

“Overwhelming Majority” of Internet “Health Seekers” Found Worried

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A new study released at the end of November, entitled "The Online Health Care Revolution: How The Web Helps Americans Take Better Care Of Themselves," finds that 89% of Internet Users are worried that Internet companies might sell or give away information and 85% fear that insurance companies might change their coverage after finding out what online information they accessed.

This study is the product of The Pew Internet & American Life Project, assisted by the Georgetown University's Health Privacy Project. The Pew Project's mission is to "create and fund original, academic-quality research" and function as "an authoritative source of timely information on the Internet's growth and societal impact, through research that is scrupulously impartial." The Health Privacy Project "is dedicated to raising public awareness of the importance of ensuring health privacy." It leads a Consumer Coalition for Health Privacy, whose mission is to "inform and empower the consumer community" to "more fully engage in the national and local debate on health privacy." Both projects are headquartered in Washington, D.C.

HIPAA Rules Link

The study report is expressly coordinated with the "new privacy rules that are expected to be released" by "the Clinton administration's Department of Health and Human Services." It stresses both that "there is no comprehensive federal law that protects the privacy of medical records" and the perception that "a great deal of health information collected on health web sites will *not* be covered by the new regulation."

In that context, the study concludes that "most Internet users are anxious about their privacy online and this general feeling becomes quite acute when it comes to medical and health information." The reported results reflect a three-layered survey, the most comprehensive part produced through "roughly six months of telephone interviewing conducted by Princeton Survey Research Associates between March 1, 2000 and August 20, 2000, among a sample of 12,751 adults" that included 6,413 Internet users. This data was supplemented by a "special survey of 2,109 adults" that "dealt primarily with health privacy issues" and by "a special survey of 521 Internet users who go online for health information." Results from the smallest group are subject to a "margin of error" of "plus or minus 5 percentage points," and those from the largest, "plus or minus 2.5 percentage points."

The findings on privacy concerns draw increased importance from the findings on the prevalence of Internet use as a health information source. Thus, "fifty-two million adult Americans—55% of the Internet-user population—have turned to Internet sources to seek health information." That is more "than have shopped online," more than "have looked up stock quotes" and more than have "checked sports scores" online. The study labels those fifty-two million Americans "health seekers," because they seek "information that will help them at a time when they or their loved ones are sick."

Privacy Related Conclusions

The study's privacy-related findings include that "eighty percent of health seekers say it's important that Internet users can get health information anonymously." Some 60% "think that putting medical records online is a bad thing, even if they are on a secure, password-protected site, because they worry about other people seeing their personal information." The study further concludes that "the vast majority of health seekers are concerned that a health site might disclose what they did online," and "most worry about their insurance companies or employers finding out what web sites they have accessed." The high level of use in the face of such concerns may be explained by the finding that "fully 92% of health seekers say the information they found was useful and 81% said they learned something new the last time they went online for health information."

The study's emphasis areas include "profiling," a term that the report does not define but which is a label invoked by many advocates who seek increased regulation of various types of market research. The actual research reported here addressed "tracking" the activities of people who visit web sites, with 87% of health seekers found to "think there should be rules about how health and medical companies on the Internet can track activities." Some "81% of health seekers think people should be able to sue a health or medical company if it gave away or sold information about its web site users after saying it would not," a result reported in the context of the Project's belief that presently "individuals have no federal right to sue."

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