



Patient Consent in the Electronic Exchange of Health Information

Joy Pritts, J.D.

Research Associate Professor

Health Policy Institute

Georgetown University

jlp@georgetown.edu



Privacy

◆ “... the right to be let alone.”

Samuel Warren and Louis Brandeis,
“The Right to Privacy” (1890)

◆ “... individuals need to determine for themselves when, how, and to what extent information about them is communicated to others.”

Alan Westin, *Privacy and Freedom* (1967)



Hippocratic Oath

(4th Century B.C.)

Whatsoever I shall see or hear in the course of my dealings with men... I will never divulge, holding such things to be holy secrets.



Privacy in Health Care

- ◆ Cornerstone of provider – patient relationship
- ◆ Facilitates patients accessing health care
- ◆ Instills trust



Consent

- ◆ Patient's release of promise of confidentiality
- ◆ Permission to disclose information



Consent

- ◆ Required for disclosure of health information by many professional standards of conduct
- ◆ Required by many state statutes and regulations
- ◆ Minnesota has some of the highest standards for consent in the country



Typical Consent Requirements

- ◆ Written, signed by individual, dated
- ◆ Most often pertains to disclosing to one other person/entity
- ◆ Obtained by party requesting the information
- ◆ Presented to the party holding the information in order to secure the release of the information



Electronic Exchange of Health Information (eHIE)

- ◆ HIPAA intended to foster eHIE
- ◆ Involve networks of parties
 - Physicians, hospitals, pharmacies, health plans, laboratories, consumers, governmental agencies, pharmacy benefit managers
- ◆ Exchanging health information via computer technology



eHIE-Benefits

- ◆ Higher quality of care
- ◆ More efficient delivery of services
- ◆ Safer patient care
- ◆ Cost savings

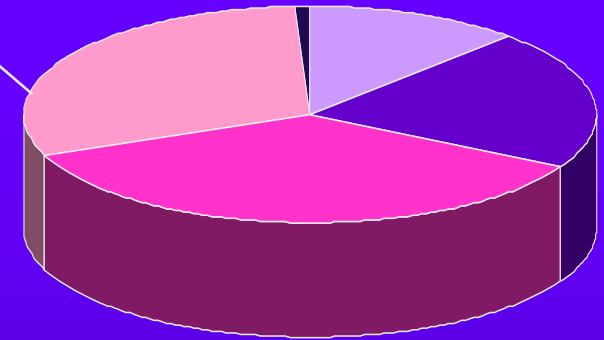


eHIE-Concerns

Security

69% American Adults -
Very/somewhat
concerned that “Sensitive
personal medical-record
information might be
leaked because of weak
data security.”

Very
concerned



Somewhat
concerned

*Harris Interactive Nationwide Telephone Survey (Feb.
2005)

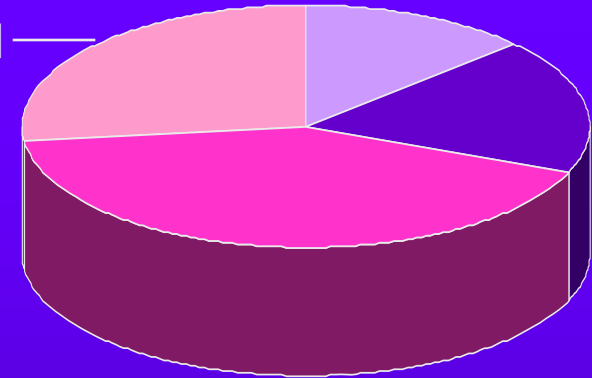


eHIE-Concerns

Privacy

69% - Very/somewhat concerned that “There could be more sharing of your medical information without your knowledge.”

Very
concerned



Somewhat
concerned

*Harris Interactive Nationwide Telephone Survey
(Feb. 2005)



eHIE-Concerns

- ◆ 79% polled listed as a top/high priority that only with an individual's permission could their medical information be shared in a nationwide eHIE network.*

* Markle Foundation, 2005.



Consent and eHIE

◆ HIPAA

- *No* consent required to disclose health information for treatment, payment, health care operations



HIPAA - Federal Floor of Privacy Protection

The Privacy Rule provides a floor of privacy protection. State laws that are more stringent remain in force. *In order to not interfere with such laws and ethical standards, this Rule permits covered entities to obtain consent.* Nor is the Privacy Rule intended to serve as a “best practice” standard.

Preamble, Standards for Privacy of Individually Identifiable Health Information; Final Rule (as Modified) 67 Fed. Reg.53192 at 53212 (August 14, 2002).



Consent

- ◆ Professional standards and state statutes and regulations that require consent prior to disclosing identifiable health information remain in place.
- ◆ Minnesota statute requiring consent for most purposes, even treatment, remains in effect



Consent Post-HIPAA

- ◆ Many, if not most, health care providers continue to obtain consent.
- ◆ Why?
 - Compliance with state law
 - Deeply rooted ethical concerns
 - Liability concerns



Consent and eHIE: Perceived Challenges

- ◆ More access seen as more risk
- ◆ Technically difficult to obtain, maintain and implement in an electronic environment



Consent and e-Health: Proposed Solutions

- ◆ Some states are eliminating consent requirement to facilitate eHIE
- ◆ Some are maintaining core policy of requiring consent
 - Revising laws to address eHIE (electronic signatures)
 - Realigning risk
 - Exploring technological solutions



Consent and e-HIE: Key Questions

- ◆ Have the core policy reasons for requiring consent changed just because the information is in electronic form?
- ◆ Doesn't obtaining consent continue to
 - Facilitate patients accessing health care
 - Instill trust in system



Final Thoughts

We are at a decision point. depending on what we do, revolutions in health care, biotechnology, and communications can hold great promise or great peril...

When all is said and done, will our health care records be used to heal us or reveal us?

(Donna Shalala, U.S. Secretary of Health and Human Services)



The End