

Public Attitudes Toward Medical Privacy

Submitted to:

The Institute for Health Freedom

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Submitted by:

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Introduction

This report is based on the results of a survey conducted by The Gallup Organization on behalf of the Institute for Health Freedom. The opinions of a national cross-section of adults in telephone owning households, 18 years of age or older, concerning access and the confidentiality of their medical records were obtained.

A national cross-section of telephone households was systematically selected using random digit dialing techniques to ensure the inclusion of households with both listed and unlisted telephone numbers. Everyone was interviewed between August 11, 2000 to August 26, 2000. A total of 1,000 interviews were completed. Results based on the entire sample are accurate with a plus or minus 3-percentage point margin of error at the 95% confidence level. The sampling tolerances will be found in the technical appendix of this report.

Overview of Survey Findings

For most adults the confidentiality of their medical records is very important, and only the confidentiality of financial information is judged very important by a greater proportion. Over eight in ten adults (84%) report it is very important that their financial information be kept confidential. Almost as many (78%) feel it is very important that their medical records be kept confidential. While important to many adults, less than half (39%) feel it is very important that their employment history be kept confidential, and fewer (30%) feel it is very important that their educational history be kept confidential.

Women are more likely than men to feel it is very important their medical records should be kept confidential (81% and 74%, respectively). In addition, older adults, particularly those 35 to 49, are more likely than adults 18 to 34 years of age to say it is very important that their medical records be kept confidential.

Given the importance attached to keeping their medical records confidential, it is not surprising that many adults oppose access by any group. Asked if they favored or opposed allowing various groups to see their medical records without permission there is no group that a majority of adults would favor allowing access to their medical records without their authorization.

The most “acceptable” group would be pharmacists, four in ten adults (40%) would favor allowing pharmacists to see their medical records without permission while 59% would be opposed.

There is strong opposition to non-medical groups gaining access to their medical records. Nine out of ten (92%) oppose giving government agencies access. About as many (88%) oppose the police or lawyers, or employers (84%) being allowed to see their medical records. Similarly, 82% oppose letting insurance companies see their medical records without permission. Over nine in ten (95%) oppose allowing banks to see their medical records without permission.

Local and state health departments are acceptable to a larger proportion compared to government agencies overall, nevertheless, 71% oppose giving these agencies access to medical information without permission.

Opinion is no different when it comes to medical doctors other than those given permission by the respondent. Seven in ten (71%) oppose giving doctors access to their medical records without permission. Medical researchers would be denied access too – two-thirds (67%) oppose allowing researchers permission to see their medical records without permission.

While controlling access to their medical records is important to many, relatively few adults (16%) have heard or read anything recently about new federal regulations that would change the rules regarding access to medical records. Adults, age 50 or older (20%) and college-educated adults (19%) are more likely than others to say they have heard about the issue.

Asked their opinion of keeping their medical records in a national computerized database, most adults (88%) are opposed. Only 10% would favor keeping records in a national database. Adults, ages 35 to 49 are more likely than younger or older adults to oppose a national database for medical records. Similarly, college-educated adults are more likely than those with fewer years of formal education to oppose a national database (93% and 83%, respectively).

Few adults (12%) have seen or heard anything recently about a proposal to assign medical identification numbers. Even fewer (8%) adults support a plan that requires every American to be assigned a medical identification number. Adults 35 years of age or older are more likely than younger adults to be aware of the medical identification proposals.

Over nine in ten adults (95%) say doctors and hospitals should have to obtain their permission before releasing medical records to a national database. In addition, only 4% believe personal information told a doctor in confidence and entered into their medical records should be included in the national database.

Most adults (86%) feel a physician should ask permission first before running additional tests, during the course of regular testing, for genetic factors that may be related to possible health

problems. Approximately one in seven (14%) feel the physician should be allowed to run the additional tests without asking permission.

Over nine in ten adults (93%) feel medical and government researchers should obtain permission before studying a person's genetic information. Less than one in ten (6%) feel it isn't necessary to obtain the person's permission.

Detailed Findings

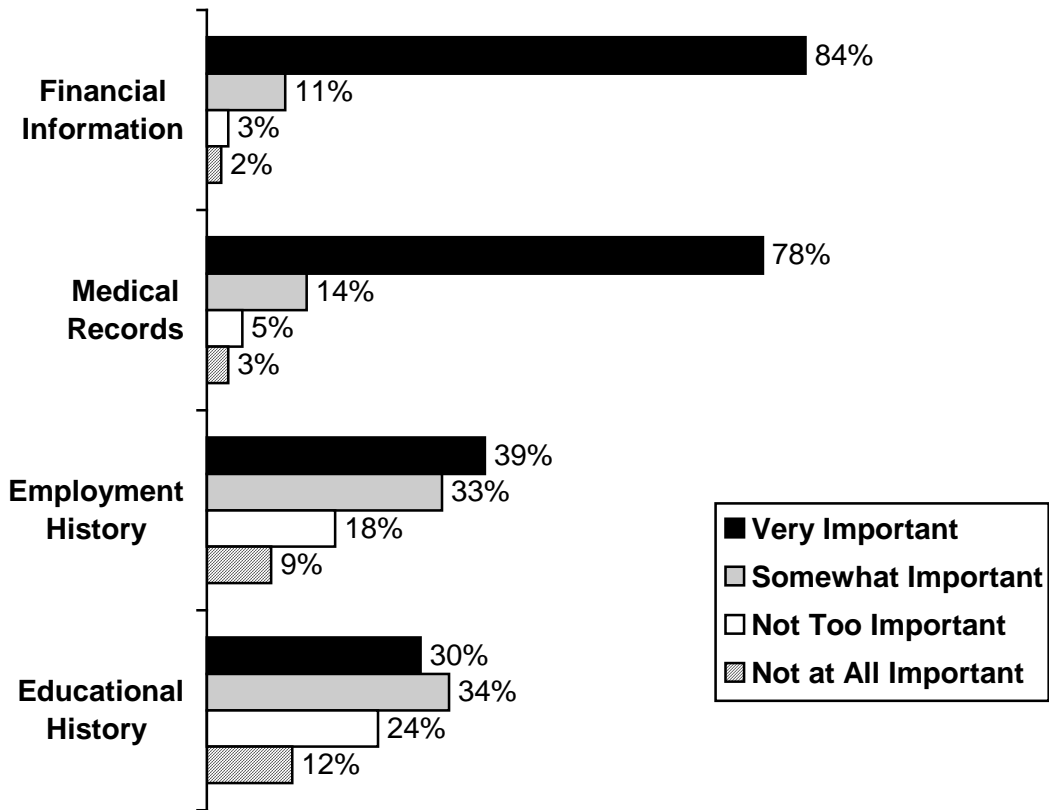
Importance of Confidentiality of Information

Question 1

How important is it to you that information in the following areas be kept confidential; that is, no one can see it without your permission - very important, somewhat important, not too important, or not at all important?

- Financial information*
- Employment history*
- Medical records*
- Educational history*

Over eight in ten adults (84%) report it is very important that their financial information be kept confidential. Almost as many (78%) feel it is very important that their medical records be kept confidential. While important to most adults, less than half (39%) feel it is very important that their employment history be kept confidential, and fewer (30%) feel it is very important that their educational history be kept confidential.

IMPORTANCE OF CONFIDENTIALITY (n=1000)


-
- Women are more likely than men to feel it is very important their medical records should be kept confidential (81% and 74%, respectively).
 - Older adults, particularly those 35 to 49 (83%), are more likely than adults 18 to 34 years of age (71%) to say their medical records should be kept confidential.
 - Women and adults, 35 to 49 years of age, are more likely than others to consider keeping their financial information confidential very important.

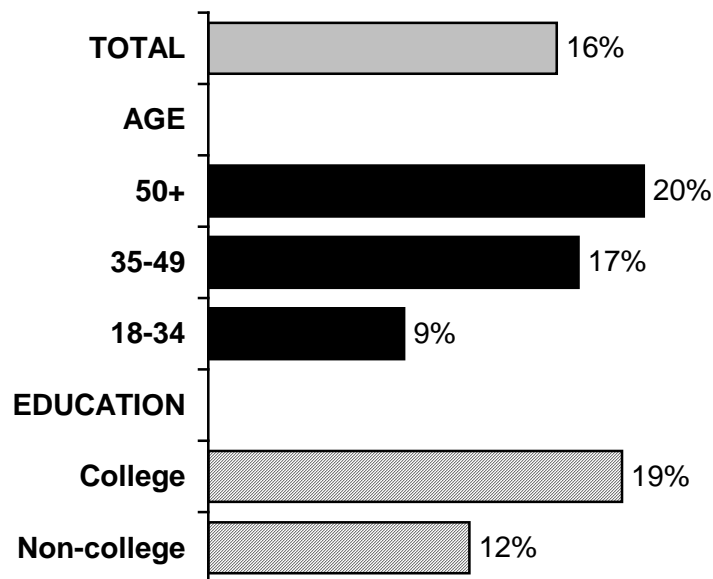
Awareness of Federal Regulations Regarding Access to Medical Records

Question 2

Have you heard, read or seen anything recently about new federal regulations that would change the rules regarding who is allowed to see your medical records?

Relatively few adults (16%) have heard or read anything recently about new federal regulations that would change the rules regarding access to medical records. Adults, age 50 or older (20%) and college-educated adults (19%) are more likely than others to say they have heard about the issue.

AWARE OF NEW FEDERAL REGULATIONS REGARDING MEDICAL RECORDS (n=1000)



Favor or Oppose Access to Medical Records by Selected Groups

Question 3

Who do you think should be allowed to see your medical records without your permission? I am going to read you a list of some groups; for each, please tell me whether you favor or oppose allowing them to see YOUR medical records without FIRST obtaining YOUR permission. How about . . . ?

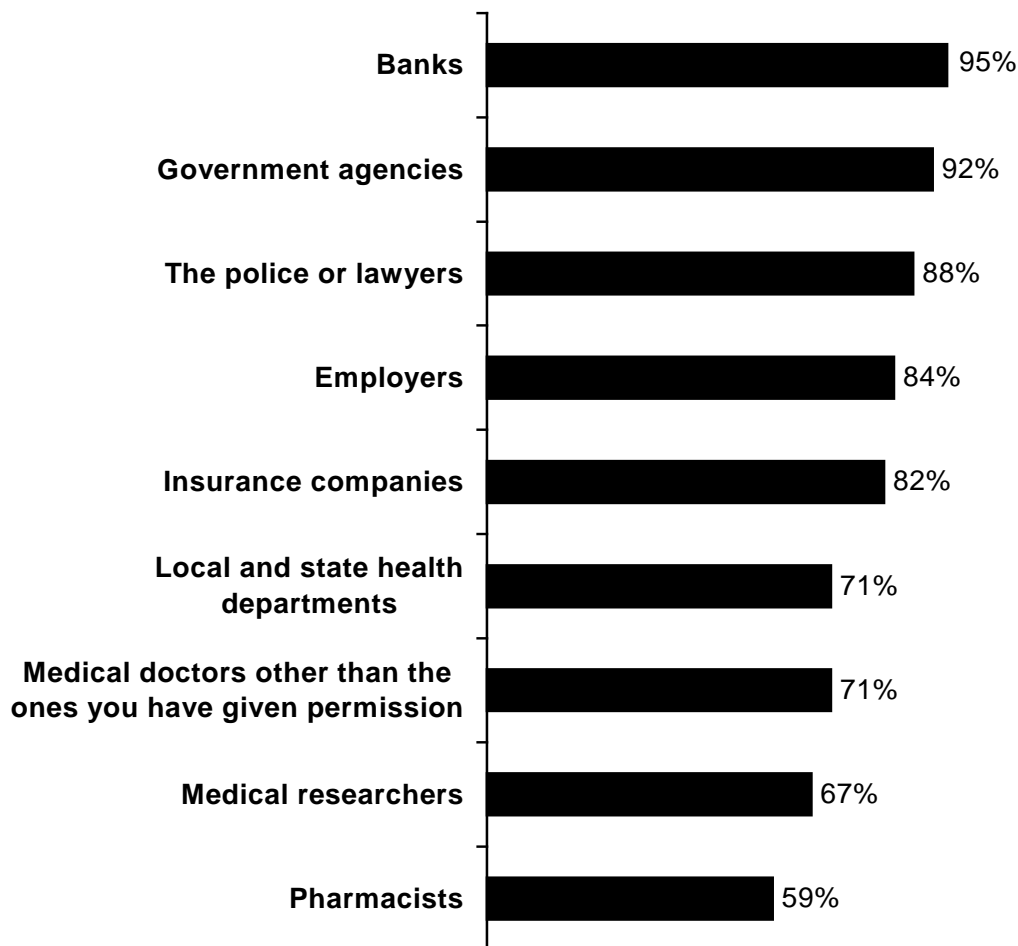
- *Medical doctors OTHER than the ones you have given permission*
- *Pharmacists*
- *Medical researchers*
- *The police or lawyers*
- *Local and state health departments*
- *Banks*
- *Insurance companies*
- *Employers*
- *Government agencies*

Asked if they favored or opposed allowing various groups to see their medical records without permission there is no group that a majority of adults would favor allowing access to their medical records without their authorization.

The most “acceptable” group would be pharmacists. Four in ten adults would favor allowing pharmacists to see their medical records without permission while 59% would be opposed. In contrast, the least “acceptable” group would be banks, only 5% would favor allowing banks to see their medical records without permission.

There is strong opposition to other non-medical groups seeing their medical records. Nine out of ten (92%) oppose giving government agencies access. About as many (88%) oppose the police or lawyers, or employers (84%) being allowed to see their medical records. Similarly, 82% oppose letting insurance companies see their medical records without permission.

Local and state health departments are acceptable to a larger proportion compared to government agencies overall, however, 71% oppose giving these agencies access to medical information without permission, too. Opinion is no different when it comes to medical doctors other than ones given permission by the respondent. Seven in ten (71%) oppose giving doctors access to their medical records without permission. Medical researchers fare no better than doctors – two-thirds (67%) oppose allowing researchers permission to see their medical records without permission.

PROPORTION OPPOSED TO ALLOWING GROUP TO SEE MEDICAL RECORDS (n=1000)

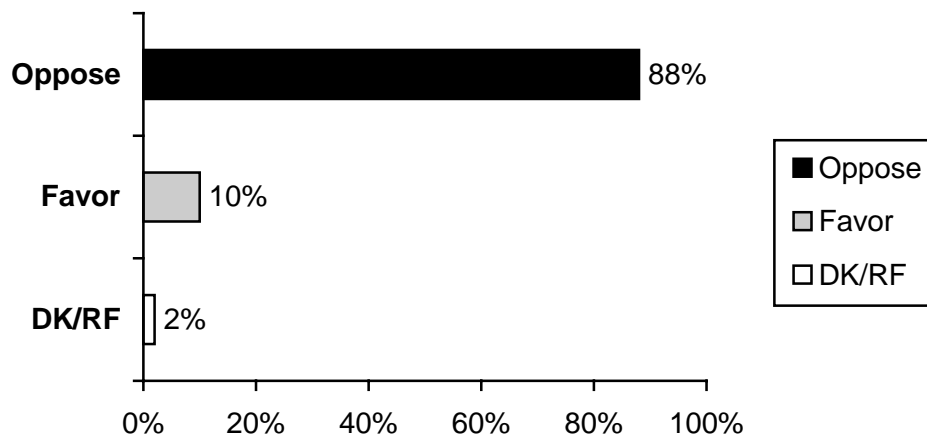
Attitude Toward National Database

Question 4

*There has been a lot of discussion lately about **REQUIRING** that all patient medical records be stored in a national computerized database. The database would store medical records on patients over their lifetime. Others would be able to use the information without first obtaining a patient's permission. Would you favor or oppose keeping your medical records this way?*

Most adults (88%) are opposed to keeping their medical records in a national computerized database. Only 10% would favor the plan described to them.

FAVOR/OPOSE STORING MEDICAL RECORDS IN COMPUTERIZED DATABASE (n=1000)



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- Adults, ages 35 to 49 are more likely than younger or older adults to oppose a national database for medical records (92%).
 - College-educated adults are more likely than those with fewer years of formal education to oppose a national database (93% and 83%, respectively).

Awareness and Support for Medical Identification Numbers

Question 5

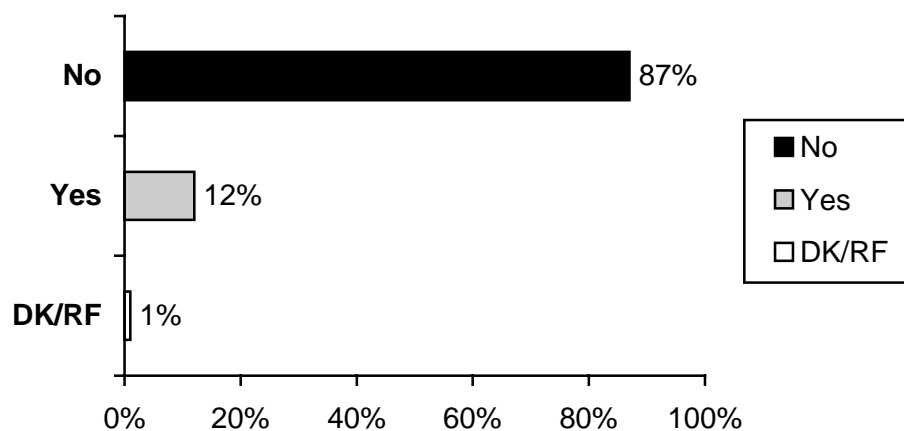
Have you heard, read or seen anything recently about a federal proposal to assign medical identification numbers, similar to a social security number, to you and all other Americans to create a national database of medical records?

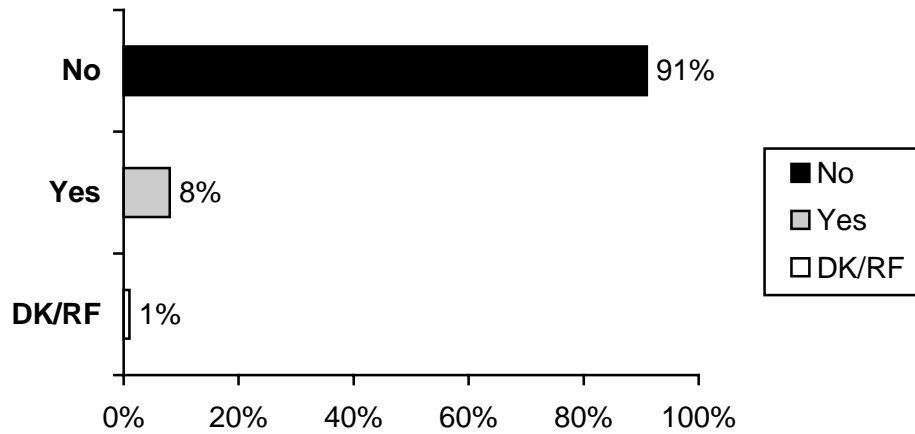
Question 6

*Would you support a plan that **REQUIRES** every American, including you, to be assigned a medical identification number, similar to a social security number, to track your medical records and place them in a national computer database without your permission?*

One in eight adults (12%) have seen or heard something recently about a proposal to assign medical identification numbers. Somewhat fewer (8%) adults support a plan that requires every American to be assigned a medical identification number.

AWARE OF FEDERAL PROPOSAL REGARDING MEDICAL ID NUMBERS (n=1000)



SUPPORT PLAN THAT REQUIRES ASSIGNED MEDICAL ID NUMBER (n=1000)

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- Adults 35 years of age or older are more likely than younger adults to be aware of the medical identification proposals (14% and 7%, respectively).
 - College-educated adults (16%) are more likely than those with less than a college education (8%) to say they are aware of proposals for medical identification numbers.
 - Support for medical identification numbers is highest in the Midwest (12%) and lowest in the West (3%).

Should Permission Be Obtained Before Releasing Information to National Database?

Question 7

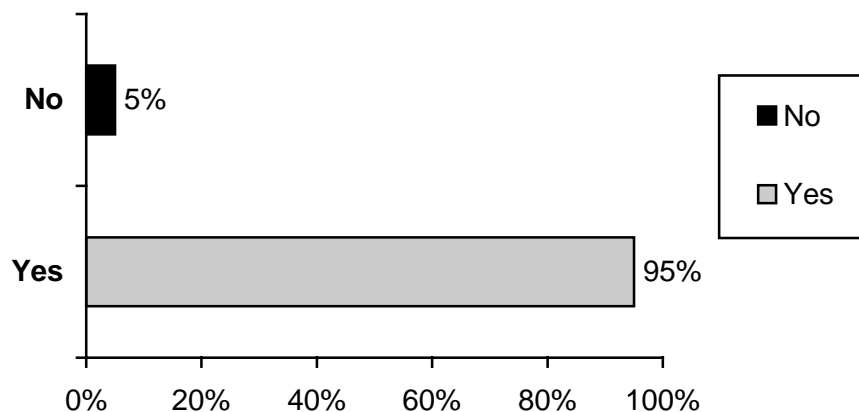
Do you think doctors and hospitals should have to obtain your PERMISSION before they could release your medical records to a national computerized database?

Question 8

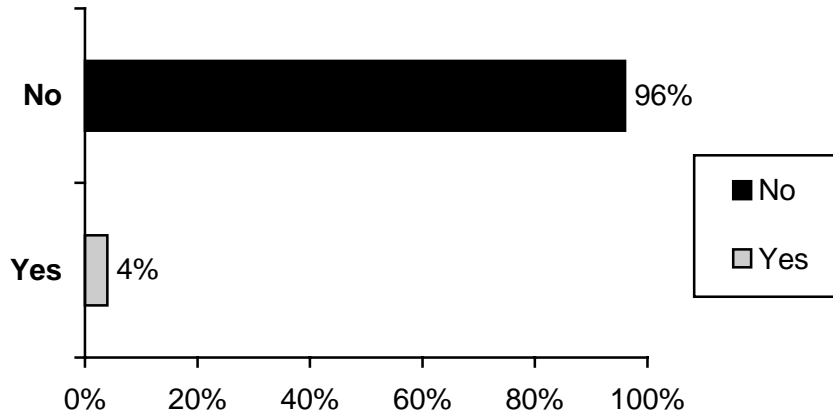
If you tell a doctor personal things about yourself in confidence, and the doctor records that information in your medical records, should the doctor be required to include that information in a national database without your permission?

Over nine in ten adults (95%) say doctors and hospitals should have to obtain their permission before releasing medical records to a national database. In addition, only 4% believe personal information told a doctor in confidence and entered into their medical records should be included in the national database.

PERMISSION SHOULD BE OBTAINED BEFORE RELEASING MEDICAL RECORDS (n=1000)



SHOULD PERSONAL INFORMATION TOLD TO MEDICAL DOCTOR IN CONFIDENCE BE INCLUDED IN NATIONAL DATABASE? (n=1000)



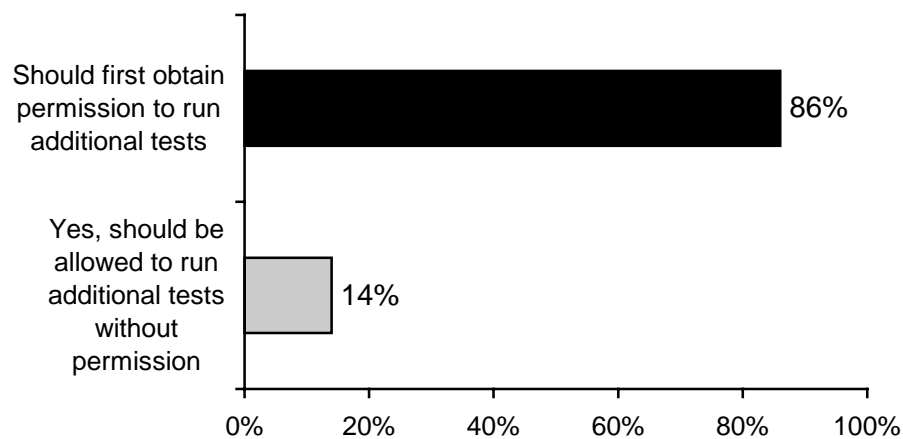
Should Physicians Be Allowed to Test for Genetic Factors Without Permission?

Question 9

If you go to a DOCTOR to have your blood tested for sugar or for high cholesterol, should your doctor also be allowed to test your blood for genetic factors that, for example, could reveal whether you are prone to cancer later in life, without first obtaining your permission, or do you feel your doctor should first obtain your permission?

Most adults (86%) feel a physician should ask permission first before running additional tests, during the course of regular testing, for genetic factors that may be related to possible health problems. Approximately one in seven (14%) feel the physician should be allowed to run the additional tests without asking permission.

SHOULD DOCTOR TEST FOR GENETIC FACTORS WITHOUT PERMISSION? (n=1000)



- Women (88%) are more likely than men (84%) to feel a physician should ask permission before conducting additional tests.

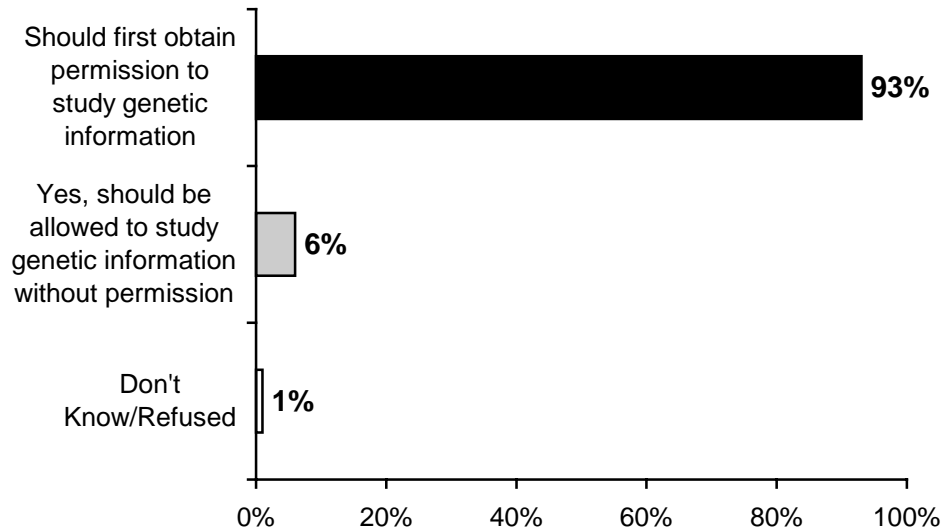
Should Researchers Be Allowed to Study Genetic Information Without Permission?

Question 10

Should medical and government RESEARCHERS be allowed to STUDY your genetic information (for example, to identify genes thought to be associated with various medical conditions) without first obtaining your permission, or do you feel they should first obtain your permission?

Over nine in ten adults (93%) feel medical and government researchers should obtain permission before studying a person's genetic information. Less than one in ten (6%) feel it isn't necessary to obtain the person's permission.

SHOULD RESEARCHERS BE ALLOWED TO STUDY GENETIC INFORMATION WITHOUT PERMISSION? (n=1000)



Appendix A

Sampling Tolerances

Sampling Tolerances

In interpreting survey results, it should be borne in mind that all sample surveys are subject to sampling error, that is, the extent to which the results may differ from what would be obtained if the whole population had been interviewed. The size of such sampling errors depends largely on the number of interviews.

The following tables may be used in estimating the sampling error of any percentage in this report. The computed allowances have taken into account the effect of the sample design upon sampling error. They may be interpreted as indicating the range (plus or minus the figure shown) within which the results of repeated samplings in the same time period could be expected to vary, 95 percent of the time, assuming the same sampling procedures, the same interviewers, and the same questionnaire.

The first table shows how much allowance should be made for the sampling error of a percentage:

	Recommended Allowance for Sampling Error of a Percentage						
	In Percentage Points (at 95 in 100 confidence level)*						
	Sample Size						
	1000	800	600	400	300	200	
PERCENTAGES NEAR 10	2	2	3	3	4	5	
PERCENTAGES NEAR 20	3	3	4	4	5	6	
PERCENTAGES NEAR 30	3	3	4	5	6	7	
PERCENTAGES NEAR 40	3	4	4	5	6	7	
PERCENTAGES NEAR 50	3	4	4	5	6	8	
PERCENTAGES NEAR 60	3	4	4	5	6	7	
PERCENTAGES NEAR 70	3	3	4	5	6	7	
PERCENTAGES NEAR 80	3	3	4	4	5	6	
PERCENTAGES NEAR 90	2	2	3	3	4	5	

* THE CHANCES ARE 95 IN 100 THAT THE SAMPLING ERROR IS NOT LARGER THAN THE FIGURE SHOWN.

The table would be used in the following manner: Let us say a reported percentage is 33 for a group which includes 1000 respondents. Then we go to row "percentages near 30" in the table and go across to the column headed "1000". The number at this point is 3, which means that the 33 percent obtained in the sample is subject to a sampling error of plus or minus 3 points.

Another way of saying it is that very probably (95 chances of 100) the true figure would be somewhere between 30 and 36, with the most likely figure the 33 obtained.

In comparing survey results in two samples, such as, for example, men and women, the question arises as to how large a difference between them must be before one can be reasonably sure that it reflects a real difference. In the tables below, the number of points which must be allowed for in such comparisons is indicated.

Two tables are provided. One is for percentages near 20 or 80; the other for percentages near 50. For percentages in between, the error to be allowed for is between those shown in the two tables.

		Recommended Allowance for Sampling Error of the Difference In Percentage Points (at 95 in 100 confidence level)*					
		<u>Percentages near 20 or percentages near 80</u>					
TABLE A		1000	800	600	400	300	200
1000		4					
800		4	4				
600		4	5	5			
400		5	5	6	6		
300		6	6	6	7	7	
200		7	7	7	7	8	9
TABLE B		<u>Percentages near 50</u>					
		1000	800	600	400	300	200
1000		5					
800		5	5				
600		6	6	6			
400		6	7	7	8		
300		7	7	8	8	9	
200		8	9	9	9	10	11

* THE CHANCES ARE 95 IN 100 THAT THE SAMPLING ERROR IS NOT LARGER THAN THE FIGURE SHOWN.

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