

Public Attitudes Toward Electronic Health Records

By Dr. Alan F. Westin

In his State of the Union Address, and in later speeches throughout the Midwest, President Bush proposed a \$125 million commitment to a national electronic medical record system. The value, he said, is in bringing better care to patients, improving the healthcare system and bringing the industry into the 21st century. With \$50 million of government funds already invested, most experts believe that increased computerization and a potential national network of electronic health records (EHR) are highly likely.

So, what about privacy?

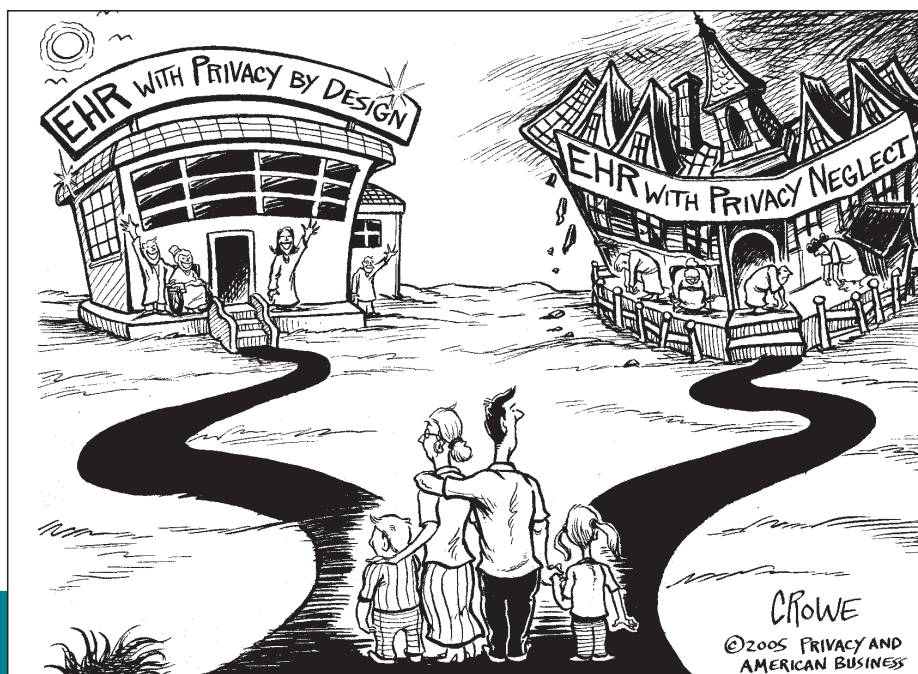
To address these issues, *P&AB's* IT, Health Records and Privacy Program (see page 9 for more information) collaborated with Harris Interactive to place a set of exploratory questions on a representative national survey by telephone that Harris Interactive conducted February 8-13. This survey, *How the Public Sees Health Records and an EHR System*, was publicly released at the February 23 HHS Hearings on Privacy and Health Information Technology.

The American Public and Healthcare Privacy: A Baseline Summary

Before describing our February 2005 survey results focused on the Electronic Health Records program, it is helpful to lay in the core findings of past health privacy surveys. In summary:

- Surveys show consumers rate personal health information and financial information the two most sensitive types of consumer personal information.
- Persons with chronic and especially genetically-based health conditions express sharp concerns about circulation and use of their health status to deny them important consumer opportunities and benefits.
- Consumers also express concerns about privacy and security in the current move to greater collection and use of medical records electronically.

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- While 80% of online consumers go to health sites for information, they express high concerns about privacy and security in their surfing.
- Because of their privacy concerns, many consumers using health information web sites do not share their personal data, and take full advantage of these sites.
- Consumers also express fears that their health information might be accessed or used improperly to commit identity thefts.

30 million Americans believe their personal medical data has been improperly disclosed

(Sources for these findings are available in the Program's publication, *How the Public Views Health Privacy: Survey Findings from 1978-2005* available at www.pandab.org.)



*Dr. Alan Westin,
P&AB's President
and Publisher*

How the Public Sees Handling of Personal Health Information in the Healthcare System Today

We were able to use a trend question from 1993 to probe the public's views on this issue, so that we could have a pre- and post-HIPAA reading.

In the Westin-Harris 1993 national survey, *Health Information Privacy*, we asked respondents whether they believed that a list of health system participants had disclosed their personal medical information in a way that they felt was improper.

Over a fourth of the public – 27% – then representing 50 million adults, said they believed one or more of the listed persons or organizations had disclosed their personal medical information improperly:

A doctor who has treated you or a family member	7%
A clinic or hospital that treated you or a family member	11%
Your employer or a family member's employer	9%
A health insurance company	15%
A public health agency	10%

(Source: Health Information Privacy, 1993)

When we repeated this question in 2005, we asked about improperly-considered release by these same persons or organizations "in the past three years." We recorded a dramatic drop in public perceptions of such improperly handled personal medical information.

In 2005, only 14% of the public – almost in half from 1993 – now believe their personal medical information has been released improperly. While substantially lower than the 1993 results, it should be noted that this still represents 30 million adults in the current U.S. population.

A doctor who has treated you or a family member	5%
A clinic or hospital that treated you or a family member	8%
Your employer or a family member's employer	5%
A health insurance company	8%
A public health agency	5%

(Source: How the Public Sees Health Records and an EMR System, 2005)

This drop from 27% to 14% of the public may well represent effects with the public from the HIPAA Privacy Rule rollout since April 2003. We tested that in our next set of questions.

Experience With HIPAA Privacy Notices

We informed respondents that "a Federal Health Privacy Regulation (called the HIPAA rule) has required all healthcare organizations to give patients a privacy notice explaining how the organization will collect and use the patient's health information, how it will keep the information secure, how patients can get access to their own health records, correct any errors, and control most disclosures of their information to people outside the healthcare system." We then asked: "Have you ever received one of these HIPAA health privacy notices?"

Given the ubiquity of HIPAA privacy notices – handed out by every doctor, dentist, clinic, hospital, pharmacy, health insurer, etc. – I had anticipated a yes response from well over 90% of respondents. I assumed that persons away studying in Tibet since April 2003 would be the kind of respondents who would say no.

I was wrong.

A third of the American public – 32%, representing 68 million adults – say they had never received a HIPAA privacy notice (and only 1% chose to say Not Sure). This is both a surprising and disturbing result, since it seems sure that most of these persons did have a Privacy Notice given to them since April 2003. Obviously, they do not recall the paperwork as the Privacy Notice we described.

Two-thirds of the public – 67% – recalled that they had received a HIPAA notice, representing 148 million adults.

Confidence in Health Record Handling Post-HIPAA

We followed up by asking respondents who remembered getting a HIPAA privacy notice personally – two thirds of the public – this question:

“Based on your experiences and what you may have heard, how much has this federal privacy regulation and the Privacy Notices affected your confidence that your personal medical information is being handled today in what you feel is the proper way?”

Two-thirds of the public (67%) said their confidence had been increased. Of these, however, only 23% said their confidence had been increased “a great deal,” while a much larger 44% chose “only somewhat.” Thirteen percent said “not very much” and 18% “not at all.”

EHR – Levels of Public Awareness

With the questions just reported as a foundation, we moved on to probe public attitudes toward the EHR program. We first described what we called Electronic Medical Records:

“The Federal Government has called for medical and healthcare organizations to work with technology firms to create a nationwide system of patient Electronic Health Records over the next few years. The goal is to improve the effectiveness of patient care, lessen medical errors, and reduce the costs of paper handling. Have you read or heard anything about this program?”

Our survey was conducted after President Bush had described the EHR program in his State of the Union message in January, and had also gone out to the Midwest in early February in several public meetings outlining and promoting EHR. However,

since this remains a rather specialized issue, not directly affecting consumers now, and not generating much public debate, I assumed knowledge would be low.

This time I was right.

Less than a third of the public – only 29% – said they had read or heard about a national EHR program. This represents 62 million adults, and a quick look at our demographic data showed that these were, predictably, primarily the better-educated, higher-income, technology-using members of the public.

EHR: Privacy and Security Concerns

Having laid a foundation about EHR, we posed the following multi-part question to respondents:

“Here are some things that some people have said might happen under such a patient Electronic Health system. How concerned are you [about each item read] very concerned, somewhat concerned, not very concerned, or not concerned at all?”

The following list was used in a randomized order, with these results:

The Public's Privacy and Security Concerns in an EHR System		
ITEM	Concerned (Very + Somewhat)	Very
Sensitive personal medical-record information might be leaked because of weak data security	70%	38%
There could be more sharing of your medical information without your knowledge	69%	42%
Strong enough data security will not be installed in the new computer system	69%	34%
Computerization could increase rather than decrease medical errors	65%	29%
Some people will not disclose sensitive but necessary information to doctors and other healthcare providers, because of worries that it will go into computerized records	65%	29%
The existing federal health privacy rules protecting patient information will be reduced in the name of efficiency	62%	28%

Only 29% say they have read or heard about a national EHR program

Some observers of our survey may feel that respondents given a list of potential concerns in any program are likely to say that they share such feelings. This is not the record in most social-issue surveys and especially in privacy surveys over the past four decades.

In other consumer, citizen, and employee privacy surveys, including health privacy surveys, the public majority has demonstrated an ability to modulate its expressed concerns depending on its perceptions of the issues. In other words, when a list of potential privacy problems is offered to survey respondents, the American public majority can usually sort them out in a pretty sophisticated way – reflecting the public's actual mood and perceptions on social issues, and not controlled by a general pro-privacy or anti-government or anti-business orientation.

The views of those concerned about medical data leaks are shaped by general public awareness of identity theft

This is proved in dozens of privacy surveys where concern levels expressed by respondents run the gamut from heavy to light to non-existent, depending on the public's sense of the services offered, the privacy or anti-discrimination interests at stake, and how respondents believe a given program or process will be conducted.

Here, a solid two-thirds of the current American public – in a range from 62-70% – say they share the concerns of “some people” about adverse privacy and data security results taking place in the operations of an Electronic Health Record system. And, those saying they are Very Concerned ranged from 28 to 42%.

These views are obviously shaped by general public awareness about the high incidence of identity theft, a constant media “drip-drip” of stories about leakage or disclosure of personal consumer data from organizational databases, and accounts of hackers penetrating business and government websites to steal personally identifying consumer files.

With these larger privacy-violation and data insecurity trends in the background, I believe our six-topic list represents the core of the privacy concerns that two-thirds of the public will be looking at – and want to have successfully addressed – before most Americans will be comfortable with an EHR system.

How the Public Divides on the Benefits and Privacy Risks of an EHR System

It is common in surveys of this kind, after describing a new program and then measuring various concerns about it, to pose a “tie-breaker” question. This asks, essentially, taking into account supposed benefits of some business or government program or action and also the risks to privacy or other social value you may see, where do you come out on the program's acceptability to you?

Our tie-breaker question on EHR was framed as follows:

“Supporters of the new patient Electronic Health Record system say that strong privacy and data security regulations will be applied. Critics worry that these will not be applied or will not be sufficient. Overall, do you feel that the expected benefits to patients and society of this patient Electronic Health Record system outweigh potential risks to privacy, or do you feel that the privacy risks outweigh the expected benefits?”

Half the American public feels an EHR system isn't worth the privacy risks

The two alternatives were rotated in presentation to respondents to avoid presentation bias.

And the winner was... NO ONE.

The public divides equally on this fundamental question – 48% saying the benefits outweigh risks to privacy and 47% saying the privacy risks outweigh the expected benefits. The deciding 4% said they just weren't sure.

What I draw from this key question is that half the American public does not feel today that an EHR program is worth the risks to privacy that they perceive as accompanying this development.

That is the reality that program advocates will need to consider, respond to, and overcome by a range of laws, rules, practices, technology arrangements, privacy promotions, and positive patient experiences – if EHRs are to win majority public support and high patient participation.

Segmenting the Public on EHR Privacy Concerns

In privacy surveys since 1991, I have created various segmentations of the public on consumer, citizen, and employee privacy issues. The goal is to

ask sets of questions that tap basic orientations and preferences of respondents and, on most issues in a given area of privacy (health, financial, anti-terrorist powers, etc.) will identify High, Medium, and Low Privacy Concern segments of the public.

If the segmentation is sound, the total respondents will scale in their answers to the substantive policy issues involved in that area. The High respondents will express the sharpest privacy concerns, reject competing values, call for legal interventions, etc., while the Medium and Low respondents will each record less intense or little to no concerns. We can then look at the demographic characteristics of each segment, and gain some insights into the underlying bases of each position.

We created our EHR Privacy Concern Segmentation from responses to the six issues posed in the previous question discussed. Our units were:

Concern chosen in 5 or 6 statements	High EHR Privacy	14%
Concern chosen in 3 or 4 statements	Medium EHR Privacy Concern	56%
Concern chosen in 1 or 2 statements	Low EHR Privacy Concern	16%
Concern not chosen in any statement	Not Concerned About EHR Privacy Concern	14%

The most obvious and important thing to note is that a solid majority of the American public today is in the High EHR Privacy Concern camp, representing a whopping 120 million adults. In comparison, only 35% of the public is in the High Privacy camp when it comes to overall consumer privacy issues.

Empowering Patients From the Outset

We considered it important to see how the public felt about the role that patients might play directly in any EHR system, not as passive subjects but as technologically-aided participants. Our question was:

“Since most adults now use computers, the new patient Electronic Health Record system could arrange ways for consumers to track their own personal information in the new system and exercise the privacy rights they were promised. How important do you think it is that such individual consumer tools be incorporated in the new patient Electronic Health Record system from the start?”

More than eight out of ten respondents – 82% – rated such consumer empowerment as important, and 45% of these considered it Very Important. Only 17% did not see this as important, with 1% not sure.

I view this result as a powerful, publicly-derived Privacy Design Specification for any national EHR system. It is a design approach that will be ignored, put off until a later time, or rejected as unworkable at the peril of any EHR system's entire future.

**82% say
consumer
empowerment
is important in
an EHR system
from the start**

Our Program and I are most appreciative of the contribution of David Krane of Harris Interactive to this survey and, as always, to the Harris Poll Chairman, Humphrey Taylor.

The topline results, full testimony and the Program's first publication, How the Public Views Health Privacy: Findings from 1978-2005, are all available at www.pandab.org. The full survey report and a White Paper will be posted at our website soon.

Methodology

Harris Interactive® conducted this survey by telephone within the United States between February 8 and 13, 2005 among a nationwide cross section of 1,012 adults (ages 18 and over). Figures for age, sex, race, education, number of adults, number of voice/telephone lines in the household, region and size of place were weighted where necessary to align them with their actual proportions in the population.

In theory, with a probability sample of this size, one can say with 95 percent certainty that the results for the overall sample have a sampling error of plus or minus 3 percentage points. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (nonresponse), question wording and question order, interviewer bias, weighting by demographic control data and screening (e.g., for likely voters). It is impossible to quantify the errors that may result from these factors. ■

IT, Health Records & Privacy Program



The Facts:

The nation's healthcare system is being reshaped through advanced technology applications. This is one of the most important developments of the next two decades.

Our Mission:

The Program on IT, Health Records & Privacy was formed to examine the government's initiative in this area, the response by the healthcare industry and the public's concerns.

Program Activities:

- Develop Legal and Policy Analyses of the privacy, confidentiality, subject access, and due process aspects of a national or decentralized-model EHR system.
- Conduct Empirical Case Studies of the privacy experiences in emerging health information technology experiments and programs.
- Conduct Continuing Public Opinion Surveys of the public and various leadership groups, with Harris Interactive as our privacy partner.
- Track the privacy rules and experiences in EHR projects of other democratic nations.
- Publish White Papers and Reports, and a Quarterly Electronic Newsletter
- Organize Tele/Web Seminars and Conferences on Program Themes

Coming Soon:

- White Paper: *Computers, Health Records, and Citizen Rights in the Twenty First Century*, co-authored by Dr. Alan Westin and the Program's Associate Director, Vivian van Gelder.
- Full Survey Report: How the Public Sees Health Records and An EHR Program

Contact Us:

If you are interested in receiving more information about participating in our new Program, contact Olga Garey at info@pandab.org or visit www.pandab.org.