint Health Networks, a for-profit corporation.

The Foundation focuses on critical issues confronting a changing health care marketplace: managed care, the uninsured, California health policy and regulation, health care quality, and public health. Grants focus on areas where the Foundation's resources can initiate meaningful policy recommendations, innovative research, and the development of model programs.

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