

Appendix FF

Violations of Patient Confidentiality and Consumer Attitudes about Health Privacy

Health Privacy, Generally

California HealthCare Foundation, survey conducted by Princeton Survey Research Associates, January 1999:

- ◆ **One in five** American adults believes that a health care provider, insurance plan, government agency or employer has improperly disclosed personal medical information. Half of these people believe that it resulted in personal embarrassment or harm.
- ◆ **One in seven** Americans has done something out of the ordinary to keep personal medical information confidential. To protect their privacy and avoid embarrassment, stigma, and discrimination, people withhold information from their health care providers, provide inaccurate information, doctor-hop to avoid a consolidated medical record, pay out-of-pocket for care that is covered by insurance, and – in the most extreme cases – avoid care altogether.
- ◆ **One in four** U.S. adults say they never trust health plans and government programs, such as Medicare, to keep their information private and confidential.

Louis Harris & Associates, multiple surveys conducted for Equifax:

- ◆ **Twenty-seven percent** of those polled believed that their medical information had been improperly disclosed. Almost a third of health care leaders could describe

confidentiality violations in their organizations in detail. (1992 poll)

- ◆ **Twenty-four percent** of health care leaders polled knew violations of patient confidentiality and could describe the violations in detail. (1992 poll)
- ◆ **Eleven percent** of consumers said that they or a family member paid out of pocket for health care, rather than submit a claim, in order to protect their privacy. (1992 poll)
- ◆ **Seven percent** of consumers chose not to seek care because they didn't want to harm their "job prospects or other life opportunities." (1992 poll)
- ◆ **Only eighteen percent** of the public considers the use of patient records for medical research without prior permission to be very acceptable. Thirty-nine percent found the use somewhat acceptable. The public's comfort level increased if the information released did not identify individual patients, but one-third found it not at all acceptable for researchers to use non-identifiable health information without patient consent. (1996 poll)

Gallup survey commissioned by MedicAlert Foundation, November 2000:

- ◆ **Seventy-seven percent** of the respondents said the privacy of their personal health information is very important; **sixty-one percent** are very concerned that their personal health information might be made available to others without their consent; **fifty-five**

percent would not trust an insurance company or a managed care company to keep their personal health information private and secure.

Harris Poll commissioned by Biogen, Inc., April 2001:

- ◆ **Nearly four out of ten people with multiple sclerosis** surveyed said that they had lied or failed to disclose their diagnosis to family members, friends, or colleagues because they feared what would happen if people knew they had MS. Concerns about having their MS diagnosis known by others included fear of job loss and stigma.

Health Privacy on the Internet

California HealthCare Foundation, survey conducted by Cyber Dialogue, January 2000:

- ◆ **Seventy-five percent** of people are concerned about health Web sites sharing information without their permission.
- ◆ A significant percentage of people do not and will not engage in certain health-related activities online because of their concerns about privacy and security: **Forty percent** of people will not give a doctor online access to their medical records; **twenty-five percent** will not buy or refill prescriptions; and **sixteen percent** will not register at sites.
- ◆ **Seventeen percent** of people don't even go online merely to seek health information due to their concerns over privacy.

California Health Care Foundation and Internet Healthcare Coalition, survey conducted by Cyber Dialogue, September 2000:

- ◆ **Seventy-six percent** of online users in very good or good health are concerned or very concerned that their health insurer will use

information they provide online to a Web site to limit or affect coverage; **sixty percent** of these individuals are concerned or very concerned about their health insurer knowing about their health-related activities online.

- ◆ **Sixty percent** of online users in very good or good health are concerned or very concerned that their employer will use health information they provide online to a Web site to limit job opportunities or affect job status; **fifty-two percent** of these individuals are concerned or very concerned about their employer knowing about their health-related activities online.

Pew Internet and American Life Project, survey conducted by Princeton Survey Research Associates, November 2000:

- ◆ On overwhelming majority of Internet users are worried about others finding out about their online activities: **eighty-nine percent** of Internet users are worried that Internet companies might sell or give away information and **eighty-five percent** fear that insurance companies might change their coverage after finding out what online information they accessed.
- ◆ **Sixty-three percent** of Internet "health-seekers" and **sixty percent** of all Internet users oppose the idea of keeping medical records online, even at a secure, password-protected site, because they fear other people will see those records.
- ◆ **Eighty-one percent** of Internet "health-seekers" want the right to sue a Web company if they violate their own privacy policy.
- ◆ **Eighty percent** of "health seekers" say it is important to them that they can get information anonymously. For the most part, users don't share personal information: only **twenty-one percent** have

provided their email address to a health Web site; only **seventeen percent** have provided their name or other identifying information; and only **nine percent** have participated in an online support group about a health condition. (Note that **fifty-four percent** of all Internet users have shared personal information at a Web site.)

Genetic Privacy

1995 Harris poll:

- ◆ **Eighty-five percent** of those polled indicated that they were very concerned or somewhat concerned that insurers or employers might have access to and use their genetic information.

1997 National Center for Genome Resources survey:

- ◆ **Sixty-three percent** of people reported that they would not take genetic tests for diseases if insurers or employers could access the tests; **eighty-five percent** felt that employers should be prohibited from obtaining information about an individual's genetic conditions, risks, and predispositions.

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