



Privacy Attitudes of EHR Users: Some Results of a New National Survey

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Survey of EHR Users Now Under Way

- **Believed to be first national survey to explore in depth the attitudes, experiences, and judgments of EHR users on HIT operations, and to compare these to experiences and HIT perceptions of Paper-System users**
- **Especially to explore connections between EHR users' trust orientations and their impact on desired patient care-management behaviors in HIT systems**
- **Survey was in the field (with Harris Interactive) in August; data now being analyzed; expect to make public in October**
- **This presentation an advance look at one important area: top-line health privacy views of the two user communities**

Survey background

- **The survey is a project of the National Partnership for Women and Families**
- **Co-directed by Alan F. Westin and Christine Bechtel**
- **Co-sponsored by the Commonwealth Fund, Merck, WellPoint, and the California Healthcare Foundation**
- **With an Advisory Committee of experts from healthcare, HIT, academia and consumer groups**
- **Survey fieldwork conducted online in August by Harris Interactive**
- **Informed by analysis of 95 published surveys with health privacy questions between 1990 and 2011**

Survey Methodology -- 1

- **Harris drew representative sample of 4,073 U.S. adults 18+ who go online, and asked all two screener questions**
- **Selected for interviews 1,961 respondents who said they had a main or primary doctor they saw most often AND who also understood generally what kind of record system their doctor uses**
- **Definition of EHR/Paper systems we gave to respondents:**
“Some doctors and health care organizations use computers or mobile devices to record their patients’ medical and health information. These electronic health records – or ‘EHRs’ – contain notes from your doctor or other medical personnel about your visits., diagnoses, test results, prescriptions, lifestyle and other elements of your medical history. Other doctors keep medical records primarily in paper forms, which might mean using electronic systems only for things like making appointments or handling billing.”

Survey Methodology – 2

- Produced 1,153 respondents who said their doctor used an EHR system and 808 respondents who said their doctor had primarily a Paper System
- The two samples were generally similar in Standard Demographics (e.g. age, gender, race, education, income, etc.) and in Health Demographics (general health status self-reported and incidence of various chronic and/or privacy-sensitive health conditions)
- So the key variable we explored was -- and is -- the type of patient record system used and the differences patient users see in the healthcare operations and provider-patient relationships that this variable is producing

A Very Comprehensive Survey

- **One of the longest surveys I've been involved with over the past 45 years**
- **In addition to collecting extensive standard and health demographics on respondents, we presented 20 substantive topics, exploring patient experiences, concerns, and judgments from users of both EHR and Paper Systems.**
- **Also collected valuable narrative answers to some key questions, along with the regular closed-end responses**
- **Since data analysis is still under way, and our report will be reviewed by our Advisory Committee before finalization, I will be presenting today just the questions we asked both EHR Users and Paper-System Users on their Health Privacy Attitudes.**

General Health Privacy Attitudes

- **We presented respondents with four assertive statements about health privacy and HIT issues**
- Three of these four had been used in previous Harris-Westin privacy surveys since the mid-1990s, some in consumer-privacy surveys and some in health privacy surveys (such as an IOM privacy and health research survey in 2007)
- **Respondents were asked to Agree (Strongly or Somewhat) or Disagree (Somewhat or Strongly) with each statement**
- The four statements were rotated in order of presentation to avoid any positional influences

Privacy Statement # 1

“I generally trust my health care providers – doctors and hospitals – to protect the privacy and confidentiality of my personal medical records and health information”

	EHR	PAPER SYSTEMS
TOTAL AGREE	91%	92%
Strongly.....	42%	44%
Somewhat.....	49%	48%
TOTAL DISAGREE.....	9%	8%
Somewhat.....	7%	7%
Strongly.....	2%	2%

- This Very High Trust in providers, by both EHR and Paper-System users, has been documented in virtually all health privacy surveys over past two decades
- **And are even higher than in the Harris/Westin IOM survey in 2007**

Privacy Statement # 2

“Patients today have reasonably good opportunities to decide who can get access to their medical records and information for purposes beyond their direct health care.”

	EHR	Paper Systems
TOTAL AGREE.....	76%	74%
Strongly	21%	20%
Somewhat	55%	53%
TOTAL DISAGREE.....	24%	26%
Somewhat	19%	19%
Strongly	5%	7%

- Striking that 3/4ths of both types of users believe consumers **do** have **“reasonable”** ability today to control additional uses of their health information (though most experts would question that reality). But note this is mostly **“somewhat”** agreement

Privacy Statement #3

“Widespread adoption of electronic health record systems will lead to even more personal information being lost or stolen than we have now.”

	EHR	PAPER SYSTEMS
TOTAL AGREE.....	59%	66%
Strongly	14%	24%
Somewhat	45%	42%
TOTAL DISAGREE.....	41%	34%
Somewhat	31%	28%
Strongly	10%	7%

Both groups affected by widespread current national publicity of health data breaches from both types of record systems

However, EHR users less ready to assume that “even more” data beaches will be inevitable in EHR systems

Privacy Statement # 4

“The privacy of personal medical records and health information is not currently well protected by federal and state laws and organizational practices.”

	EHR	Paper Systems
TOTAL AGREE.....	51%	53%
Strongly.....	12%	13%
Somewhat.....	39%	40%
TOTAL DISAGREE.....	49%	47%
Somewhat.....	37%	33%
Strongly.....	12%	14%

- Again, very similar positions by the two user groups
- **This bare-majority skepticism about adequate legal/organizational protections in healthcare privacy probably reflects the overall privacy-concerned state of U.S. national public opinion today**

Summary and Observations

- **On all four of these projective statements about health privacy, EHR and Paper-System users were very close, with the exception being speculation about increased data breaches in electronic systems (66% of Paper-System users think this likely, compared to 59% of EHR users)**
- **When the data are all analyzed and the report done, we will have all the Standard and Health Demographic variations for these four privacy attitudes by both EHR and Paper-System users**
- **Will also see how factors such as record-system experiences of patients, examples of patient-rights dispute- resolution, and management explanations to patients of record-system operations and patient rights, are shaping these views**
- **And – especially – how patients in both systems arrive at their trust levels and how those affect desirable patient self-care activities**

Survey Publication and Access

- **As already noted, our full survey report expected in October**
- **If you would like to learn when the report is available, and to get a link to download it, please give me a business card or email your interest to me (address on next slide) and we will see that you are notified.**

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