

Americans Overwhelmingly Believe Electronic Personal Health Records Could Improve Their Health

Nearly 9 in 10 Say Privacy Practices Are a Factor In Their Decision to Sign Up for One

June 2008

Professor Alan F. Westin developed and Knowledge Networks conducted a survey among 1,580 American adults (18+) nationwide, May 13-22, 2008, commissioned by the Markle Foundation. The survey examined public opinions on the potential and privacy considerations of individually controlled electronic personal health records (PHRs).

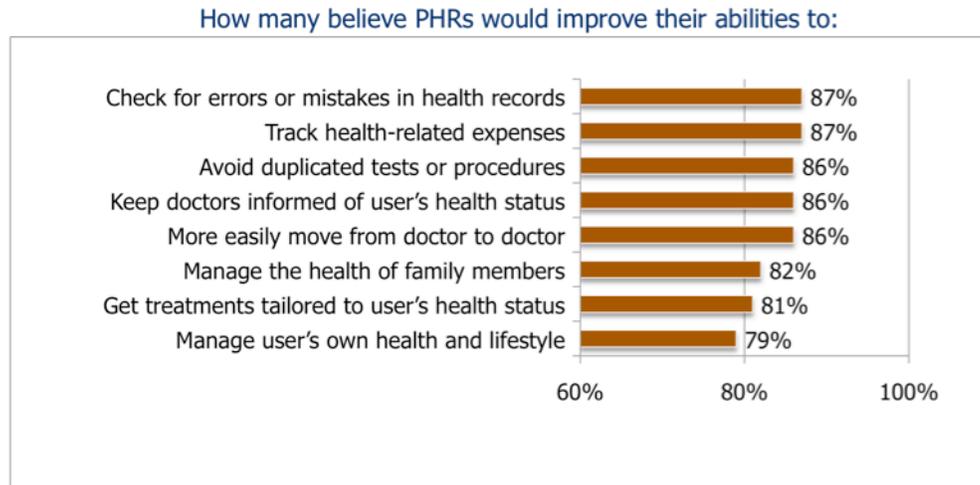
It is the first national survey to explore consumer perceptions about PHRs in the context of the entrance of Google, Intuit, Microsoft, Revolution Health and WebMD in the marketplace, and to measure perceptions of the importance of privacy practices in consumers' decision to adopt such services. The results documented firm attitudes in a majority of adults surveyed regarding privacy practices in the unfolding world of online PHR services. Among the findings:

1. **High perception of value:** Regardless of their interest in using an online PHR service, 79 percent or more of the public believe using an online PHR would provide major benefits to individuals in managing their health and health care services.
2. **High interest:** Almost half of the public — 46.5 percent — say they would be interested in using an online PHR service. This represents about 106 million adults.
3. **Privacy concerns:** Among those saying they are not interested, 56.8 percent cited worries about privacy and confidentiality as a reason for their reluctance.
4. **Practices matter:** By majorities ranging from 87 percent to 92 percent, the public feels that provision of six privacy, record-access, and user remedies would be either "essential" or a significant factor in their decisions whether to join an online PHR service. More than 90 percent said their express agreement should be required for each use of their information.
5. **Utilization of electronic PHRs remains low:** Only 2.7 percent of adults have an electronic PHR today (representing about 6.1 million persons). Most (57.3 percent) do not keep any form of personal health records, and 40 percent keep some paper health records.
6. **Variations by sponsor:** Interest in using a PHR online service varies according to the PHR service's sponsoring organization, with the health care services individuals now use or have available locally rating most highly.
7. **Variety of enforcement:** When asked about enforcement of privacy policies, more than 75 percent of the respondents considered each of the following to be useful: market forces, new federal health privacy law, action by the Federal Trade Commission and state attorneys general, and independent organizational-compliance audits.

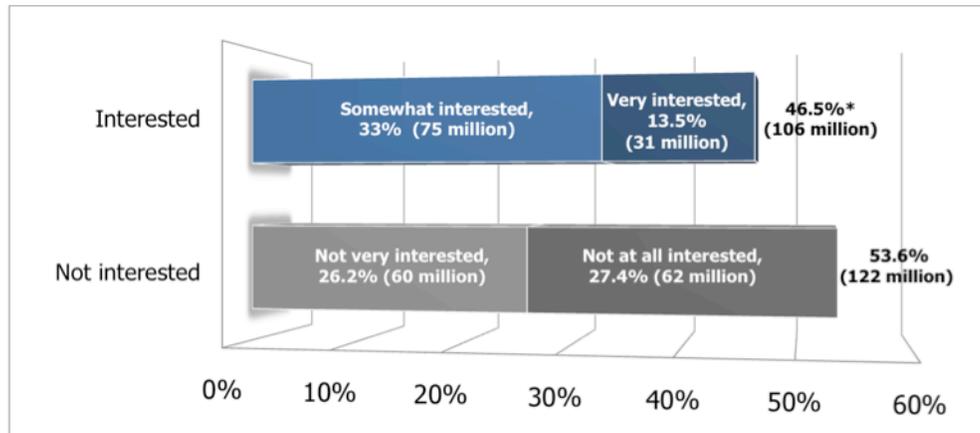
Conclusion: Public attitudes strongly support the need for a comprehensive approach to privacy practices and consumer control in emerging internet-based PHRs and related services. Most consumers see a wide variety of potential benefits; they strongly favor a set of privacy and information access practices, and they view at least four different enforcement mechanisms as being effective.

Key Finding Details

1. **High perception of value:** *When the general public was asked how use of an online PHR service would affect individual handling of health and health care, large majorities said such services could improve several activities "a great deal" or "somewhat."*

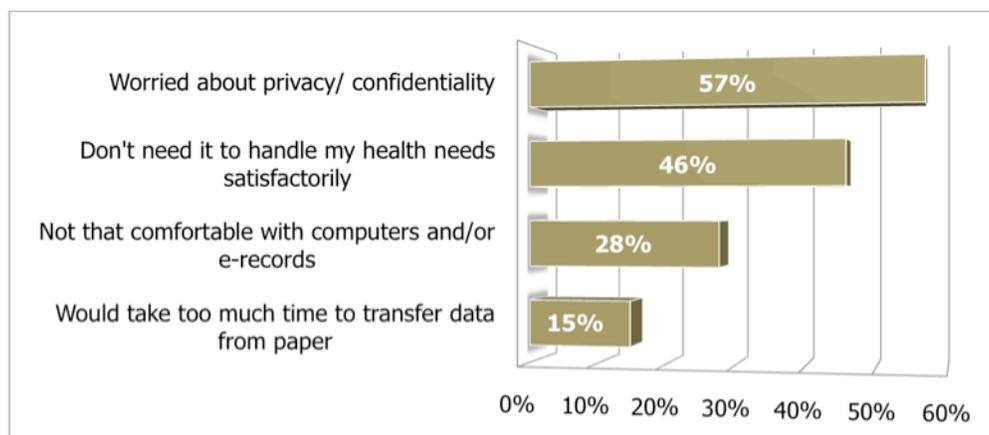


2. **High interest:** *Almost half the public – 46.5 percent, representing about 106 million adults – say they are interested in joining a free online PHR system*, with 13.5% (representing about 31 million adults) saying they are "very interested."*



* **Question wording:** "Some Internet technology companies and health care organizations are inviting individuals to join free online electronic personal health record services. You could obtain, store, and update your health information on a secure web site. You could control which health care providers can see or update your PHR, and you could automatically receive valuable information from the Internet related to the medical and health conditions and interests you indicated in your PHR. How interested would you be in enrolling in such a free online PHR system?"

3. **Privacy concerns: More than half (56.8 percent) of these respondents not interested in PHRs cited "worries about privacy and confidentiality."**



Traits of people with privacy concerns higher than the general public included \$100,000 or greater annual income, married, 30-44 years in age, female, some college or BA, with a major disability, in very good health, and caregiver for a child.

4. **Practices matter: When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said each of these would either be "essential" or "a factor in making their decision."**

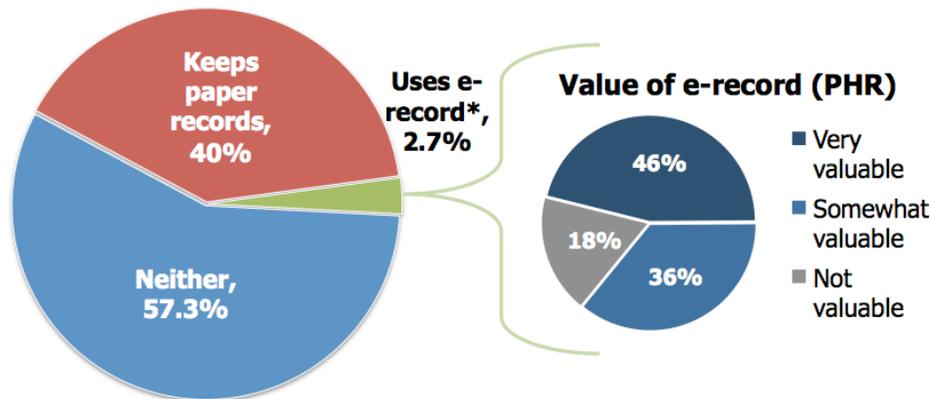
	Essential	One Factor	Nice
Affected people would be notified if their information falls into unauthorized hands in a way that could compromise their identity or expose their health information...	60%	32%	8%
An individual would be able to review who has had access to their personal health information...	53%	37%	10%
Individuals would have a clear process to request corrections or dispute the way their information is handled...	53%	38%	9%
Individuals would NOT be denied care or penalized financially based on whether they decided to provide certain medical information to an Internet-based service...	49%	40%	12%
Having individuals control what information from their medical records is made available to others. For example, an individual with a sensitive medical condition could decide NOT to include information about treatment for that condition...	44%	43%	13%
Individuals could make informed choices about how their information is collected and used...	42%	45%	13%

Ninety-one percent of respondents agree that "how my health information is handled online is so important to me that the online services should always require my express agreement for each use." Most (68.3 percent) say they "strongly agree" with this statement.

When asked about internet sites in general, more than half (54.4 percent) did not believe that internet privacy polices are easy to read and understand. And 39.3 percent admitted that they don't always know and understand the privacy policies they click 'I agree' to.

Respondents overwhelmingly said that they wanted permission to be specific (i.e., not just based on agreeing to a general privacy policy) when their information will be sent to third parties. A large majority (84.7 percent) agreed with the following statement: "No matter what policies I click 'I agree' to when I sign up, my information should not be disclosed or sold to third parties unless I say 'yes' separately and specifically to it."

5. **Utilization of electronic PHRs remains low: Most Americans (57.3 percent) do not keep health records at home, while 40 percent keep health records in paper form. Only 2.7% (representing about 6.1 million persons) say they have an electronic PHR today – 4 in 5 of this small group considered them valuable.**



* Most have their PHR with health insurer or HMO

Those more likely than the general public to have a PHR include people who visited the doctor seven or more times in the past year, those in poor health, have a disability or a long-term health condition, users of the Internet, incomes over \$100,000 annually, between 30-44 years of age, and Hispanics.

6. **Variations by sponsor: Interest in using a PHR online service varies according to sponsoring organization, with the health care services individuals now use or have available locally rating most highly.**

Would your interest in joining such an online PHR system be greater, the same, or less if the sponsoring organization were...	Greater	Same	Less
Hospital or medical practice you use...	33%	58%	9%
Group of doctors and hospitals in your area...	25%	62%	13%
Your health insurance plan...	25%	57%	18%
Disease support organization (e.g. Cancer, Diabetes, or Stroke Victim Society)...	13%	66%	21%
Your employer...	10%	52%	38%
A government agency (e.g. Veterans Affairs, Medicare)...	9%	55%	36%
An affinity group (e.g. AARP)...	9%	64%	28%
An Internet company (e.g. Google, Intuit, Microsoft, Revolution Health, WebMD)...	6%	56%	38%

7. **Variety of enforcement tools: The public expresses about equal confidence in the effectiveness of four different mechanisms for assuring that online PHR services comply with their privacy policies.**

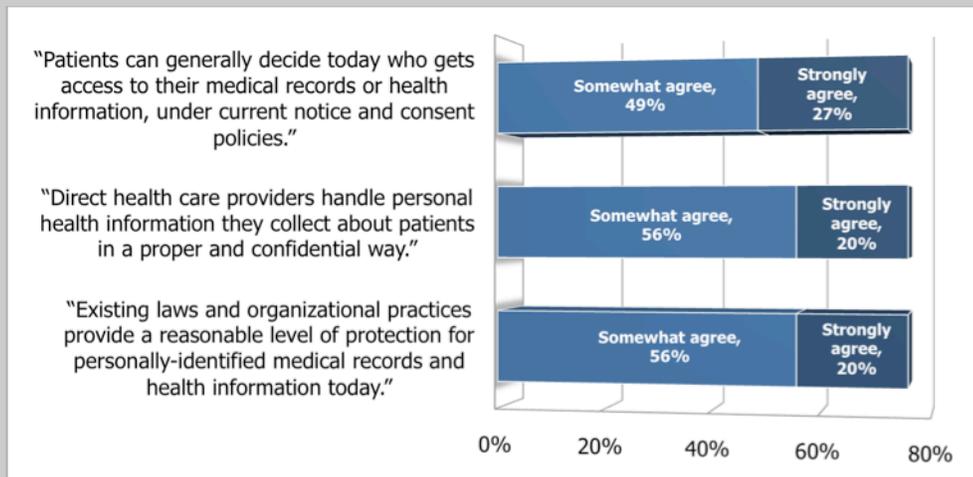
Eighty percent said they thought each of these two options would be effective:

- Having an independent organization audit the PHR organization and provide a seal of approval to certify it is following good practices.
- The Federal Trade Commission or state attorneys general enforcing existing consumer protection laws, by finding any PHR that does not follow its own policies is engaging in false and misleading practices.

Seventy-six percent said they thought each of these two options would be effective:

- Market forces — consumers choosing the products and brands they trust and not using others that do not follow good privacy practices.
- Congress passing a new health privacy law to cover the special features of online PHR services.

Overall, based on their responses to three broad policy statements about privacy and confidentiality practices and protections today, the American public divides into three segments: high health privacy concerns (24%); moderate health privacy concerns (49-56%) and low health privacy concerns (20-27%).



24% of respondents DISAGREE with all three statements.

Conclusion

The following key findings are most salient in informing the conclusion below:

- Four in 5 U.S. adults believe that online PHRs would be beneficial in managing their health and health care.
- Nearly half the public expresses some interest in using one.
- Yet less than 3 percent of the general adult population has an electronic PHR today.
- Among those not interested, concern for privacy is the most frequently cited reason why.
- Majorities of 87 percent to 92 percent say six key privacy practices are factors in their decision to use an online PHR.
- More than 90 percent said their express agreement should be required for each use of their online health information.
- More than 75 percent said each of four possible policy enforcement mechanisms would be effective.

Our key conclusion is that public attitudes strongly support the need for a comprehensive approach to privacy practices and consumer control in emerging internet-based PHRs and related services.

The six key privacy and consumer-control practices that we probed **each** scored 87 percent or higher in being a factor in the consumer's decision to participate in an online PHR service. *(See Finding 4 above.)* Similarly, each of the four possible societal mechanisms scored 76 percent or greater in terms of its perceived effectiveness. The respondents did not identify any one or two of these options as particularly important or effective — they all were considered important or effective, respectively. *(See Finding 7 above.)*

When assessing the value of PHRs, the public sees a high potential in a number of different activities for managing personal health and health care, including improving communication with current and new doctors, checking for mistakes in their records, avoiding duplicated tests and procedures, and managing individual and family health and lifestyle. Of the eight separate possible benefits of online PHRs that we measured, 79 percent or more of the public found each to be plausible. Again, no one or two possible benefits stood out — they all did. *(See Finding 1 above.)*

We therefore conclude that, among many possible keys to stimulate broader public adoption of online PHRs and related services, a majority of the public sees a comprehensive set of privacy practices to be essential. And, they support the effectiveness of a variety of possible mechanisms to enforce these practices.

Methodology

The questionnaire was developed by Professor Alan F. Westin and Josh Lemieux of the Markle Foundation, with inputs from the Markle staff. Knowledge Networks created a national sample of 1,580 respondents representative of the total adult (19+) U.S. population (estimated at 228 million), covering both persons who use the Internet and those who have not. Responses were collected by a special online process between May 13-22, 2008. Knowledge Networks places the error rate for this sample at +/- 2.5%.

About Markle Foundation

Emerging information and communication technologies possess enormous potential to improve people's lives. The Markle Foundation works to realize this potential by accelerating the use of these technologies to address critical public needs, particularly in the areas of health and national security. Contact: Josh Lemieux (jlemieux@markle.org).

About Connecting for Health

Connecting for Health is a public-private collaborative with representatives from more than 100 organizations across the spectrum of health care stakeholders. Its purpose is to catalyze the widespread changes necessary to realize the full benefits of health information technology (HIT), while protecting patient privacy and the security of personal health information. Connecting for Health is continuing to tackle the key challenges to creating a networked health information environment that enables secure and private information sharing when and where it's needed to improve health and health care.

About Knowledge Networks

Founded in 1998, Knowledge Networks developed and features now a process for conducting Internet-based survey research with a nationally-representative probability sample of the full U.S. adult population. Its technique has been used by a wide range of government, academic, business, and non-profit clients. Stefan Subias (ssubias@knowledgenetworks.com) was the project leader for this survey from Knowledge Networks.

About Professor Alan F. Westin

Alan F. Westin (afwestin@gmail.com) is Professor of Public Law & Government Emeritus at Columbia University, author of Privacy and Freedom (1967), and co-founder of the Privacy Consulting Group (1993). Since the 1970's, he has specialized in both national surveys and field research into the application of information technologies in the U.S. health care system, and the privacy, confidentiality, and security issues these applications present.