

Public Policy & Connected Health: Anticipating Public & Political Concerns

Moderator:

David Lansky, PhD, Markle Foundation

Panelists:

Paul Feldman, Deputy Director, Health Privacy Project

Lee Schwamm, MD, Director, Telestroke and Acute Stroke Services, MGH

Jessica Wolfe, PhD, MPH, Trustee, Spaulding Rehabilitation Hospital

(Amphitheater)

ALL PROCEEDINGS WILL BE VIDEO RECORDED

Why privacy matters

- **Trust** is fundamental for patients and consumers to:
 - Share personal information accurately and completely
 - Believe in data feedback
 - Support e-health and NHIN
- Public opinion is wary
 - Identity theft, errors, and breaches
 - Privacy protective behaviors by ~15%
- Advocates feeling their way
 - Patients must consent for these uses of data
 - Wireless environment is unfamiliar, raises security issues
- Legal requirements, federal and state
- Professional confidence, liability fears

Evolving Public Awareness

The New York Times
nytimes.com

August 9, 2006

A Face Is Exposed for AOL Searcher No. 4417749

By MICHAEL BARBARO AND TOM ZELLER, JR.; SAUL HANSELL CONTRIBUTED REPORTING FOR THIS ARTICLE.

Buried in a list of 20 million Web search queries collected by AOL and recently released on the Internet is user No. 4417749. The number was assigned by the company to protect the searcher's anonymity, but it was not much of a shield.

No. 4417749 conducted hundreds of searches over a three-month period on topics ranging from "numb fingers" to "60 single men" to "dog that urinates on everything."

And search by search, click by click, the identity of AOL user No. 4417749 became easier to discern. There are queries for "landscapers in Lilburn, Ga.," several people with the last name Arnold and "homes sold in shadow lake subdivision gwinnett county georgia."

It did not take much investigating to follow that data trail to Thelma Arnold, a 62-year-old widow who lives in Lilburn, Ga., frequently researches her friends' medical ailments and loves her three dogs. "Those are my searches," she said, after a reporter read part of the list to her.

AOL removed the search data from its site over the weekend and apologized for its release, saying it was an unauthorized move by a team that had hoped it would benefit academic researchers.

The New York Times - 9/4/06

In 2000, using data from the Social Security Administration, the Utah attorney general's office found that the Social Security numbers of 132,000 people in the state were being used by other people, far more than the state could prosecute.

Privacy Principles: An “Architecture” for Privacy

1. Openness and Transparency
2. Purpose Specification and Minimization
3. Collection Limitation
4. Use Limitation
5. Individual Participation and Control
6. Data Integrity and Quality
7. Security Safeguards and Controls
8. Accountability and Oversight
9. Remedies

Code is law (Larry Lessig)

- Technology choices can dictate policy
- Values and Principles should drive policy
- Policy should drive technology (while also being constrained by it)

Policy Issues for Mobile e-Health

- Wireless environment, security, identity
- Interoperability
- Used as loyalty product vs. empowering?
Analogous to EMR/Stark issues
- Relationship to PHR
 - Mobile suppliers offering mini-PHR? Interface to others?
 - Relationship to EHR(s) and NHIN/RHIO

Consumer & Patient Principles

1. Individuals should be able to access their personally identifiable health information conveniently and affordably.
2. Individuals should know how their personally identifiable health information may be used and who has access to it.
3. Individuals should have control over whether and how their personally identifiable health information is shared.
4. Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information.
5. The governance and administration of electronic health information networks should be transparent, and publicly accountable.