

Americans' Changing Concerns About Health Privacy

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At the NAS Workshop, Washington,
D.C., November 18, 2008



Privacy A Key Issue of Information Age

- **Privacy a major social issue in high-technology societies with democratic values**
- **Have rich supply of over 200 published privacy surveys since 1978 – varied sponsors, topics, and techniques**
- **Health privacy surveys (about 50) especially frequent since 2004, as HIT, EHR, and PHR programs have unfolded**
- **Includes surveys on how public feels about uses of their medical records for health research**
- **Will draw on this body of surveys – with a reminder of always using survey findings critically – examine the topics, question formulation, responses offered, and findings drawn**

Overall Finding of Privacy Surveys

- **People differ in how they want their privacy boundaries set**
- **Four different environments of information collection**
 - **consumer-business**
 - **patient-healthcare**
 - **citizen-government**
 - **employee-employer**
- **Generally, public divides into three continuing privacy orientations, with percentages varying by sector**
 - **Privacy Intense..... 25-35%**
 - **Privacy Unconcerned..... 10-15%**
 - **Privacy Pragmatic..... 50-55%**

Overall Health Privacy Findings -- 1

- **Public ranks medical and health records as their most sensitive personal information**
- **High trust in health care providers to handle properly**
- **But major fears about uses by third parties -- insurers, employers, government -- or disclosed publicly**
- **Especially strong for persons with health problems or sensitive conditions -- fearing discrimination**
- **Also worries about data breaches and uses for marketing**
- **Broad support for potential patient and societal benefits from EHR and online PHR programs but strong privacy and data security worries**
- **Overall skepticism about effectiveness of current federal and state health privacy laws and administration**

Health Research and Privacy Findings

- **2007 Westin/Harris Interactive survey for Institute of Medicine on “How The Public Views Privacy and Health Research”**
- **Most detailed survey on this topic to date**
- **Registered the general health privacy themes noted earlier**
- **78% say interested in learning about health research results**
- **(and 75-80% in other surveys say health research important for American society)**
- **69% believe “health researchers can generally be trusted to protect the privacy and confidentiality of the medical records and health information they get about research subjects”**
- **But key issue is how health researchers can/should obtain access to those medical records and health information**

Divisions Over Consent

- Presented respondents with competing views on whether and how to obtain patient consent for research , and offered five alternatives:
 - Never contact me asking to use..... 13%
 - OK to use without having to ask..... 1%
 - Willing to give general consent in advance..... 8%
 - Consent not needed if my identity will never be revealed and IRB supervises..... 19%
 - Want each research study to describe it and get my specific consent each time..... 38%
- Adds up to 57% agreeing to use only if privacy-oriented conditions met

Demographic and Attitudinal Factors

- **Sixteen demographic groups higher by 5% than total 38% in wanting notice and express consent**
- **Examples:**

Blacks..... 45%	College grads..... 46%
Single women..... 43%	35-49K income..... 45%
50-64 in age..... 43%	
- **Generally parallels the groups more intense on consumer/citizen privacy**
- **Groups interested in health research also higher (46%); participants in health research (44%); and research participants who felt comfortable in such participation (49%)**

Health Status Factors

- **Persons with various health statuses or conditions higher by 5% or more in wanting specific notice and express consent:**
 - **Have long term health condition..... 45%**
 - **Used mental health services..... 44%**
 - **Have sexually-oriented condition..... 49%**
 - **Have taken genetic test..... 48%**

These persons are likely to be high among the groups targeted for health research, from clinical trials to social surveys

Implications of the Health Research and Privacy Surveys for The Workshop

- **Social surveys using biological materials represent a sub-set of the health research process, raising all the privacy and data security issues involved in collecting, using, and protecting personal health information for research**
- **Would be seen in that light by the public, and especially by persons with special health conditions**
- **In addition, many biological materials would be seen by public to be extra sensitive types of medical/health information, when used in research (e.g. genetic data)**
- **And, privacy issues would be further heightened if personal IDs were preserved in individual records, for longitudinal or comparative purposes**

Key Developments Unfolding Re Health Research and Privacy

- **While direct amendment of HIPAA Privacy Rule unlikely, new privacy rules are likely to be written into federal HIT support legislation now pending. Express consent for secondary uses in HIT systems is a top priority of privacy/consumer groups**
- **Major new online PHR programs (Google Microsoft, etc.) have adopted express patient-control policies that could set the bar for potential research-access to these data-rich treasuries**
- **In addition, new Patient Trustee systems -- “switch but don’t store” operations -- could revolutionize the recruitment and informed-consent features of health research, including social surveys**

Case Study in Privacy-Directed Health Research, Using Biological Materials - 1

- **A partnership between the Genetic Alliance and Private Access (further details in Workshop Agenda book)**

GENETIC ALLIANCE (GA) -- founded 1986

- **non-profit organization made up of over 1,000 disease-advocacy organizations affecting over 25 million persons**
- **GA organized in 2003 a centralized repository of biological materials (blood, tissue and other) plus data (family history, clinical results, environmental data)**
- **applied a web-based informatics core to locate, combine, and use these materials for research and product-development**
- **GA disease advocacy groups enjoy high member trust**
- **and these members have the high-privacy concerns but research receptivity the IOM survey documented**

Case Study in Privacy-Directed Health Research, Using Biological Materials - 2

PRIVATE ACCESS* (further details in Workshop Agenda Book)

- In 2006, applied internet search tools developed by founder, Robert Shelton, to create process that allows individuals, providers, and researchers to share valuable medical/health information in a trusted environment under direct individual control
- Based on four inter-related functionalities:
 - Trials Finder -- locate studies of interest to members of disease affinity organizations and communicates participation opportunity to potential subjects
 - Recruit Source -- find potential study subjects for researchers
 - Records Agent -- obtain copies of manual or electronic patient records
 - Privacy Layer -- assures compliance with all state and federal privacy laws and follows each consumer's expressed privacy preferences

* Disclosure Note: I serve on the Advisory Board of Private Access

Case Study in Privacy-Directed Health Research, Using Biological Materials - 3

- **Beginning Stage One of the Partnership in 1st Quarter, 2009**
- **PA will enroll individual members from up to 100 disease advocacy organizations in the GA, obtaining and recording their privacy preferences for research participation**
- **PA will enroll up to 100 properly authenticated Researchers selected by the disease advocacy organization**
- **PA will inform the enrolled individual members about relevant research projects and participant characteristics sought; collect “I’m interested” responses; and insure Researcher meets the member’s preferences**
- **Later in 2009, will use its Records Agent to collect the individual’s medical data from his/her providers and also locate and provide materials from the BioBank to the Researcher**

All expected to be done at a fraction of the average subject-recruitment costs and existing time-requirements

Summing Up...

- IOM survey lays out the pattern of majority concerns, attitudes, and policy preferences of current US public on general health research and privacy
- Many likely subjects of social surveys using biological materials will have the health statuses that marry intense privacy concerns with higher-than-general interest in participating in health research -- if robust yet easy to adopt patient privacy rights are followed
- The Genetic Alliance Bio-Bank partnership with Private Access's model patient-control system offers a promising process for applying individual privacy preferences while connecting subjects and researchers in ways that meet the national majorities sense of how health research should be conducted without compromising basic privacy interests

**TO OBTAIN A COPY OF THE FULL 2007
IOM SURVEY REPORT, “How the Public
Views Privacy and Health Research,”
contact afwestin@gmail.com**