Electronic Health Records and Privacy: Public Concerns, Public Choices

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My Experiences with HC and Privacy

- **opinion surveys and empirical field studies my prime tools**
- **developer of 10 national surveys on HC and privacy since 1978**
- **field studies for NAS, NBS AND OTA -- e.g. Computers, Health Records, and Citizen Rights (1975)**
- **policy proposals, e.g. Building Privacy by Design into Emerging EHR Systems (2005)**
- **speeches at national health forums: AHRQ, IBM, Markle, etc.**
- **since 1993, privacy assessments for HC providers, insurers, pharmacy firms, and HR departments, through my Privacy Consulting Group (PCG)**

Pre-EHR Privacy Surveys

- health information most sensitive personal information
- trust in HC practitioners to handle PHI very high
- main worry: health information going to non-health organizations or publicly disclosed
- concerns also over data security and uses of new genetic information
- public majority ambivalent about HC computer effects -- a "worried positive…"
- led to demands for -- and passage of -- federal health privacy law and additional state laws
- but HIPAA Privacy Rule and enforcement not seen as solving all privacy problems, <u>even pre-EHR</u>

Surveys on EHR and Privacy

- 23 published surveys with health privacy Qs, 2005-2007

- Three Harris surveys I will draw on most:
  - Harris/Westin, on EHR and Privacy; online, 2747 adult respondents, September, 2006; adjusted to represent entire adult population
  - Harris /Wall St. Journal, Health Care Poll; online, 2624 adult respondents, September 2006
  - -- Harris-Westin, Uses of Personal Health Information; 2337adult respondents; January, 2007

Low Awareness of EHR National Program

- Harris/Westin 2006 described current U.S. EHR national program efforts; asked: “Have you read or heard anything about this program?”
- only 26% of the adult public said yes; represents 60 million out of 230 million adults. (62% said had not read or heard; 12% weren’t sure) About the same result as in 2005
- awareness highest -- as expected -- among better-educated, higher-income, and online-using
- rather surprising -- given extensive mass media coverage
- 3 out of 4 adults not yet “involved with” or paying attention to EHR developments

Online Users See EHR Positives

- Harris-WSJ 2006 documented broad public optimism re EHR benefits -- but at lower majorities than recorded in 2005 WSJ survey
- 55% believe EHR can decrease frequency of medical errors significantly (was 62% in 2005)
- 60% believe EHR can reduce healthcare costs significantly (was 73% in 2005)
- 68% believe EHR can improve patient care by reducing unnecessary tests and procedures (was 73% in 2005)
- 62% of online users also believe “The use of Electronic Medical Records makes it more difficult to ensure patients’ privacy” (was 67% in 2005 -- a small gain in confidence)

EHR Privacy Concerns, From Harris/Westin 2005

- sensitive health data may be leaked……………………………… 70%
- increased sharing without patient's knowledge…………. 69%
- may be inadequate data security………………………………. 69%
- could <u>increase</u> not decrease medical errors……………… 65%
- computer-worried patients won't give sensitive information to providers……………………………………. 65%
- federal health privacy rules will be reduced ………………. 62%

EHR Developers and Privacy and Security

- when asked how much attention developers and managers of EHR programs “are paying to insure adequate patient privacy and data security measures”

- 69% think they <u>are</u> paying attention
  (36% ‘a great deal” and 33% “some”)

- 19% did not think so (12% paying “only a little attention” and 7% paying “not much attention at all”)

- positive belief is an EHR system developers asset
  -- for now

How Public Sees Privacy Risks and Benefits

- when asked whether expected benefits to patients and society of EHR systems outweigh potential risks to privacy OR whether privacy risks outweigh expected benefits, privacy fears trump potential benefits:
  - 42% feel “privacy risks outweigh expected benefits”
  - 29% feel “expected benefits outweigh the privacy risks”
  - BUT -- 29% say they are not sure…
- shows that the creation of a majority opinion on the risk-benefit judgment is still out there -- not yet formed
- will be shaped by what EHR system developers DO and how they COMMUNICATE to patients and public
- also by debates in Congress over privacy rules for EHR programs

Latest Harris-Westin Probe -- 2007

- 70% satisfied with how doctors and hospitals protect privacy
- By 63-25%, believe increased use of electronic records "can be accomplished without jeopardizing proper patient privacy rights."
- By 60-27%, believe existing federal and state health privacy protection laws provide a reasonable level of privacy
- By 63-27%, would consent to have their medical records used for medical research "as long as there were guarantees that no personally-identifying information would be released"
- The 25-27% with Intense Health Privacy Concerns matches the 25-30% of the public expressing Intense <u>Consumer</u> Privacy

Key Emerging Issue -- Consumer Participation in EHR Programs

- most major EHR programs being rolled out without advance descriptions and choices for patients or members, as just an "administrative enhancement"

- is NOT how a majority of patients or members feel this change should be carried out:

- Harris/Westin 2006 survey asked:

  – "How would you like to be involved when organizations providing you with health care records transition from mostly paper records to a complete electronic health record system? Please select ONE answer that best represents your view"

Majorities (60%) Want to Be Informed and/or Exercise Choices

- four answers provided
- “I might be okay with this but I would want to be notified of this change and have the effects of the handling of my personal medical information explained to me” ……..27%
- “I might be okay with this but I would want to be able to designate which parts of my medical records were entered or not entered into the electronic health record system” ……..12%

Patient/Member Involvement -- 2

- “I would want to be given the right not to have any of my medical records entered into the new electronic record system” …….. 21%
- “I don’t need to be notified of the change since I don’t think it will affect my relationship with my doctors and how they handle my information” ……. 22%
- “Not sure” ….. 17% (note the large figure here)
- while resting on low public majority awareness of EHR programs, these attitudes spell major potential trouble for EHR efforts

What is Being Done to Inform and Offer Choices?

- not aware of any field studies of how EHR programs are being introduced to patients or members and how new EHR-based rights are presented

- not aware of patient/member surveys at EHR sites exploring how consumers react to the changes and rights policies
- also not aware of any experiments with allowing patients or members the right to designate record portions not to go into the general EHR system, and if these are being studied
- Finally, are there any EHR programs that offer a general “opt out”? If so, are these being studied?

A Looming Conflict?

- given 42+% of public feeling potential privacy risks outweigh potential EHR benefits
- and 60% of the public wanting advance explanations of EHR impacts and rights to choose how records used
- could be a sharp bump ahead for EHR developers, as weak communications and a “just say yes” approach prevail
- also, patient rights groups and privacy advocates calling for new EHR-privacy rules in Congress
- push-back already happening in UK, where 53% of public and 52% of GPs oppose the UK national EHR plan, in organized campaign

Informing <u>Can</u> Be Done Well

- **every EHR program should develop and provide a <u>Patient's Guide to Your New EHR System: For Enhanced Participation, Privacy and Security</u>**
- **customized to each EHR system; cover changes to all health care processes and information uses**
- **spell out health-care advantages of new system**
- **show opportunities for greater patient participation in own health care processes and individual EHR-program choices**
- **describe privacy/fair information practices rules and rights under EHR, in clear, non-HIPAA-style prose**
- **outline data security program and safeguards**
- **offer lively Qs and As, scenarios, and personal contacts**

Implications

- privacy and data security remain absolutely critical issues for the national EHR effort and each individual system
- majorities fear privacy risks, but adequate patient and member communications and choice options not present yet
- calls for <u>empirical field studies</u> of the EHR introduction process, patient and member communications, and new privacy, security, and participation policies
- along with <u>surveys of patient and member</u> perceptions, concerns, and experiences in various EHR program settings
- now is the right time in EHR activities for such studies -- not too soon and not too late

Westin/PCG publications and ppt presentations

PCG website under reconstruction; please contact me at afwestin@gmail.com to obtain these materials

1. Building Privacy by Design into Emerging Electronic Health Record systems, White Paper, 2005
2. “Public Attitudes Toward Privacy and EHR Programs,” AHRQ Conference, 2005
3. “Beyond HIPAA: Assuring Patients’ Interests in EHR Programs,” IBM Forum, 2005
4. “Patient Participation and Privacy in EHR Programs,” IBM Forum 2005
5. Uses of Personal Health Information, Harris-Westin, 2007