

# Surveys on Privacy and Health Research, pre-9/07



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**at the IOM Committee Meeting,  
Washington, D.C., October 2, 2007**

# Health Research and Privacy, 1993-2007

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- **We examined 43 national surveys with health privacy questions fielded between 1993 and September 2007**
- Found 9 surveys with questions on health research and privacy
- **In some, majorities not comfortable with their PHI being provided for health research except with notice and express consent**
- In others, majorities became accepting if various safeguards and specific types of research were offered
- **And, opinions varied according to developments on the health care scene and with consumer privacy trends**
- Selected a representative group to present here -- and we used these in developing the IOM Committee 2007 survey

# The Nine Surveys....

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- **Located surveys in three time periods -- 1993-1996, in 2000, and 2006-2007**
- **Wide range of sponsors: Markle Foundation, Equifax, Institute for Health Freedom, Geneforum, Privacy Consulting Group**
- **And wide range of surveyors: Harris; Public Opinion Strategies; Genetics and Public Policy Center**
- **But no whole survey on health research and privacy; rather, one or a few questions in larger sets**

# Always Need to Use Surveys With Care

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- **Selection of the topics to probe on a policy issue**
- Representativeness of the sample
- **Whether judgments come from direct experiences of respondents, family or friends**
- If a policy issue, is this already framed in public debates or is it something new for respondents to evaluate
- **Formulation of questions and their operative terms**
- Range and formulation of responses
- **How to interpret the “very” and “somewhat” responses**
- How persuasive are the conclusions drawn from the results

# First Set of Inquiries, 1993-1996

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- **Healthcare: Clinton Healthcare Reform proposal; included a health ID card for every American; both conservatives and civil libertarians raised privacy issues; computerization of medical records gets public attention; debates over enactment of federal health privacy protection legislation (unsuccessful)**
- **Consumer privacy issues sharpening up -- creation of consumer profile databases, personalized (“target”) marketing, tracking on the Internet, Caller-ID phone technology, surveillance at the workplace, etc.**
- **Have three surveys with health research and privacy questions in this period -- 1993, 1994, and 1996**

# “Health Information Privacy Survey, 1993”

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- **Harris-Westin survey for Equifax**
- Found high privacy concerns by public for handling of their medical records and health information
- **While providers were trusted (doctors and hospitals) large majorities worried about secondary uses of their health information by employers, health and life insurers, and in government programs.**
- Also concerned about marketing uses of their health information
- **As a result, strong majority support for passage of federal health privacy protection legislation**

# “Health Information Privacy Survey, 1993”

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- “Medical researchers sometimes need to use individual patient records to study the causes of diseases or the value of specific drugs or treatments. However, they do not release any information identifying specific patients. If you are not personally identified in any publication, should your permission be required before your medical records are used for research, or isn’t that necessary?”

**Should be required ..... 64%**

**Isn’t necessary ..... 35%**

# “Health Information Privacy Survey, 1993”

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- **Follow up question to the 64% saying permission should be required:**
- **“Should your permission be required each time a researcher seeks to use your medical records or would asking for general advance permission to use your records for medical research be sufficient?”**

**Should be required each time..... 56%**

**General permission is sufficient..... 42%**

**Harris-Westin surveys followed up with new questions in 1994 and 1996...**

# Second Try..... 1994

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- **Presented an expanded main question, spelling out research and privacy procedures**
- **“When medical researchers study the causes of diseases or the value of specific medications or treatments, it is often necessary for them to consult individual medical records in hospitals, doctor’s offices, and other health care institutions. When such research is done, no personally identified medical information is released or published by the researcher. In addition, a Board in each health care institution ensures that researchers and hospitals follow proper procedures for assuring the confidentiality of all records used. Assuming you would not be personally identified, how acceptable would it be if your records were used for such medical research without contacting you about this?”**

## Second Try (continued)

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- **58% said not acceptable to use personal medical records for health research in this way without advance permission; 41% said would be acceptable.**
- **Then, asked those saying not acceptable if they would change their view if federal law made it illegal for a medical researcher to disclose the identity of a research subject. 28% said would change their view.**
- **Produced a total of 58% who would accept advance general permission under that assumption**
- **Illustrates the “what if safeguards” situation in probing the public’s privacy attitudes**

## Third try.... 1996

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- **Posed a new formulation**
- **“Health care system researchers sometimes use patient records to study the value and costs of specific medication and treatments in order to improve programs for handling diseases. These researchers do not release any information that would identify specific patients. If your identity were kept strictly confidential and obtaining your permission in advance was not feasible, how acceptable would it be for your medical information to be used as part of that type of general research project?”**

## Third Try... (continued)

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- A majority of respondents -- 57% -- said they would find this acceptable (18% very acceptable and 39% somewhat acceptable)
- **Of the 43% saying it would not be acceptable, 16% found it somewhat unacceptable and 31% not acceptable at all**
- The specific type of research and the stated infeasibility of getting advance permission seem to have influenced this outcome

# Health Surveys Between 2000--2005

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- **In this period public attention began to focus on increasing computerization of medical records in larger health care facilities and expanding use of the Internet by consumers to get health information**
- **Launching of President Bush's Electronic Health Records initiative took place in April of 2004 and set off dialogues on the privacy implications of EHRs**
- **Also debates over the scope of the HHS Privacy Rule drew several major health surveys in these years**
- **The explosion of Identity Thefts and cases of medical data breaches added a concrete harm component to consumer health privacy concerns**

# Institute for Health Freedom Survey, 2000

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- **“Who do you think should be allowed to see your medical records without your permission? For each of the following groups, do you favor or oppose allowing them to see your medical records without first obtaining your permission?”**
- **Set out nine groups, a strange list including banks and “the police or lawyers” along with logical ones such as pharmacists, employers, insurance companies, etc.**
- **No group drew majority support for access. 41% would allow pharmacists and 33% would allow “medical researchers” Support for banks was 5%; government agencies 8%; employers 12%; and insurers 18%.**
- **Starkness of question and absence of any context explains the “it’s my right” response**

# Surveys Between 2006 and Sept. 2007

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- **National EHR development programs, widespread publicity about electronic networks, development and promotion of Personal Health Records (PHRs) all stimulated active healthcare, technology and privacy surveys**
- **Also stimulated by growing use of the Internet by a majority of consumers to find health information, by healthcare organizations to transmit medical data online, and by some consumers to create and store their own PHRs online**
- **Questions about health research and privacy now embedded into whole surveys on healthcare and privacy issues, allowing better total insights into consumer attitudes**

# Harris-Westin Survey, 2006

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- Online survey, focused on use of the Internet for seeking health information, storing PHRs, etc.
- “How willing would you be to provide an anonymous version of your health information (e.g. medications, conditions, etc.) to medical researchers who are trying to discover things, such as which treatments work for certain diseases?”

**WILLING..... 80%**

Extremely willing..... 12%

Very willing..... 19%

Somewhat willing..... 49%

**NOT AT ALL WILLING..... 20%**

- “to provide” is ambiguous; didn’t say how -- general advance or express consent; whether specific notice, etc.

# Markle Foundation Survey, 2006

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- **When asked would they be willing to share their personal health information -- “with their identity protected” -- for various purposes, respondents said:**
  - 73% OK to share with public officials to detect disease outbreaks or 58% to detect bio-terrorist attacks
  - 72% OK “with researchers, doctors, and hospitals to improve quality of care”
  - 71% OK with “appropriate officials to detect medical fraud”
- **However “most Americans say they want to have some control over the use of their information for these purposes”**
- **Essentially finessed the notice/consent issue...**

# Harris-Westin Survey, January 2007

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- **Respondents asked to Agree or Disagree:**
- **“I would give general consent to use my medical records for medical research projects as long as I was guaranteed that no personally-identifying information about me was ever released from such studies.”**
  - **TOTAL AGREE..... 63%**
    - Agree completely..... 25%
    - Agree somewhat..... 38%
  - **TOTAL DISAGREE..... 27%**
- Shows a general willingness but, again, no details on how the consent would be initially obtained, and with what notice

# Genetics Survey, 2007

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- Sponsored by Genetics and Public Policy Center
- **Illustrates probe in a specific medical field**
- 93% support the uses of genetic testing “by researchers, to find new ways to diagnose, prevent or treat disease”
- **66% said they trust “researchers studying genetics to have access to their genetic test results”**
- Only 16% would trust employers and 24% their health insurer; 84% trust their doctor and 82% their spouse
- **Heavy concern over use of genetic tests to limit employment or insurability; favor laws to prevent that and control misuses of such test data**
- Again, no testing of the process by which access to a person’s genetic test information would be supplied to medical researchers

# My Conclusions from the 1993-2007 Surveys

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- **Majorities of consumers are positive about health research and, if asked in general terms, support their medical information being made available**
- **But most of these surveys presented the choice in ways that did not articulate the key permission process**
- **Also, much ambiguity in who are the “researchers,” what kind of “health research” is involved, and just how promised protection of personal identities would be assured**
- **These are obviously issues for the IOM project to explore -- and the IOM-project survey I will report on tomorrow addressed them...**

# My Contacts

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