



What Two Decades of Surveys Tell Us About Privacy and HIT Today

Dr. Alan F. Westin

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

**Of Counsel and Senior Policy Advisor
ARNALL GOLDEN GREGORY**

**At the Health Privacy Summit
Washington, D.C. June 13, 2011**

Rich Body of Surveys, 1990-2011

- **95 published surveys with health privacy questions**
- **Wide range of sponsors, survey firms, interview methods**
and samples
- **Also wide range of question and response formulations**
- **Reflects that survey research is both art and science**
- **Survey reports must be read carefully and critically – to gauge the fairness and full-context of questions**
- **And need to note external events shaping consumer concerns and attitudes**

My Central Thesis

- Two decades of surveys document a very consistent pattern of majority consumer health privacy and security concerns, experiences, and general policy preferences
- **HIT programs will not earn the vital trust and cooperation of most patients if these privacy and security concerns are not successfully addressed**
- While other social interests must obviously be balanced with the privacy issues, unless privacy is put into a prime position, HIT systems are in for a very rough ride...

Overall Consumer Privacy Segmentation

- **Important to understand the larger pattern of health privacy dynamics, before looking at specific surveys**
- **By presenting respondents with positive and negative statements on health privacy to agree or disagree with, Harris-Westin surveys since 1990 show the U.S. public dividing, on a continuing basis, into three basic orientations on health privacy:**
 - **The Privacy Intense** about 35-40%
 - **The Privacy Pragmatic** about 50-55%
 - **The Privacy Unconcerned** about 10-15%

The Health Privacy Intense Segment

- Distrustful about many government and business data practices, especially if through technology systems
- **Worried about secondary uses of their personally-identified health data, by insurers, employers, government programs**
- Also concerned about researchers getting access to their personal health data without notice and direct consent
- **Strongest concern: discrimination against persons with potentially stigmatizing conditions**
- Not impressed by voluntary practices -- want legal controls and strong regulatory enforcement
- **While the Privacy Intense in general consumer privacy areas are about 25%, health privacy raises this to 35-40%**

The Health Privacy Pragmatists

- Go through a four-step process in deciding about health privacy issues:
 1. What's the benefit to them or to society in this use of personal health data, and how valuable is it?
 2. What are the privacy and security risks?
 3. What does the organization promise to do to minimize or even eliminate those risks?
 4. Do they trust this organization or believe there are adequate legal protections covering this situation?

If “yes” to all four, the Health Privacy Pragmatists will support the data-use program or HIT system

The Health Privacy Unconcerned

- Generally trustful of business and government data programs, and of health care givers
- **Generally positive about technology systems**
- Mostly in good health, without potentially stigmatizing health conditions
- **Have not had adverse experiences with uses of their personally identified health information (including medical record data breaches)**
- Resemble the Privacy Unconcerned in general consumer affairs, such as in online activities. For ten cents off, they would provide their family histories...

The Health Privacy Policy Dynamic

- In terms of adopting health privacy policies for HIT programs or systems -- by legislation or regulatory actions as well as through voluntary organizational measures – the key battle is for the hearts and minds of the Privacy Pragmatists
- **That battle is coming into focus right now...**
- So, on to what the survey trends tell us about public attitudes

Three Periods of Surveys – 1990-2011

- **1. “The Pre-HIT Baseline”** – 26 published surveys between 1990 and 2003
- **2. “Early HIT Public Responses”** – 38 surveys published between 2004 and 2007
- **3. “Current HIT and Privacy Trends”** -- 34 surveys published between 2008 and June 2011

(Incidentally, 16 of the surveys between 1990 and the present are ones for which I served as director or academic advisor.)

The Pre-HIT Baseline, 1990-2003 -- 1

- Health (and financial) information ranked most sensitive
- **High trust in healthcare providers to use patient data properly, protecting its confidentiality**
- Majorities worried about secondary uses of their data and potential discriminatory actions
- **Clinton healthcare reform plan of 1993 drew concerns about a national health ID card and how a national computerized health record would affect individual's privacy**
- Identity thefts arose in this period. Included medical records. Produced new data-security concerns about direct-care record keepers

The Pre-HIT Baseline, 1990-2003 -- 2

- Limited computerization of medical records in this era; early EHRs coming into use; not a topic of public attention
- **Major health privacy battle was over providing patients a right of access to their own records (accomplished)**
- Consumers flocking to the Internet seeking useful health information, but nervous about providing any personal information online
- Overall, majority believed : **“Existing privacy laws and regulations and organizational practices do not provide an adequate level of privacy protection today”**

Early HIT Public Reactions 2004-2007 -- 1

- **Publicity unfolded about EHRs and HIT. But only 29% in 2005 aware of Bush national HIT initiative**
- **When asked, majorities expressed belief that HIT would produce healthcare benefits – better coordination of care, fewer duplicate tests, cost reductions, etc.**
- **However, three surveys between 2005-2007 found high levels of concern that use of EHRs would make patient privacy and security more difficult**
- **A 2005 Harris-Westin survey found the public divided 50-50 on whether the potential benefits of EHRs outweighed potential threats to privacy**

Early HIT Public Reactions 2004-2007 -- 2

- However, by 2007 – at least when potential benefits were described in the question – a Kaiser Permanente survey found 73% of the public agreeing that:
 - “The benefits of electronic medical records, such as better treatment in an emergency and a reduction in medical errors, outweigh any potential risk to patient privacy or the security of patient information.”
- Looking at the total healthcare scene – not just HIT – majorities expressed view that “consumers have lost all control over how their health information is used today beyond direct care.”
- **And called for stronger health privacy laws**

The Current Scene 2008-June 2011 -- 1

- Surveys in this period applied the privacy and security concerns and policy preferences of 1990-2007
- A 2011 survey confirmed 67% trust in doctors to use patient information properly but only 10% trust in insurers, 7% for employers, and 6% for “the federal government”
- A 2008 survey found medical-record data breaches now the largest concern, followed by worries about unauthorized access by marketing firms, employers, and health insurers
- A 2011 survey found 64% saying benefits of EHRs outweighed privacy risks. But respondents still wanted government and industry to enhance privacy and security

The Current Scene 2008-June 2011 -- 2

- **Markle Foundation survey in 2008 showed heavy majorities endorsing the importance of basic Fair Information Practices for emerging online Personal Health Record services (PHRs).**
- **For example:**
 - **notify patients if data breach**
 - **individual right to review who accessed record**
 - **correction and dispute processes must be provided**
 - **informed choice by individual on how information used**

The Current Scene 2008-June 2011 -- 3

- 76% said in a 2009 survey they were concerned about the privacy and security of their personal health information and 60% said it was essential that government establish standards for how medical data is collected, stored, and exchanged
- A Patient Privacy Rights/Zogby survey in 2010 found that 78% of respondents said they were very likely (50%) or somewhat likely (28%) “to use a website that allowed [them] to decide who can see and use all [their] health information”

Can Technology Help? -- 1

- With public majorities so concerned about privacy, especially unwanted secondary uses, can information technology itself provide both strong patient consent mechanisms and socially-valuable uses of patient data?
- **Answer: yes, if such techniques are directly pursued**
- Example – a company called Private Access. It enrolls individuals in its patient-control system; helps them set the disclosure balances they are comfortable with; connects them to data seekers (such as researchers doing clinical trials) and unites patients and data seeker for direct data transfers.

Can Technology Help? -- 2

- **Private Access operates as a privacy agent for patients. It never records or handles the patient's medical data in its system.**
- **It is a “switch” but never a “store” for those data**
- **To see how Private Access operates, go to:
www.privateaccess.info or call 949-502-7890**

Disclosure: I serve as a privacy advisor to Private Access

New HIT Trust Survey Under Way

- I am co-directing this with the National Partnership for Women and Families, sponsored by the Commonwealth Fund, WellPoint and Merck, and Harris Interactive as the survey firm
- **1500 respondents, 750 of them members of EHR systems and 750 in primarily paper-based record systems**
- **Key issues:**
 - **patient-perceived benefits from EHR systems**
 - **experiences with privacy communications and practices**
 - **factors producing trust or distrust in HIT systems**
 - **effects of trust levels on patient's own care management**
- Survey in field this summer; report in early Fall

Contacts

- **Email: afwestin@gmail.com**
- **Fax: 201-836-6813**
- **Tel. 201-836-9152**
- **Postal:**
 - **1100 Trafalgar Street**
 - **Teaneck, New Jersey 07666**