

# How the Public Views Privacy and Health Research



**Results of a National Survey Commissioned by the  
Institute of Medicine Committee on  
“Health Research and the Privacy of Health Information:  
The HIPAA Privacy Rule”**

Survey Conducted by  
Harris Interactive and Dr. Alan F. Westin

**Report by Dr. Alan F. Westin** Professor of Public Law and  
Government Emeritus, Columbia University; Director, Health Privacy  
Program, Privacy Consulting Group

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**Background: 2007 and 2008 Activities**

This survey report, the round-up of other U.S. and foreign surveys on health research and privacy, and my analysis of the survey's implications developed in two phases:

- In 2007, the IOM Committee on “Health Research and the Privacy of Health Information: The HIPAA Privacy Rule” commissioned Alan Westin and Harris Interactive to conduct a representative national survey of the public's experiences and attitudes toward health research, and the privacy issues involved in using personal medical records in research activities. How the questions were developed, the fieldwork done, the results presented by Alan Westin at the IOM Committee Conference on October 1, 2007, and this Report written and revised are described below.

- In 2008, another IOM Committee, the IOM Roundtable on Evidence-Based Medicine, organized a Workshop on “Clinical Data as the Basic Staple of Health Learning: Creating and Protecting a Public Good.” I chaired its panel on Privacy and Security Issues on February 28, 2008, and presented an updated version of the 2007 survey, reflecting in my analysis events in the health privacy arena as of early 2008. I then revised this report as of March 3, 2008

## **Acknowledgements**

### **For the 2007 IOM Activities**

I am grateful to the IOM Project Committee and its Chair, Professor Lawrence Gostin, for the opportunity to conduct this survey. The sub-committee that was designated to work with me on the Questionnaire was of enormous assistance, and I want to thank its chair, Thomas Croghan, and its members – James Jackson, Mark Rotenberg, Marc Boutin, Paul Appelbaum, Wendy Visscher, and Stanley Crosley—as well as Roberta Ness, a Committee consultant. Roger Herdman, Sharyl Nass, and Laura Levit provided excellent staff support.

At Harris Interactive, Chairman of The Harris Poll Humphrey Taylor and Vice President David Krane were invaluable in the initial conceptualization of the survey, perfecting the questionnaire, and identifying the best cross-tabulations. Harris Interactive is, in my judgment, the premier survey firm in the nation working on the full range of

consumer, citizen, employee, and patient privacy issues, and it has been my pleasure to work with them since our first joint venture – “The Dimensions of Privacy” – in 1978.

My colleague, Vivian van Gelder, provided research and editorial inputs throughout the survey process, and – as always – improved my final product greatly.

Dr. Deborah Peel, chair of the Patients Privacy Rights organization and its 40+ member coalition, was very helpful in the final revision of the Questionnaire.

My partner in Privacy Consulting Group, Robert R. Belair, provided his usual wisdom and balance to the entire project.

## **2. For the 2008 IOM Activities**

I am grateful to Dr. J. Michael McGinnis, Executive Director of the IOM Roundtable on Evidence-Based Medicine for including the 2007 survey results and my analysis of them in the IOM February Workshop on clinical data as a public good. Alex Goolsby, Dan O’Neill, and Katherine Bothner of the NAS project staff were most helpful in arranging the Privacy and Security panel that I chaired at the workshop. The members of this panel were Marcy J. Wilder of Hogan & Hartson; Elliot E. Maxwell of John Hopkins; and Alexander D. Eremia from MedStar Health.

**Alan F. Westin**

My contact information:

Email:

Telephone:

Fax:

Postal:

**The IOM Committee and the Objectives of the 2007 Survey**

A committee convened by the Institute of Medicine was assembled to “investigate the effects on health research of the Privacy Rule regulations implementing the Health Insurance Portability and Accountability Act of 1996 (HIPAA)...” The Committee was tasked to consider a wide range of study types and types of health researchers, and cover both profit and non-profit sponsors. It would review the provisions and administration of the Privacy Rule relevant to health research, examine the potential impact of the Privacy Rule on public health research, and “consider the needs for privacy of identifiable personal health information and the value of such privacy to patients and the public.”

“As data and evidence allow,” the committee specified, “the needs and benefits of patient privacy will be balanced against the needs, risks, and benefits of identifiable health information for various kinds of health research. The committee will formulate recommendations for alterations or retention of the status quo accordingly.”

### **What the IOM Survey Set Out to Learn**

To assist its work, the IOM Committee commissioned Alan Westin and Harris Interactive to develop a national survey that would collect reliable public opinions on a set of key issues germane to the Committee’s assignment:

- How interested is the public in the results of health research?
- How does the public view the overall health privacy scene today?
- How many persons have participated in a health research study?
- What are the details on and experiences with such studies?
- How many persons were invited to have their PHI used in a health research study but declined -- and why?
- What kind of notice and consent does the public want before their PHI is used in health studies?
- What kind of privacy harms worry those respondents who want to have express notice and consent before their PHI is used in health research?
- What are the significant demographic variations for key findings?
- How do the survey findings relate to the privacy and health research issues the IOM Committee is considering?

### **Developing the Survey**

As background for designing this survey, Westin prepared for the IOM committee a summary of questions on health research and privacy asked in previous published national surveys in the U.S. from 1993 through September of 2007. This summary was presented by Westin at the first day of the IOM Committee's October 1-2 public session. (We have reproduced the text of this presentation in Appendix D to this Report.)

Successive drafts of the new survey questionnaire prepared by Alan Westin were reviewed by Committee members and revised to reflect their valuable inputs. The final version was then reviewed and edited by David Krane, Vice President, Harris Interactive.

## **Survey Methodology**

The survey was conducted online by Harris Interactive, between Sept 11 and 18, 2007, with 2,392 respondents. Both closed and open-ended questions were used. The full questionnaire, with top line results, appears in Appendix A of this report. The results were adjusted by Harris to be representative of the total adult U.S. population in 2007, estimated at 225 million persons, not just those who go online. (A more detailed methodology description is on page 1 of the Questionnaire, in Appendix A.)

For analytic purposes, standard demographics for cross-tabulations were collected for region, age, generation, gender, race, party ID, education, income, marital status, children in the household, sexual orientation, disabilities, political philosophy, and employment.

In addition, a set of custom health demographics was created from respondents' answers to questions about their overall health status, whether they have been caregivers, whether they have or had six specified types of health conditions, and whether they have had a genetic test.

A final set of custom cross-tabulations was created based on respondents' answers to nine selected questions. These include whether respondents have participated in a health research study and information about their experiences; whether respondents were ever invited to participate in a health research study but declined, and why; and how respondents would want to be notified and to decide whether their medical records could be used in health studies.

Generally, we report as a significant demographic variation a group with a 5% or higher variation from the total public's response, from one of our demographic, health-aspect, or attitudinal sub-sets. When the public total is 18% or less, we use a 3% or 4% higher variation.

To avoid interrupting our presentation of the main flow of findings, we have put into Appendix B the demographic variations for most of the questions explored in the survey, and include in this main report only those variations that seem of particular importance to the survey's policy concerns.

While we usually reproduce the exact question and response categories in reporting the results, we have not always done so in this report. Readers can find all of the exact questions and response alternatives in the Questionnaire in Appendix A.

From time to time, we use the abbreviation PHI to refer to personal health information; EHRs to refer to electronic health records; and PHRs to refer to personal health records, usually in electronic formats.

### **Strengths and Limitations of Survey Research**

Survey research combines art and science. The scientific aspects include many different components such as relying on a survey firm's expertise in creating representative samples, conducting the fieldwork, designing custom cross-tabulations, preparing data reports, and applying statistical analyses to the data acquired. The art aspects - sometimes provided by the survey firm's specialists in a topical area or by outside experts in the field -- include selecting the topics, developing the wording of questions, framing the responses provided, analyzing the relationship and potential influence of questions to each other in the survey process, presenting the question-by-question results, and drawing policy implications of the survey trends, including comparisons to the results of other surveys on the topic.

A central issue in survey research is the degree to which the sample used is truly representative of the population being surveyed - such as the total adult public (18 years and older); or persons who play video games; or persons who go online; or persons who say they will vote in the next presidential election. Based on the number of respondents surveyed, some survey firms will present a calculation of the sampling error for their



survey, such as plus or minus 2% when the sample is about 2000 respondents or 3% when the sample is about 1,000. These margins are said to be the percentages greater or lesser than a wholly accurate representation of the population being surveyed.

Harris Interactive, which was the survey firm for the IOM survey, does not provide sampling errors for their surveys, because they believe that there are multiple factors that can affect representativeness. Their explanation of representativeness appears at the beginning of Appendix A to this report, at the opening of the full Questionnaire top line document. It should also be noted that the smaller the sub-sample adopting a position or having an experience, the weaker the inference of representativeness that should be drawn (e.g. if only 5 or 10% of the total sample takes that position or has that view.)

In reporting the results of our survey, I will follow the general practice of saying that a given percentage of the survey respondents represents such and such a percentage of “the total adult public.” This is the typical way most surveys project the respondents' answers as the attitudes or opinion of that percentage of “the adult public.”

In addition, from time to time, I will use the July 2006 U.S. Census estimate of U.S. adults aged 18 and over (225,000,000) to indicate “approximately” how many individuals a given percentage of the respondents represents in the total adult population. This approximation would also be subject to a margin of error calculation, if that were used.

Following a widespread convention in survey research, respondents are generally not asked simply if they are for or against some issue, or whether they agree or disagree with a statement but, rather, they are given a scale or spread of responses. For example, we use Agree Strongly, Agree Somewhat, Disagree Somewhat or Disagree Strongly, or whether respondents consider a policy Very Important, Somewhat Important, Not Very Important or Not Important At All. We have followed this convention, reporting the total who Agree or Disagree or consider something Important or Not Important, but also showing the percentages that choose Strongly or Somewhat Agree or Very or Somewhat Important. Frequently, we comment on the policy significance of respondents choosing the “somewhat” over the “very” or “strongly” response.

One other point needs to be made about privacy surveys in particular. When consumer issues are the focus, experts have noted that while very large majorities say they are concerned about their privacy, both on and off line, the reality is that most consumers will supply their personal information or patronize profile-collecting web sites if the consumers feel this is very useful and a valued benefit to them. Most consumers will also not use a variety of privacy-protecting tools that could safeguard their personal information from abuses, because using these tools is seen as inconvenient or impeding expected efficiencies in consumer processes. In short, consumer convenience often trumps professed privacy concerns in the real world of consumer affairs. (Creation of the national FTC's "Do-Not-Call system for blocking marketer telephone calls illustrates that if the intrusions are particularly offensive and an easy-to-use register process is offered, a majority of consumers will enroll, and have their privacy wishes enforced.)

Patient concerns over health information privacy are clearly stronger than general consumer-business privacy concerns. However, it is wise to appreciate that if benefits from personal health-information disclosure are seen by the public, or especially by sub-groups with particular serious health problems, a similar benefit-risk analysis will take place, whatever the high expressions of health privacy concern may show up on health-information privacy surveys.

With these explanations, we turn to the question-by-question report on the survey results.

## **Interest in Health Research**

As a baseline, we wanted to establish how much the public today is interested in following health research findings, and to use such an "interest" segmentation of the public when analyzing our privacy-and-research question responses. We asked:

*“How interested are you in reading or hearing about the results of new health research studies, such as the causes and prevention of diseases, effectiveness of new medications or treatments, findings of genetic effects, ways to enhance wellness, evaluations of medical facilities and operations, successful and unsuccessful diets, and similar topics?”*

Mirroring other survey findings, as well as the 80% of online users who say they go to the Internet to get health information, 78% of our respondents say they are interested in these health research results (31% very; 47% somewhat). Twenty-two percent say they are not interested (14% not very, 8% not at all). (Groups registering higher than this 78% are listed in Appendix B.)

(A 2006 survey by Research America, the only previous survey we are aware of that explored public attitudes toward health research in depth, found that 95% of the public considered “health-related research” to be very or somewhat important as a national priority, while 51% said the “national commitment” to such research should be higher, and with increased funding.)

### **Health Profile of the Adult U.S. Public**

Earlier surveys on health privacy have shown that a person’s health status and medical conditions have significant effects on that individual’s attitudes toward health privacy and data security issues.

To create a profile of such characteristics, and to identify the sub-groups for cross-tabulation with the substantive questions, we asked respondents to indicate, overall, the state of their health. The responses were:

Excellent.....	14%	(about 32M)
Pretty Good.....	61%	(about 137M)
Fair.....	22%	(about 50M)
Poor.....	3%	(about 7M)

When we asked whether respondents had “been a caregiver for a family member with a chronic or serious medical condition,” 23% said yes, representing about 52 million persons. And, when asked whether they had ever had a genetic test, 5% said they had, representing about 11 million persons.

We then listed six types of medical conditions and asked whether respondents had ever had or currently have each of these. The results were:

Used a psychologist, psychiatrist, mental health professional.....	27%	(about 61M)
Had a long-term medical condition such as diabetes or epilepsy .....	16%	(about 36M)
Had major physical or mental disability.....	11%	(about 25M)
Had serious illness such as heart attack, stroke or cancer.....	9%	(about 20M)
Had any sexually-related health condition.....	7%	(about 16M)
Had an alcohol or drug abuse problem.....	6%	(about 14M)

## **Overall Public Views on Health Privacy, Health Research and Health Researchers**

To create a snapshot of the public’s overall orientation toward health privacy and health researchers, we presented respondents with four declaratory statements and asked them to Agree (Strongly or Somewhat) or Disagree (Strongly or Somewhat) with each. The four statements were rotated to the respondent population to minimize any effects of presentation order. (We used such randomization throughout the survey.)

### **A. Trust in Health Care Providers**

To get an overview of public attitudes toward direct health care providers, we presented this statement:

***“I generally trust my health care providers -- doctors and hospitals -- to protect the privacy and confidentiality of my personal medical records and health information.”***

Paralleling the findings of many previous health privacy surveys, there was high public trust in providers: 83% of respondents agreed with the statement (30% strongly, 54% somewhat), while 17% disagreed (12% somewhat, 5% strongly). That 54% say they trust only “somewhat” suggests that firm trust in providers does not command a majority of the public but is held by slightly less than a third, while a majority of the public (54%) is only generally in agreement with the statement.

## B. Trust in Health Researchers

Using a general and undefined term – “health researchers” -- we asked respondents to agree or disagree that:

***“Health researchers can generally be trusted to protect the privacy and confidentiality of the medical records and health information they get about research subjects.”***

Sixty-nine percent of respondents said they agreed (11% strongly, 58% somewhat) and 31% disagreed (24% somewhat, 7% not at all). While this was a lower level of trust than held for providers (by 14%), it still represents more than two-thirds of the public holding a generally positive view of protection of privacy and confidentiality in health research.

However, the fact that 58% are trustful of researchers only somewhat suggests that such trust would probably vary according to the specific type of health researcher and the particular nature of the research topic (a point we will return to later in this Report).

## C. Views on The State of Health Privacy Protection Today

Respondents were asked to Agree or Disagree that:

***“The privacy of personal medical records and health information is not protected well enough today by federal and state laws and organizational practices.”***

Past Westin/Harris privacy surveys sometimes presented this question for agreement or disagreement in positive terms (“privacy...is protected well enough today...”) and sometimes negatively (“not protected well enough...”), as we did here. Generally, we find that respondents register similar attitudes whichever way the initial statement has been framed.

Here, 58% agree that medical-records privacy is not sufficiently protected today by law and organizational practices (17% strongly and 41% somewhat) with 42% disagreeing (10% strongly and 33% somewhat). There were only a few demographic variations present: persons in only fair health felt privacy not well enough protected

today, by 64%; persons 65 years of age or older by 66%; and persons who had a genetic test by 67%.

A clear implication of this 58% skepticism is that the HIPAA Privacy Rule and its enforcement does not seem to have given a national majority confidence in current national health privacy protection, though only 17% of the 58% total hold that negative view strongly. To some extent, this attitude is probably conditioned by the continuing stream of stories in the mass media about breaches of personally identified medical data – through improper disposal of hard copy records, thefts of laptops with patient’s or insured’s PHI, and medical ID thefts.

Another contributing factor in this 58% concern arises from the legal but privacy-conflicting supply (or required submission) of PHI for life insurance or employment decisions, when adverse health conditions of various types result in denial of these important consumer benefits. This registers the fact that consumer concerns about privacy and anti-discrimination are twin components, with privacy – don’t collect it or don’t disclose it beyond the primary use – the way for consumers to avoid having their health conditions, especially any genetic test results, used by insurers, employers, or government programs to exclude individuals or charge higher premiums for services.

Overall, this 58% overall belief in inadequate health privacy protection helps to explain some of the later attitudes we found on health research and privacy issues, as we will note.

#### **D. Sensitivity to Health Researchers Seeing Their Medical Records**

To test possible underlying factors in consumer attitudes toward their PHI being used in health research, we provided this statement:

***“Even if nothing that identifies me were ever published or given to an organization making consumer or employee decisions about me, I still worry about a professional health researcher seeing my medical records.”***

Past surveys exploring health privacy and health research issues have tried to understand just what troubles some consumers about professional health researchers

using their medical records, even where protection of the consumer's identity is promised. What we found was a U.S. public divided right down the middle on this matter: 50% agree that they would still worry about such researcher access (12% strongly and 38% somewhat) and 50% disagree and would not be worried (15% strongly and 35% somewhat)

The worried 50%, I believe, are expressing the "pure privacy" position -- a sense of violation or intrusion if their sensitive health information is seen by an unknown third party, even if "research" (not insurance or employer access) is involved; even if a promise of anonymity is offered; and even if no actual harm to reputation is likely to result from such research activity.

On this sensitivity reading, we found a number of groups significantly higher (by 5% or more) in not wanting researchers to see their medical records. Among the standard demographic groups, these were respondents living in the East (56%), those between 50 and 64 years of age (56%), those 65 years or older (56%), blacks (60%) and Hispanics (56%). In terms of health status, higher respondents were those in only fair health (55%), those who have had a genetic test (55%), and persons with disabilities (55%).

### **Belief That Their PHI Was Disclosed Improperly**

To probe whether consumers believe that their PHI has ever been disclosed improperly, and by whom, we repeated a Westin/Harris question asked in 1993 and again in 2005. We asked respondents:

***"Have any of the following organizations involved in your health care ever disclosed your personally identified medical or health information in a way you felt was improper?" (select all that apply)***

Twelve percent of respondents, representing about 27 million adults, believed that one of the following organizations had disclosed their information in a way they felt to be improper:

A doctor who treated you.....	4%
A hospital or clinic where you received services.....	3%

A health insurance company of which you were a member.....	3%
A life insurance company you applied to.....	2%
A pharmacy/druggist you used for prescriptions.....	2%
An employer who had your medical or health-insurance records.....	2%
A government health program, such as Medicare.....	1%

What is interesting about these responses is that direct care providers – doctors and hospitals/clinics – were slightly more likely to be perceived by these respondents as having made improper disclosures than life insurers, employers or pharmacists.

### **Declined to Participate in a Health Study**

Health researchers who must give notice and obtain consents from consumers to use their medical/health records worry about refusal rates and their potential for producing a sample unrepresentative of the population and issues being studied. To probe this issue, we first asked respondents:

*“Have you ever been asked to have your personal medical or health information used in a health research project but you decided not to participate?”*

Eight percent said yes, representing about 18 million adults. (Groups scoring higher are listed in Appendix B.)

We then asked this 8% which of seven possible listed reasons for not participating might have accounted for their decision, and to designate all of the reasons that applied in their case. The results were:

**30% -- “concerned my personal information would not be kept private and confidential”**

**24% -- worried that “participation would be risky, painful or unpleasant”**

**22% -- “didn’t have trust in the people or organization conducting the research”**

**16% -- “would not have helped my health conditions”**



**6%** -- **“would not have helped the health of present or future members of my family”**

**6%** -- **“didn’t think the research was important”**

**5%** -- **“would have been costly for me or my family**

Concern about confidentiality emerged as the most frequently chosen reason for not participating in health research, expressed by almost a third of this group of respondents and representing about 5 million adults.

The 2006 Research America survey mentioned earlier provides some useful additional material. When asked if they would participate in a “clinical research study” if asked, 63% said they would. And when asked what factors would be important to them in deciding whether to participate, 86% said “privacy and confidentiality” (with 58% saying that would be a major concern and 28% saying it would be “some concern”)

### **Participated in a Health Research Study**

A major objective of the survey was to obtain a representative sample of persons who had been invited to participate in a health research study, who had accepted, who would describe that experience in narrative answers, and who would also answer a set of questions about their satisfaction with the event. We also wanted to learn details of the demographics of these research participants. We asked:

***“Have you ever participated in a research study that used your personally identified medical or health information? This might have been a clinical trial, a university study, a public health study, a mental health project, a study of health services, or other type of medical or health research.”***

Thirteen percent of respondents, representing about 29 million adults, said they had participated in a health study (87% said they had not). This provided us with 349 actual respondents whom we then questioned in detail about their participation. (Groups higher than 13% are shown in Appendix B.)

We collected the following information, in narrative responses:

- year the research was conducted
- organization conducting the research
- how the participant was recruited
- what the research was about
- what kind of personal medical or health information was used
- whether testing a new drug or procedure was involved, and
- whether genetic information was used

The Harris staff coded the responses, and their figures appear in the top line results of the Questionnaire, in Appendix A. Since these are not directly relevant to the privacy policy issues this survey report is presenting, we will not be analyzing them here.

What we went on to ask study participants was a series of questions nominated by the IOM Committee as important to collect for the Committee's tasks:

***“How informed did you feel about the purposes and procedures of the study before it started?”***

A high 85% percent of participants felt they were informed (50% very, 35% somewhat), with 15% saying they were not informed (12% not very, 4% not at all).

We then asked respondents:

***“Where did the researcher get your personal medical or health information used in the study?”***

- 69% said it was supplied in a questionnaire or interview
- 38% by a sample of blood or tissue or test result
- 25% through a medical record from a doctor
- 20% through a medical record from a health care facility
- 4% from a disease register; and
- 4% from a prescription record from a pharmacy.

Seven percent gave another response, and a further 12% said they didn't know or remember.

Next, we asked about these participants' recollection of a confidentiality pledge in these studies:

***“Were you given a promise that no personally identified medical or health information of yours used in the study would ever be given to anyone outside the research staff?”***

Three quarters of the participants (76%) said yes, and only 3% said no. But one in five respondents (21%) said they were not sure whether they were given such a promise. While the explanation might be that they just did not remember a promise being given, it also suggests that, for these respondents, a confidentiality pledge was not so important that they had paid it enough attention originally to be able to recall whether it was or was not provided.

The survey then asked respondents:

***“To your knowledge, was any of your personally-identified medical or health information used in the study ever given to anyone outside the research staff?”***

Two percent said yes, 59% said no, and 38% said they don't know or can't recall. (This 2% was made up of only 10 respondents.) We can read this result as a very strong finding that the great majority of participants either felt that no personally-identified medical or health information was disclosed or had no knowledge that this had occurred.

While our intention in the question was to probe improper disclosures, half of the 10 respondents who reported disclosures said these were to other researchers or research institutions, not to employers, insurers, government, friends or other such “improper” receivers.

To learn their general evaluation of the health study experience, we asked all of the study participants:

***“Overall, which of the following statements best describes what you felt about participating in this health research study -- very comfortable, somewhat comfortable, not very comfortable, not comfortable at all?”***

Eighty-seven percent said it was a comfortable experience (58% very, 28% somewhat) and 13% not comfortable (10% not very; 3% not at all).

### **How Should Researchers Seek to Get Individuals' PHI?**

A central focus of the IOM project is the question of what kind of patient or consumer notice and consent should be required (as it is now under the HIPAA Privacy Rule) to obtain personally-identified medical records and personal health information for health research. In turn, this involves exploring the various alternative circumstances under which consumers are willing to have their PHI used in health research.

This has been an issue probed in more than a dozen surveys on health privacy issues since 1993, with a wide variety of question formulations. Some of these named specific types of researchers; others designated the topics of research; and some also mentioned the societal interests served by the research. Some spelled out a specific consent process by which patients/consumers would be asked and others mentioned PHI being used with just a general advance consent from the consumer. (See the Westin Summary of these survey questions in Appendix D.)

The IOM Committee and I went through five iterations to get a question that we felt captured the right elements. Because our questionnaire was online, we were able to present a detailed set-up question, hopefully with all the right elements, and in a way that would not have been feasible in a telephone survey.

What we did was to spell out the ways that health research studies are constructed, what the laws require and research practices carry out by way of privacy and data security, why some commentators believe only notice and express consent serves patients fully, and why this concerns health researchers. By laying out all of these elements, and with a pro and con statement of alternative positions, we hoped to present respondents, as we said above, “with all the right elements” to capture how respondents would balance the research and privacy interests.

Our question was as follows:

***“When conducting health studies, researchers often want to select patients whose personally-identified medical or health information is contained in patient records. Sometimes, the patients will be invited to give general approval to have their***

*records used in future health research. Or, the researchers may seek patient consent to join a specific study. For some studies, researchers seek to include the patient information automatically in the research, without seeking any consent.*

*“The researchers promise, as required by federal and/or state health privacy laws, that no personally-identified health information of research subjects will be disclosed outside the research group and that security measures will be applied to protect the data.*

*“Researchers must also have the project approved by a Human Subject Protection or Privacy Board. These groups decide whether the importance of the research and the safeguards promised outweigh potential risks to privacy or data security, or other risks to research participants.*

*“Some say that patient interests in privacy and data security are not protected well by such procedures, and there is little policing of researcher practices. It is argued that patients must be asked for consents -- either specific or general -- for all health research.*

*“Health researchers say many patients would not respond or agree to requests for permission, creating a sample that would not accurately reflect the group whose health condition or status are being studied. They also say obtaining permission for each health study would be very costly and time-consuming, and there is no pattern of health researchers disclosing the personal medical information of research subjects.*

*“In these situations [which one of the following answers] is closer to your opinion?”*

Following this presentation, we gave respondents five alternative answers (in randomized order), and asked them to select the one that best reflected their view. Going from most permissive to most restrictive, the responses were:

- **“Researchers would be free to use my personal medical and health information without my consent at all” ..... 1% (about 2M)**
- **“I would be willing to give a general consent in advance to have my personally-identified medical or health information used in future research projects without the researchers having to contact me”..... 8% (about 18M)**
- **“My consent to use my personal medical and health information would not be needed as long as the study never revealed my personal identity and it was supervised by an institutional review board”..... 19% (about 43M)**

- **“I would want each research study seeking to use my personally-identified medical or health information to first describe the study to me and get my specific consent for such use”..... 38% (about 86M)**
- **“I would not want the researchers to contact me or to use my personal or health information under any circumstances”..... 13% (about 29M)**
- **Not Sure ..... 20% (about 45M)**

It is important to note at the outset that a fifth of respondents -- 20% -- said they were not sure. Since five positions were spelled out, reflecting what we felt were all the logical policy alternatives, it would seem that these respondents had such conflicting feelings about what they favor or would do in this situation that they were simply not able to make a choice.

Looking at the patterns in these five responses, we see that 57% would agree to have their PHI used in a health research project only if privacy-oriented conditions are met – 38% requiring notice and express consent case-by-case and 19% with advance agreement only if assured that their identity was protected and the project was supervised by an institutional review board.

### **Demographics on How Permission Should Be Obtained**

The demographics on the various responses to this central question were of high interest to the IOM Committee, as they are likely to be to everyone interested in health-research-and-privacy tensions.

- Where we found 13% saying don't use my PHI and don't ever contact me, we used 3% or higher to designate stronger groups. This showed that Easterners, those 65 or older and those making \$35,000 or less annually each took this view (at 16%), as did 21% of persons in poor health, 19% of persons not interested in health research, 18% of persons not well informed about the study they participated in, and 28% of those who were invited to participate in a health study but who declined.

- At the other end, groups higher by 3% than the 8% who would give advance general consent without consultation were only two – persons in excellent health (12%) and liberals (11%).

- Groups higher by 5% or more than the 19% who would require identity-protection and institutional review board supervision were: persons 25-29 years of age (24%), post graduates (26%), study participants (25%), persons who were invited but declined participation in a study (25%), participants who were well informed (26%), persons comfortable with participation in a study (26%), persons in alcohol or drug programs (30%) and persons who have had a genetic test (24%).

- Looking at the 38% of the public who want notice and specific consent for their PHI to be obtained for health research, sixteen groups were higher by 5% or more. These are largely the groups normally reflecting higher sensitivity on PHI privacy issues:

- Among the standard demographic groups, blacks were higher at 45%; college graduates at 46%; single women at 43%; persons with \$35,000 to \$49,000 income at 45%; and persons aged 50-64 at 43%.

- Among those groups classified by health aspects, persons with long-term health conditions were higher at 45%; those who used mental health services at 44%; persons with a sexually-oriented condition at 49%; and persons who have taken a genetic test at 48%.

- In terms of attitudes and experiences, those very interested in health research were higher at 46%; participants in health studies at 44%; those feeling very well informed in a study at 51%; and those very comfortable in a study at 49%.

The fact that 44% of persons who have participated in a health study feel that notice and express consent should be the rule – six percent higher than this position in the total public -- is especially interesting to note. Of equal interest is the fact that these participants were also six points higher than the total in choosing identity-protection and institutional review board supervision as their model. Together, then, participants in

health studies by 69% would require privacy-based qualifications before allowing their PHI to be obtained by researchers.

## **Reasons For Seeking Notice and Express Consent**

We provided four possible reasons to those 38% of respondents who said they would want notice and express consent, and asked them to choose all of these reasons that applied:

- **80% -- “I would want to know what the purposes of the research are before I consent”**
- **62% -- “Knowing about the specific research study and who would be running it would allow me to decide whether I trusted them or not.”**
- **54% -- “I would be worried that my personally-identified medical or health information may be disclosed outside the study”**
- **46% --“I would want to know whether the research could help my health conditions or those of my family”**

Looking at groups that scored higher (by 5% or more) than the 54% who worried that their PHI might be disclosed outside the study, we found:

- Ages 18-24..... 63%
- Ages 25-29..... 63%
- Ages 40-49..... 59%
- College grads..... 60%
- Gay..... 61%
- Liberals..... 60%
- Not interested in health research..... 62%
- Didn’t join study/privacy..... 76%
- Believed their PHI disclosed improperly.. 61%
- Excellent health..... 65%



## Potential Privacy Harms That Would Concern Some Consumers

Our next step was to ask the “notice and express consent” seeking respondents who said they were worried about their PHI being disclosed “outside the study” to indicate – from a list we provided – what potential harms concerned them. The results were a solid catalog of rational health privacy concerns:

- **77% -- “I would feel violated and my trust in the researchers betrayed”**
- **67% -- “I could be discriminated against in getting health insurance”**
- **56% -- “I could be discriminated against in getting life insurance”**
- **44% -- “I could be discriminated against by an employer”**
- **39% -- “I could be discriminated against in a government program”**
- **33% -- “I could be embarrassed before friends, associates or the public”**

That between 39% and 67% of these respondents felt that discrimination in their consumer opportunities and benefits was the harm in outside disclosure that concerned them underscores our earlier observation about the close linkage of privacy and anti-discrimination when the handling and security of PHI is involved – and in research settings, not just direct health care.

## Comparisons With Parallel Surveys in Other Nations

Questions on health research and privacy have been placed on national surveys in several other nations between 2003 and the present, specifically Canada, the United Kingdom, and Australia. We summarize their findings in Appendix C.

In general, despite national health care systems very different from the U.S., and the presence in these nations of strong privacy protection laws, their results echo our U.S. findings. Majorities want some level of notice and consent for their PHI to be used in health research -- notice so that they know who would be doing the research and the purposes for which it would be conducted and consent so that they feel they have not lost all control over how their PHI is being used, even for socially-useful research.

## **2007 Westin Commentary on the Survey Findings and Their Implications**

As noted in the opening of this report, the IOM Committee commissioned this survey as an input to its project investigations and policy consideration. As such, it represents one resource in a wide-ranging set of studies the Committee has obtained on conducting health research under the HIPAA Rule, including other relevant public opinion surveys, health research expert assessments, and advocacy presentations reflecting the full range of policy positions on the Committee's issues.

While I have already commented on the results of many questions as I presented them in the main report, it seems useful for me to offer, in a conclusion section, some overall judgments on how I see the IOM survey results relating to the health research and privacy issues under Committee consideration.

These comments draw on my experiences in serving as the advisor to seven other national surveys on health privacy issues from 1993 to the present; in conducting field studies of how computerization from the 1970s to today has affected privacy interests and prompted protective laws and organizational policies; in serving as a privacy consultant since the 1960s to several dozen health care institutions, research organizations, and healthcare technology firms; and as an expert witness advocating federal health privacy legislation in various Congressional hearings since the 1970s.

Of course, my comments do not represent the opinions of either the 2007 or 2008 IOM Committees to which the survey was reported.

### **1. The Intensity of Health Privacy Concerns**

Our results confirmed what many other recent and current surveys have found – that large majorities of the public continue to hold strong privacy perspectives in the handling of their PHI, especially when secondary uses are involved. Our survey found that 58% of the public does not believe that federal and state laws and organizational practices provide enough privacy protection today for consumers' personal health information. Though we did not ask about it directly, other surveys have found that concerns over the security of health information and continuing well-publicized data breaches involving PHI are part of this "privacy" concern.

This suggests that any set of solutions to the process of obtaining PHI for health studies will have to find ways to meet – and satisfy – the privacy and data security concerns of a rather skeptical public majority.

It also suggests to me, apart from the IOM project, that writing up-dated health privacy protections for when health care reform is taken up in the next Congress, or when federal funding for EHR programs is considered, will draw a strong advocacy drive and much public support. (Indeed, this is already taking place in Congressional consideration of EHR funding bills. See, for example, Proposed Amendment to S. 1693, introduced by Senator Leahy (D-Vt), “to provide for the privacy and security of protected health information in the adoption of a nationwide interoperable health information technology system.”)

## **2. Interpreting The Recruitment Alternatives**

As we reported, none of the five alternative responses to our question about respondents’ willingness to have their PHI used in health research could command a majority, and 20% of respondents could not even make a choice.

The largest group -- 38% -- would insist on having the study described to them and obtaining their specific consent. Many important demographic groups chose this option by 43% to 51%, and persons who have actually participated in health studies hold this view at 44%. Though these respondents were informed in the set-up question that researchers were concerned about the costs, delays, and sampling issues in requiring such notice and express consent, four out of ten respondents did not find those arguments sufficient to persuade them to forego the notice and specific consent procedures.

I see a possibility that satisfying the first condition – describing the study and its executors – might sometimes obviate the desire for express or positive consent from some members of the 38% group we identified. In some cases – namely, where the research is seen by the individual as socially valuable and the researchers as “trustworthy” - there might be an opt out choice. That is, having been given a description of the purposes of the research and the organization/researchers conducting it, a patient might be informed that his or her PHI would be used unless the potential participant

objected.

We did not pose that procedure in the IOM survey. But my sense, gained from having conducted many surveys where the opt-out and opt-in choices were posed in various consumer settings, is that a significant segment of the 38% privacy-concerned respondents would find full notice and an opt-out choice to be satisfactory. Having a “privacy veto” could well be seen as acceptable for what were judged to be socially-valuable health studies by trusted researchers.

I found it especially interesting that only 19% of respondents were willing to have their PHI used without consultation if their anonymity was assured and there was IRB review. Those two elements make up what many health researchers hope potential participants in health studies would find sufficient.

However, I believe that if those two elements were combined with notice (the study description) more than 19% might be willing to have their PHI used without a specific choice. I take this view because several surveys summarized in Appendix D suggest that the specific nature and goals of a research study and perceptions by respondents about the trustworthiness and social value of various types of health researchers are key factors in an individual’s decision whether to participate on a health research study.

### **3. Implications of the Survey for Future Health Data Systems**

While the IOM study focuses on the here and now, it seems to me valuable to think about the implications of the IOM survey for emerging EHR programs and Net-based PHR systems. While still limited, these programs promise to create vast pools of PHI which – if they could be used in health research – could dramatically enhance epidemiological, public-health, drug-impact, genetic, and other fundamental health studies. Many health researchers see such “health data mining” as a major goal for health research in the coming decades.

However, getting such uses accepted would, I believe, require institutionalizing the two fundamental conditions that the IOM survey documented as majority public conditions – description of the studies to be undertaken and an individual choice

mechanism – whether an opt-out or an opt-in. If notice and a choice mechanism were acceptable to EHR/PHR participants, there could even be solicitation of a general advance acceptance by individuals to have their PHI used – with anonymity assured and IRB review – for designated classes of health studies and by specified types of researchers.

It would be important to do surveys of EHR and PHR system participants to learn what processes of notice and consent were acceptable and in what different kinds of research situations, and then to do post-study surveys to assess satisfaction levels with the conduct and outcomes of the studies. This would also help health researchers to engage in more of a partnership relation with health-data subjects, and thereby enhance overall public support for health research.

### **Westin 2008 Commentary on Survey Findings and Their Implications**

While the 2007 IOM project focused on whether the HIPAA Privacy Rule needed to be modified in light of stronger privacy concerns or legitimate researcher needs, the 2008 IOM meeting focused on what was needed to have clinical data collection and a system of evidence-based medicine accepted as a “public good.” When reviewing the 2007 survey findings from that perspective, I identified at the February 28<sup>th</sup> IOM Workshop six steps that seemed to me vital to support such a “public good” campaign.

1. As part of Congressional measures in 2008-2009 to fund and promote health information technologies and EHRs, such as bills offered by Senators Edward Kennedy and Hillary Clinton, it seems to me essential to write a new health privacy code for the increasingly electronic health data environment. (See, for example, the health privacy bills introduced by Senator Patrick Leahy and Congressman Ed Markey.)

2. The leading new online PHR storage and updating services – such as Google Health and Microsoft’s HealthVault – have adopted excellent user control and privacy policies, and their experiences will provide important learning on successful privacy management of such data systems. At some point, and with proper notice and consent mechanisms, these potentially huge patient-population sites could greatly enhance evidence-based health data research. But these systems are not covered entities under

HIPAA, and extending basic legal privacy rules to these online systems seems to me essential.

3. Many privacy surveys have shown that providing independent audit and verification procedures – showing that an organization is following its privacy and security policies and identifying any shortcomings – is an essential ingredient in assuring an often-skeptical public that they can trust a personal-data using system. Building such an independent audit process seems to me especially needed for EHR and online-PHR systems. (For one example of such a health-information verification program, see the process being offered by the Patients Privacy Rights Coalition, described at: [www.patientprivacyrights.org](http://www.patientprivacyrights.org))

4. “Patient empowerment” is an often-voiced mantra of U.S. health system reform, and this needs to be incorporated in easy-to-use patient control processes. Fortunately, new technologies are emerging that would register a patient and then act as a “switch” to connect personal-health data holders to data-seekers, by informing the member patient of the request for his or her health data, and letting the patient decide, but never storing the patient’s health information in the Switch facility. This avoids patients having to trust the switch facility, or worrying about the facility being forced to hand over their personal health data to third parties under various legal processes. (See, for example, You Take Control, at [www.y-t-c.org](http://www.y-t-c.org))

5. Almost all of the government and foundation funding so far for EHR and health IT has gone into front-end activities – developing interoperable systems and standards, promoting best technologies, identifying privacy and security issues and framing responsive draft policies. What has been lacking has been a program of empirical field studies into how privacy and security practices and patient-education programs on these topics have actually been unfolding in these EHR and IT systems. But now – 2008-2009 – is the time for structured research to examine those issues, with surveys of patients as well as providers, and creating reproducible instruments for evaluation, such as a Patients’ Privacy Satisfaction Survey.

6. If the steps just cited are pursued, a national educational campaign to promote privacy-compliant clinical-data research would be an important step. Our survey showed a potential public embrace of health research, but worries about privacy and data security

standing as impediments. When the research establishment can show that it has addressed the privacy and security concerns effectively, evidence-based medicine could truly come into its deserved place in an electronic world.

## Appendix A: QUESTIONNAIRE AND TOP LINE RESULTS

Harris Interactive Inc.  
161 Avenue of the Americas  
New York, NY 10013

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### IOM Privacy and Research Studies

For Dr. Alan F. Westin

### *Topline*

**Field Dates: September 11 - 18, 2007**  
**Sample size: 2,392 adults, 18 and older**

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#### **Methodology**

Harris Interactive® conducted the study online within the United States between September 11 and 18, 2007 among 2,392 adults. Figures for age, sex, race/ethnicity, education, region and household income were weighted where necessary to bring them into line with their actual proportions in the population. Propensity score weighting was also used to adjust for respondents' propensity to be online.

All sample surveys and polls, whether or not they use probability sampling, are subject to multiple sources of error which are most often not possible to quantify or estimate, including sampling error, coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments. Therefore, Harris Interactive avoids the words "margin of error" as they are misleading. All that can be calculated are different possible sampling errors with different probabilities for pure, unweighted, random samples with 100% response rates. These are only theoretical because no published polls come close to this ideal.

Respondents for this survey were selected from among those who have agreed to participate in Harris Interactive surveys. The data have been weighted to reflect the composition of the adult population. Because the sample is based on those who agreed to participate in the Harris Interactive panel, no estimates of theoretical sampling error can be calculated.

#### **About Harris Interactive®**

Harris Interactive is the 13th largest and fastest-growing market research firm in the world. The company provides innovative research, insights and strategic advice to help its clients make more confident decisions which lead to measurable and enduring improvements in performance. Harris Interactive is widely known for The Harris Poll, one of the longest running, independent opinion polls and for pioneering online market research methods. The company has built what it believes to be the world's largest panel of survey respondents, the Harris Poll Online. Harris Interactive serves clients worldwide through its North American, European and Asian offices, and through a global network of independent market research firms. More information about Harris Interactive may be obtained at [www.harrisinteractive.com](http://www.harrisinteractive.com).



**Notes on reading the results**

The percentage of respondents has been included for each item. An asterisk (\*) signifies a value of less than one-half percent. A dash represents a value of zero. Percentages may not always add up to 100% because of computer rounding or the acceptance of multiple answers from respondents answering that question.

**Q1005** Now, some questions about your experiences with and attitudes toward health research, and how medical records are used in these studies.

How interested are you in reading or hearing about the results of new health research studies, such as the causes and prevention of diseases, effectiveness of new medications or treatments, findings of genetic effects, ways to enhance wellness, evaluations of medical facilities and operations, successful and unsuccessful diets, and similar topics?

TOTAL INTERESTED	78%
Very interested	31%
Somewhat interested	47%
TOTAL NOT INTERESTED	22%
Not very interested	14%
Not interested at all	8%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1010** Have you ever participated in a research study that used your personally identified medical or health information? This might have been a clinical trial, a university study, a public health study, a mental health project, a study of health services, or other type of medical or health research.

Yes	13%
No	87%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1015** Have you ever been asked to have your personal medical or health information used in a health research project but you decided not to participate?

Yes	8%
No	92%

**BASE: DECIDED NOT TO PARTICIPATE (Q1015/1) (n=193)**

**Q1020** Which of the following reasons did you have for not participating? If you decided not to participate in response to more than one invitation, please use the most recent invitation for your answers here. Please select all that apply.

[RANDOM]

I was concerned my personal information would not be kept private and confidential  
30%

I worried that participation would be risky, painful or unpleasant  
24%

I didn't have trust in the people or organization conducting the research  
22%

The research would not have helped my health conditions  
16%

The research would not have helped the health of present or future members of my family  
6%

I didn't think the research was important  
6%

The research would have been costly for me or my family  
5%

Other – ANCHOR  
23%

None of these – ANCHOR  
16%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1025** Please tell us about your participation in the health research study. This is important and should include each of the following items. If you have participated in more than one health study, please use the most recent one for your answers.

What year was the research conducted?

2007	11%
2006	8%
2005	8%
2004	5%
2003	2%
2002	5%
2001	4%
2000	8%
1995-99	8%
1990-94	5%
1985-89	5%
1980-84	3%
1960-69	1%
Other 2000-2007	3%
Ongoing	3%
Other	4%
None	3%
Don't know	5%
Refused	1%
NA	8%

What organization conducted the research?

Other university	13%
Pharma company	6%
Hospital	4%
Univ of CA (various)	4%
Doctor's office	3%
VA	2%
Cancer related	2%
Independent research org	1%
Harvard Univ.	1%
Harris Poll	1%
Ohio State University	1%
Women's health	1%
Univ of Wisconsin	*
Government related	*
NIH	*
Univ. of Connecticut	*
Asthma, allergy center	*
Rochester	*
Stanford University	*
Other	19%
None	1%
Don't know	21%
Refused	3%
NA	14%

## How were you recruited to participate in the study?

Doctor/doctor's office/clinic	18%
Ad/notice in newspaper/magazine	15%
Mail	7%
Volunteered/asked doctor	6%
Based on medical condition	5%
Internet	4%
Email	4%
"yes"	3%
Telephone solicitation	2%
TV/Radio ad	2%
Recruited at work/school	2%
Family member	1%
Friend	1%
Brochure/flyer/pamphlet	*
Based on medication I use	*
Harris Poll	*
Other	14%
Don't know	3%
Refused	1%
NA	11%

## What was the research about?

Cancer	5%
Diabetes	4%
Women's health	4%
Blood pressure	4%
Other drug study	3%
Health (general)	3%
Smoking cessation	2%
Cholesterol	2%
Heart study	2%
New medication	2%
Asthma	2%
Weight loss	2%
Allergies	2%
Sleep related	2%
Mental health	2%
Pain management	1%
Depression/anxiety	1%
Skin study	1%
Migraines/headaches	1%
COPD	1%
Bone study	1%
Shingles	1%
Incontinence	1%
AIDS/HIV	1%
ADD/ADHD	1%
Alcohol use	*
Blood clots	*
MS	*
Other	33%
Don't know	4%
Refused	1%
NA	12%

What kind of personal medical or health information of yours was used?

Medical history/doctor's records	14%
Physical exam/other test results	8%
Blood tests	8%
All information	6%
Disease history	6%
Medication usage	5%
General health	4%
Blood pressure	3%
Height/Weight	3%
Age	3%
Questionnaire	2%
Family history	2%
Allergies	1%
Diet/Eating habits	1%
Mental health history	1%
Lifestyle	1%
Cardiac/heart related	1%
Breathing	1%
Lab tests	1%
Pulse	1%
Bone densitometry	*
Demographic information	*
Clinic/hospital records	*
Insurance	*
Disability	*
Other	16%
None	5%
Don't know	8%
Refused	2%
NA	15%

Did the research involve testing a new drug or medical procedure?

Yes	31%
New drug/medication	5%
New procedure/treatment	1%
Topical cream/lotion	1%
Diagnostic test	*
No/nothing	23%
Other	2%
Don't know	2%
Decline to answer	19%
NA	14%

Was genetic test information used in this study?

No	55%
Yes	15%
Other	3%
Don't know	12%
Decline to answer	*
NA	14%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1033** How informed did you feel about the purposes and procedures of the study before it started?

TOTAL INFORMED	85%
Very informed	50%
Somewhat informed	35%
TOTAL NOT INFORMED	15%
Not very informed	12%
Not at all informed	4%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1034** Where did the researcher get your personal medical or health information that was used in this study? Please select all that apply.

RANDOM

Personal health information that I supplied to the researchers by a questionnaire or interview	69%
A specimen or sample of my blood or tissue or results of a test done in the study	38%
My medical record in a doctor's office	25%
My medical record in a health care facility	20%
My medical information from a disease registry, such as a cancer registry, an HIV registry, or other data base	4%
My prescription record in a pharmacy	4%
Some other source – ANCHOR	7%
I don't know or cannot recall – ANCHOR	12%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1030** Were you given a promise that no personally identified medical or health information of yours, used in the study, would ever be given to anyone outside the research staff?

Yes	76%
No	3%
Not sure	21%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1035** To your knowledge, was any of your personally-identified medical or health information used in this study ever given to anyone outside the research staff?

Yes, my personally-identified medical or health information was given to someone outside the research staff.	2%
No, my personally-identified medical or health information was <u>not</u> given to someone outside the research staff.	59%
I don't know or recall if my personally-identified medical or health information was given to someone outside the research staff.	38%

**BASE: INFORMATION WAS GIVEN OUT (Q1035/1) (n=10)**

**Q1040** Please describe what happened when this information was given to someone outside the research staff and how this affected you. If you were embarrassed in your relations with other people or suffered any harms as a patient, consumer, employee, or citizen, please describe these.

Provided to other medical and research institutions	46%
Other	31%
Not applicable	20%
NA	3%

**BASE: HAVE PARTICIPATED IN RESEARCH STUDY (Q1010/1) (n=349)**

**Q1045** Overall, which one of the following statements best describes what you felt about participating in this health research study.

TOTAL COMFORTABLE EXPERIENCE	87%
This was a very comfortable experience	58%
This was a somewhat comfortable experience	28%
TOTAL NOT COMFORTABLE EXPERIENCE	13%

This was not a very comfortable experience	10%
This was not a comfortable experience at all	3%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1050** Please Read the Following Long Statement Carefully:

When conducting health studies, researchers often want to select patients whose personally-identified medical or health information is contained in patient records. Sometimes, the patients will be invited to give general approval to have their records used in future health research. Or, the researchers may seek patient consent to join a specific study. For some studies, researchers seek to include the patient information automatically in the research, without seeking any consent.

The researchers promise, as required by federal and/or state health privacy laws, that no personally-identified health information of research subjects will be disclosed outside the research group and that security measures will be applied to protect the data.

Researchers must also have the project approved by a Human Subject Protection or Privacy Board. These groups decide whether the importance of the research and the safeguards promised outweigh potential risks to privacy and data security, or other risks, to research participants.

Some say that patient interests in privacy and data security are not protected well by such procedures, and there is little policing of researcher practices. It is argued that patients must be asked for consents – either specific or general – for all health research.

Health researchers say many patients would not respond or agree to requests for permission, creating a sample that would not accurately reflect the group whose health condition or status are being studied. They also say obtaining permission for each health study would be very costly and time-consuming, and there is no pattern of health researchers disclosing the personal medical information of research subjects.

In these situations, which is closer to your opinion?

[ROTATE 1-5, 5-1]

I would want each research study seeking to use my personally-identified medical or health information to first describe the study to me and get my specific consent for such use.	38%
My consent to use my personal medical and health information would not be needed as long as the study never revealed my personal identity and it was supervised by an Institutional Review Board.	19%
I would not want the researchers to contact me or to use my personal medical or health information under any circumstances.	13%
I would be willing to give a general consent in advance to have my personally-identified medical or health information used in future research projects without the researchers having to contact me.	8%
Researchers would be free to use my personal medical and health information without my consent at all.	1%
Not sure – ANCHOR	20%

**BASE: WOULD REQUIRE SPECIFIC CONSENT (Q1050/2) (n=973)**

**Q1055** If you think there should be specific consent for each research project, what are the main reasons for your not wanting to give advance general consent or to have your information used without a consent? Please select all that apply.

[RANDOM]

I would want to know what the purposes of the research are before I consent	80%
Knowing about the specific research study and who would be running it would allow me to decide whether I trusted them or not.	62%

I would be worried that my personally-identified medical or health information may be disclosed outside the study	54%
I would want to know whether the research could help my health conditions or those of my family	46%
Other – ANCHOR	3%
None of these – ANCHOR	*

**BASE: WORRIED ABOUT INFORMATION BEING DISCLOSED (Q1055/3) (n=531)**

**Q1060** What would you be worried about if your personally-identified medical or health information was disclosed outside the study staff? Please select all that apply.

[RANDOM]

I could be embarrassed before friends, associates, or the public	33%
I could be discriminated against in getting health insurance	67%
I could be discriminated against in getting life insurance	56%
I could be discriminated against by an employer	44%
I could be discriminated against in a government program	39%
I would feel violated and my trust in the researchers betrayed	77%
Other – ANCHOR	9%
None of these – ANCHOR	4%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1065** Please indicate whether you agree or disagree with the following statements.

[RANDOM]

	AGREE (NET)	Strongly Agree	Somewhat Agree	DISAGREE (NET)	Somewhat disagree	Strongly disagree
I generally trust my health care providers – doctors and hospitals – to protect the privacy and confidentiality of my personal medical records and health information.	83%	30%	54%	17%	12%	5%
Health researchers can generally be trusted to protect the privacy and confidentiality of the medical records and health information they get about research subjects.	69%	11%	58%	31%	24%	7%
The privacy of personal medical records and health information is not protected well enough today by federal and state laws and organizational practices.	58%	17%	41%	42%	33%	10%
Even if nothing that identifies me were ever published or given to an organization making consumer or employee decisions about me, I still worry about a professional health researcher seeing my medical records.	50%	12%	38%	50%	35%	15%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1070** Have any of the following organizations involved in your health care or medical services ever disclosed your personally identified medical or health information in a way you felt was improper? Please select all that apply.

[RANDOM]

TOTAL DISCLOSURE	12%
A doctor who treated you	4%
A hospital or clinic where you received services	3%
A health insurance company of which you were a member	3%
A life insurance company you applied to or issued a policy on you	2%
A pharmacy or druggist you used for prescriptions	2%
An employer who had your medical or health insurance records	2%
A government health program in which you participated, such as Medicare	1%
Other – ANCHOR	2%
None of these – ANCHOR	88%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1075** Overall, would you say your health is...

EXCELLENT/PRETTY GOOD	75%
Excellent	14%
Pretty Good	61%
FAIR/POOR	25%
Fair	22%
Poor	3%

**BASE: U.S RESPONDENTS (Q110/244) AND 18+ (Q106/NOT 1,2)**

**Q1080** Have you ever...?

[RANDOM]

	Yes	No	Not sure
Used the services of a psychologist, psychiatrist, or other mental-health professional	27%	68%	5%
Been a caregiver for a family member with a chronic or serious medical condition	23%	73%	4%
Had a long-term medical condition such as diabetes or epilepsy	16%	80%	4%
Had any major physical or mental disabilities	11%	84%	4%
Had a serious illness such as heart attack, stroke or cancer	9%	87%	4%
Had any sexually related health condition	7%	88%	5%
Had an alcohol or drug abuse problem	6%	90%	5%
Had a genetic test	5%	91%	4%



## **Appendix B -- SELECTED GROUP VARIATIONS NOT ALREADY PRESENTED IN THE MAIN REPORT**

We show here group variations for selected questions – by standard demographics, health factors, and attitude sets – where a group is 5% or more higher than the total respondents or, when the total of respondents is 20% or less, by 3% higher.

These appear in the order that the questions were presented on the questionnaire, with standard demographic groups shown first, health aspects second, and respondent attitudes third.

A Data Book containing all of the cross-tabulations for the survey was provided to the IOM. Researchers wishing a copy can contact the Public Access Records Office of the National Academies at [publicac@nas.edu](mailto:publicac@nas.edu)

### **Interest in Health Research Findings. Total was 78%**

- Ages 50-64..... 86%
- Ages 65+..... 85%
- Females ..... 82%
- Married women ..... 86%
- Blacks..... 83%
- Some college..... 83%
- Post grads..... 86%
  
- Participated in health research study.... 87%
- Would give general advance consent... 88%
- Worried about disclosure..... 85%
- Well informed about study..... 88%
- Comfortable with study..... 88%
  
- Had/have serious illness..... 86%
- Have long term condition..... 87%
- Has been/are a caregiver..... 88%
- Had a genetic test..... 88%

### **Health Researchers Can be Trusted re Confidentiality: Total 69%**

- Ages 18-24..... 76%
- Hispanic..... 75%
- Household with children..... 74%
  
- Very interested in health research..... 75%
- Participated in study..... 78%
- Would give general advance consent..... 79%
- Informed about study.....81%
- Very comfortable with study..... 85%
  
- Used mental health service..... 74%
- Has sexual condition..... 75%
- Had a genetic test..... 77%

### **Privacy of Health Information Not Well Enough Protected: Total 58%**

- Ages 65+..... 66%
- Don't ever contact for PHI in study..... 74%
- Had own PHI disclosed improperly..... 67%
- Worried about disclosure..... 67%
- In Fair health..... 64%
- Had a genetic test..... 67%

### **Would Be Worried if Health Researcher Saw Their PHI. Total 50%**

- In East..... 56%
- Ages 50-64..... 59%
- Ages 65+..... 56%
- Blacks..... 60%
- Hispanics..... 56%
- Have disability..... 56%

- Invited but declined participation..... 62%
- Worried about disclosure..... 70%
- Require specific consent for PHI used... 55%
- Never contact for using PHI in study..... 75%
  
- In Fair health..... 55%
- Not informed in study..... 62%
- Not very comfortable in study..... 58%
- Had a genetic test..... 55%

**Believe Their PHI Disclosed Improperly: Total 12% (Used 4% or More Higher)**

- Midwest..... 17%
- Independent in political philosophy..... 16%
- Some college..... 16%
- \$75,000 plus income..... 16%
- Gay..... 22%
  
- Never contact for study..... 20%
- In Poor health..... 18%
- Major disability..... 24%
- Sexual condition..... 22%
- Had a genetic test..... 23%

**Invited to Study But Declined: Total 8% (Used 3% or More Higher)**

- West..... 11%
- Blacks..... 13%
- Post grads..... 11%
- Participated in a study..... 24%
- Not informed in the study..... 35%

- Very comfortable in study..... 18%
- Had/have serious illness..... 14%
- Major disability..... 13%
- Had/have alcohol or drug problem..... 14%

**Participated in a Health Research Study: Total 13% (Used 3% or More Higher)**

- Ages 50-64..... 19%
- Ages 65+..... 20%
- Blacks..... 23%
- Post grads..... 25%
  
- Very interested in health research..... 18%
- Invited to study but declined..... 39%
- Worried about privacy..... 31%
  
- Had/have serious illness..... 24%
- Have long term condition..... 20%
- Have major disability..... 24%
- Used mental health service..... 19%
- Alcohol or drug problem..... 21%
- Caregiver..... 19%
- Had genetic test..... 34%

## Appendix C: Parallel Surveys in Other Nations

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### *Canada*

A 2005 Canadian survey found that support for research uses of personal health data was dependent on the intended uses and users of the data, and on the privacy safeguards applied to the data.

Respondents had relatively high trust in disease-based foundations, hospitals, university researchers and data collection organizations such as Statistics Canada. Some 76% - 81% indicated that they trusted such organizations “somewhat” or “a great deal.” By contrast, 42% indicated distrust of research uses of personal health data by insurers; 28% distrusted drug companies, and 27% distrusted “government.”

Even where respondents supported research uses of their personal health information, a majority still wanted some degree of control over those uses. Only 12% of respondents felt it acceptable to use PHI in research without prior permission or notification. Over a quarter (28%) were willing to consider a broad authorization for research uses of their medical data, while 24% said that they would consider notification with an opt-out provision.

*“Alternatives to project-specific consent for access for personal information for health research. What do Canadians think?” Willison, et. al. for Canadian Institutes of Health Research and Health Canada; 1,230 respondents; telephone; March-April 2005*

In a 2003 Canadian survey, a majority of respondents were willing to have their PHI used for research purposes, though most wanted to be asked to consent first. While 26% of respondents were satisfied with being provided an opportunity to opt out, 74% wanted prior notice and the opportunity to opt-in.

As in other studies, willingness to share PHI for research purposes varied with the nature of the research and the researcher. Half of the respondents (51%) expressed concern over the use of their PHI in insurer-funded research, while 43% were concerned about participating in government-funded research. Respondents expressed least concern over research funded by foundations, and lower levels of concern over drug industry-based research.

*“Patient consent preferences for research uses of information in electronic medical records,” Willison, et. al., for Searle Canada, Ontario Ministry of Health and Long Term Care, and the Canadian Institutes of Health Research; 123 respondents; 17 face-to-face interviews and 106 written surveys; dates unspecified for fieldwork,*

but reported 2003.

### ***United Kingdom***

A 2006 British survey found strong support for the specific practice of using certain identified personal information without consent in the National Cancer Registry. Almost three in four respondents (72%) did not consider the inclusion of their postcode, the inclusion of their name and address, and the receipt of a letter inviting them to participate in a research study based on their inclusion on the Registry to be an invasion of their privacy.

*“Patients Are Concerned About the Privacy and Security of Their Medical Records,” Taylor Nelson Sofres for AMA Family Doctor Week; 1,001 respondents; 1-3 July, 2005.*

### ***Australia***

A 2005 Australian survey found relatively high levels of support for the use of de-identified personal health information in medical research, but also strong support for prior permission for such uses.

Two-thirds of respondents (67%) said that they would be willing to give their doctor permission to pass on their de-identified health records for medical research purposes, while 62% said that they would not be willing to have their de-identified PHI used for commercial purposes. At the same time, eight in ten respondents (81%) wanted to be asked permission before their doctor passed on their de-identified records.

*“Patients Are Concerned About the Privacy and Security of Their Medical Records,” Taylor Nelson Sofres for AMA Family Doctor Week; 1,001 respondents; 1-3 July, 2005.*

**Appendix D: Text of Westin Powerpoint on Survey Questions on  
Health Research and Privacy, 1993- September, 2007**

**Presented to the IOM Committee on October 1, 2007**

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**Surveys on Privacy and Health Research, 1993-2007**

**Dr. Alan F. Westin**

**Professor of Public Law and Government Emeritus, Columbia University  
Director, Health Privacy Program, Privacy Consulting Group**

**at the IOM Committee Meeting, Washington, D.C., October 2, 2007**  
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**Health Research and Privacy, 1993-2007**

- 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....**

- 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**

- 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**

- 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” – 1



- 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” -- 2

- “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” – 3

- 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

- 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 – 1994 (continued)

- 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

- 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... 1996 (continued)

- 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

- 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

- "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

- 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

- 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

- When asked would they be willing to share their personal health information for various purposes -- “with their identity protected” -- 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

- 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

- 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

- 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...

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Quali sono i dati  
e i mezzi a cui ho diritto  
e come li posso

## Westin Health and Privacy Vita

**Dr. Alan F. Westin**, LLB and PhD, is Professor of Public Law & Government Emeritus, Columbia University; author of Privacy & Freedom (1967) and Databanks in a Free Society (1972) and recipient in 2005 of the Privacy Leadership Award of the International Association of Privacy Professionals.

One of his main areas of activity has been the impact of information technology applications in health care. In 1976, he led the first field study of computer applications and privacy issues in U.S. health care, for the National Bureau of Standards (Westin, Computers, Health Records and Citizen Rights) and served in the 1980s as Research Director for the National Commission on Confidentiality of Health Records.

In 2005, with Vivian van Gelder, he wrote Building Privacy by Design into Emerging Electronic Health Record Systems.

He has made keynote presentations on health privacy issues since the 1960s to more than 120 health conferences, health professional meetings, Congressional hearings, and privacy conferences.

Dr. Westin has been the designer and academic advisor for 10 national surveys (with Harris Interactive) on health privacy issues, beginning with the 1993 survey on “Health Information Privacy” and, most recently (2003-2007) in surveys focused on HIPAA privacy issues, privacy in health research, and EHR-and-privacy developments.

Dr. Westin has been a privacy advisor to a wide range of direct health-provider organizations, pharmaceutical firms, health data organizations, Internet health data repositories, health information services, and consumer groups active in the health field.

He has also specialized in doing “privacy message testing” surveys for organizations seeking to install privacy policy presentations in health data systems that are readable, clear, and satisfying to their patients, customers, or employees, and that can generate high trust in the organization’s compliance with its privacy promises.

Currently, he is developing a privacy-impact assessment for organizations installing EHR programs at the single-organization or regional and multi-organization levels, as well as assisting organizations to prepare and circulate a ***Patient Rights Guide to Your Electronic Health Records System***.

**Contact:**