

Privacy and Health Information Technology



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The American Public and the Electronic Health Records Initiative

- **EHR Initiative a major potential re-shaping of the nation's health care system**
- **Intended to enhance patient care, reduce medical errors, reduce high paper-handling costs**
- **Will clearly affect medical records and health information handling of entire population**
- **Makes sounding out the public on its views and concerns about EHR a national priority**
- **We created a Program on Information Technology, Health Records, and Privacy, and just conducted a national Harris survey to do this**

Public Attitudes Toward Health Care and Privacy

2005 SURVEY

- Program on Information Technology, Health Records and Privacy, with Harris Interactive
- **By telephone, February 8-13**

METHODOLOGY

- **1,012 respondents, representing about 214 million adults**
- **Margin of error +/- 3**

Health Privacy Attitudes, 1978 - 2005

- **Previous surveys show consumers:**
 - **rate personal health information and financial information the two most sensitive types of consumer personal information**
 - **are concerned about privacy and security implications of □ electronic collection and use of health information**
 - **express high concerns about privacy and security about visiting health websites**
 - **because of privacy concerns, do not share their personal data or take full advantage of these sites**
 - **express fears that their health information might be accessed or used improperly to commit identity thefts**

Consumers with chronic or genetically-based health conditions are sharply concerned about use of their health status to deny them opportunities and benefits

Improper Disclosure of Health Data

- Asked respondents whether believed health system participants in past 3 years “disclosed your personal medical information in a way that you felt was improper?” (Trend question from 1993)
- Dramatic drop – from 27% in 1993 (50 million adults) to 14% (30 million)
- Lower in 2005 in all categories:
 - doctor who has treated you or a family member..... 5%
 - clinic or hospital that treated you or a family member..... 8
 - employer or a family member’s employer 5
 - health insurance company 8
 - public health agency 5

Effects of HIPAA

- Does drop represent effects on public confidence from the HIPAA Privacy Rule rollout and compliance, April of 2003?
- We described the HIPAA Privacy Rule notice requirement, and asked “Have you ever received one of these HIPAA health privacy notices?”
 - 32% (representing 68 million adults) said they had NEVER received a HIPAA privacy notice -- REMARKABLE
 - 67% (representing 148 million adults) recalled that they had received a HIPAA notice
 - Only 1% were not sure whether they had received a HIPAA notice

HIPAA Impact, on Those Who Say Received Privacy Notice (67%)

- “Based on your experiences and what you may have heard, how much has this federal privacy regulation and the Privacy Notices [increased] your confidence that your personal medical information is being handled today in what you feel is the proper way?”
 - Total confidence increase..... 67%
 - 23% -- “a great deal”
 - 44% -- “only somewhat”
 - 13% -- “not very much”
 - 18% -- “not at all”

Electronic Medical Records: Awareness

- “The Federal Government has called for medical and health-care organizations to work with technology firms to create a nationwide system of patient Electronic Medical 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?”
- 29% (representing 62 million adults) said yes
- Highest among better-educated, higher-income, technology-using members of the public

Electronic Medical Records: Privacy Issues

- Respondents asked for levels of concern about potential adverse privacy outcomes from an EMR system:
 - **Leakage of sensitive health data**
 - Increased health data sharing without patients' knowledge
 - **Insufficient security for health data stored on computer**
 - Increase in medical errors
 - **Fears of computerization reducing people's willingness to provide sensitive health data**
 - Reduction of federal health privacy rules in the name of efficiency
- Overall: Two-thirds of American public say concerned about these possibilities

EMR Privacy Concerns Tested

ITEM	Concerned: Overall	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 necessary information to health care providers, because of worries that it will go into computerized records	65%	29%
Existing federal health privacy rules will be reduced in the name of efficiency	62%	28%

Risks and Benefits of an EMR System

- “Overall, do you feel that the expected benefits to patients and society of this patient Electronic Medical Record system outweigh potential risks to privacy, or do you feel that the privacy risks outweigh the expected benefits?” (Answers rotated)
- Public divides equally:
 - 48% say the benefits outweigh risks to privacy
 - 47% say the privacy risks outweigh the expected benefits
 - 4% weren’t sure

EMR Privacy Segmentation

- **EMR Privacy Concern Segmentation created from responses to the six issues posed**
- **If respondent chose concern in:**
 - **5 or 6 statements - High EMR Privacy Concern.....56%**
 - **3 or 4 statements - Medium EMR Privacy Concern...16%**
 - **1 or 2 statements - Low EMR Privacy Concern.....14%**
 - **Not statement chosen - No EMR Privacy Concern....14%**
- **A solid national majority is in the High EMR Privacy Concern camp. **Compares with only 35% in the High Privacy camp on general consumer privacy issues****

Consumer Participation in EMR

- “Since most adults now use computers, the new patient Electronic Medical 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 individual consumer tools be incorporated in the new patient Electronic Medical Record system from the start?”
 - More than eight out of ten respondents (82%) rated such consumer empowerment as important
 - 45% of these considered it Very Important
 - Only 17% did not see this as important

Implications for the development of EMR

- **Results suggest how public sees privacy risks and responding actions in EMR system will be absolutely critical to success or failure**
- **Strong public desire for consumer participation tools a powerful, publicly-derived Privacy Design Spec for any national EMR system**
- **EMR advocates will need to consider, respond to, and overcome concerns by a mixture of laws, rules, practices, technology arrangements, privacy promotions, and positive patient experiences**

Recommendations

- EMR/EHR holds enormous promise for patients, health care delivery, break-through research, society
- **EMR system more likely to succeed now than at any time in the past (health professionals now ready to use technology and technology much more powerful than before)**
- But will not succeed if public concerns over privacy are not understood and addressed
- **What I see as needed: (1) a Privacy by Design Working Group (analogous to ELSI Program within the Human Genome Project) and (2) a stand-alone Privacy Standards Board**

Recommendations (continued)

Privacy by Design Working Group would:

- Conduct continuing EMR privacy risk and threat assessments
- Identify system design elements that would enhance rather than defeat privacy interests
- Identify powerful and effective anonymization techniques to facilitate research and data-trend analyses
- Help develop policy and legal rules for the EMR environment
- Identify and test procedures to empower individual patients to access EMR systems directly, to assert their privacy rights and carry out their individual privacy choices
- Work on these approaches with the existing Regional Programs on EMRs

The Program on Information Technology, Health Records and Privacy

Will concentrate on six main activities:

- 1. Continuing Public Opinion Surveys of public and leadership groups on EMR developments**
- 2. Do Empirical Case Studies of privacy experiences in emerging EMR experiments and programs**
- 3. Develop Legal and Policy Analyses of privacy, confidentiality, subject access, and due process rules needed for EMR programs -- beyond HIPAA**
- 4. Track the privacy rules and experiences in EMR projects of other democratic nations**

The Program on Information Technology, Health Records and Privacy (cont.)

5. Publish White Papers and Reports, and a Quarterly Electronic Newsletter

6. Organize Seminars and Conferences on Program Themes

Staff: Alan Westin, **Director**
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Program Publications and Resources

The following resources can be downloaded free from our website, at www.pandab.org:

- The top line results of our EMR and Privacy survey
- **Report:** “How The Public Views Health Privacy: Survey Findings From 1978 - 2005
- My full testimony from today’s hearing
- This PowerPoint

Program Publications and Resources (cont.)

- **Our Program also plans to publish:**
 - **An expanded survey report with full demographic data and analysis**
 - **A White Paper on “Computers, Health Records and Citizens’ Rights in the Twenty-First Century” (Westin and van Gelder)**
- **Will be available at no charge from our web site in about two weeks**