



# Public Attitudes Toward Privacy in HIPAA and HIT Programs

**Dr. Alan F. Westin**

**Professor of Public Law and Government  
Emeritus, Columbia University**

**Director, Program on Information  
Technology, Health Records and Privacy;**

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# **Public Attitudes on Health Care Privacy A Critical Issue Now**

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- **U.S. moving rapidly toward EHR and interoperable networks**
- **Privacy a “make or break” factor in public acceptance**
- **Public attitudes unfold in context of HIPAA Privacy Rule**
- **So, what does public think of HIPAA administration and EHR plans?**
- **I draw on 35 years of leading privacy surveys and technology-privacy assessments in health care**
- **And, two national health privacy surveys in 2005**

# Overall Health Privacy Views

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- Health and financial information the most sensitive, needing greatest protection
- Trust in HC practitioners for confidentiality is high but for data security is now low -- because of ID theft plague and security leaks in HC
- Core issue is movement of personal health information into organizations administering consumer, employment, and citizen-benefit programs
- And public ambivalence about computer effects on privacy -- especially in HC
- Produced strong public support for federal health privacy legislation, and for issuing a strong HHS Privacy Rule

# New Surveys on Health Privacy

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- Two 2005 Harris Interactive national surveys on health privacy issues:
- Telephone survey, February 8-13; 1,012 respondents. Represents national public of 214 million adults. Sponsored by the new EHR-Privacy Program of my Center for Social and Legal Research -- I'll cite as Harris National
- Online survey of 2,638 adults, February 17-21. This represents 163 million adults online; sponsored by Wall Street Journal's Health Industry Edition -- I'll cite as Harris Online

# Receiving a HIPAA Privacy Notice

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- **Harris National survey described HIPAA and the requirement of a privacy notice for “all healthcare organizations,” then asked:**  
“Have you ever received one of these HIPAA health privacy notices?”
- **Given the ubiquity of HIPAA notices from covered entities, might expect a near universal Yes**
- **Not so... 67% said Yes, but almost a third -- 32% -- said they had never received a HIPAA privacy notice**
- **Represents 68 million adults!**

# Who Are the Strongest “Never Received...”

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- **Total Public is 32%**
- **Significantly higher:**
  - 18-24 in age (52%)**
  - Male (43%)**
  - Black (44%)**
  - High School or less (41%)**
  - Hispanic (50%)**
  - Less than \$15K (57%)**
  - Has disability (42%)**
- **Generally tracks low income, low education, minority, youth factors present in the most intense privacy-concerned groups**

# Has HIPAA Increased Public Confidence?

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- **Asked those who recalled getting privacy notice (67%):**  
“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?”
- **67% said their confidence “had been increased” -- 23% “a great deal” but 44% “only somewhat”**
- **32% did not register such confidence -- 13% said “not very much” and 18% “not at all”**
- **The 32% tracks intense Consumer Privacy Segmentation**

# Demographic Aspects on Confidence

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- **Demographic groups higher than public (67%) in expressing increased confidence not usual ones**

South (76%)

25-30 in age (74%)

Black (83%)

Hispanic (76%)

High School or less (75%)

\$15-24,999 (71%)

\$25-34,999 (72%)

Democrat (74%)

- **Most intense privacy concerns usually among minorities, low income, older, women**
- **No obvious explanations...**



# Public Awareness of EHR Programs

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- Harris National survey described current EHR national program efforts and asked: “Have you read or heard anything about this program?”
- Only 29% of the adult public said yes -- represents 62 million of 214 million adults.
- Awareness highest -- as expected -- among better-educated, higher-income, and online-using members of the public
- Lowest among low income, least educated, non-technology-using groups

# Online Users See EHR Positives

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- Harris Online documented broad optimism re EHR:
- 62% believe EHR can decrease frequency of medical errors significantly
- 73% believe EHR can reduce healthcare costs significantly
- 76% believe EHR can improve patient care by reducing unnecessary tests and procedures
- But, 67% of online users also believe “The use of Electronic Medical Records makes it more difficult to ensure patients’ privacy”

# Six Main EHR Concerns of General Public

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- **Sensitive health data may be leaked..... 70%**
- Increased sharing of personal health data without patient's knowledge..... 69%
- **May be inadequate data security..... 69%**
- Could increase not decrease medical errors..... 65%
- **Worried about computerization, some patients won't give sensitive information to health care providers.... 65%**
- Federal health privacy rules will be reduced, in the name of efficiency..... 62%

# Public Divided on EHR and Privacy

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- When asked whether the expected benefits to patients and society of an Electronic Medical Record system outweigh potential risks to privacy, or the privacy risks outweigh the expected benefits, the American Public is currently divided right down the middle
  - 48% say the benefits outweigh risks to privacy
  - 47% say the privacy risks outweigh the expected benefit
  - 4% weren't sure

# Empowering Patients Seen as Key...

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- “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

# Conclusions

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- 1. Two-thirds of public not yet informed in early 2005 about national EHR project; only elites so far**
- 2. Total public projects their strong current health privacy concerns onto future IT systems**
- 3. Primary fears:**
  - A. EHR will enhance distribution of personal health data beyond primary care into organizations setting consumer benefits and opportunities or government uses**
  - B. Weak data security will lead to leakage of sensitive patient health information**

# Conclusions

4. Half the public concludes potential EHR benefits DO NOT outweigh privacy risks
5. If not reversed, will affect legislators considering EHR authorizations and funding
6. 2005 Harris surveys warn organizations developing EHR applications and advocating HIT network -- rhetoric promising privacy will not be enough -- public wants hard evidence
7. At same time, privacy not absolute -- must be balanced with public disclosure and societal protection values, and medical records present very special environment for administering privacy rights

# What is Needed

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- **Build Privacy by Design functions into current EHR projects, going beyond HIPAA rules**
- **Develop better, computer-aided patient empowerment processes for record access, participation, and choice**
- **Incorporate Privacy by Design concepts in the national EHR standards process unfolding in HHS**
- **Mount strong empirical studies to track these privacy issues and experiments NOW in real-world settings, collecting patient experiences and judgments**
- **Monitor public and sub-group reactions to unfolding privacy processes in EHR programs -- through sophisticated local and national surveys**



# A Privacy by Design Proposal

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- My Program on Information Technology, Health Records, and Privacy has prepared a detailed Working Paper with our judgments of what needs to be done, and by whom...
- Computers, Health Records and Citizens' Rights in the Twenty First Century
- Available (free) at our two web sites on September 14, 2005:
  - [www.privacyexchange.org](http://www.privacyexchange.org)
  - [www.pandab.org](http://www.pandab.org)
- We welcome comments and reactions...