



**VCU Center for Public Policy**

**VCU Survey of Virginians Finds Clear Support for Genetic Testing Amidst Concerns Over Keeping the Results Private**

Virginians express clear support for the idea of genetic testing and most maintain that the benefits of genetic testing outweigh any risks. At the same time, a majority is very concerned about the privacy of genetic testing results and the privacy of health and medical information, more generally.

These are among the results of a survey conducted by Virginia Commonwealth University on genetic testing. The survey was conducted by telephone November 14-25, 2003 with 804 adult Virginians. The survey has a margin of error of +/- 4 percentage points. The survey was sponsored by the Virginia Advisory Committee on Ethical, Legal, and Social Issues in Genetic Research (VAC).

**Support for Genetic Testing**

Virginians express clear support for the idea of genetic testing. About nine in ten Virginians (89%) say that genetic testing for the risk of disease is a very good or a good idea. Just 8% think it is a bad or very bad idea. Nearly six in ten (58%) say it would be very helpful to know more about one’s risk for disease in order to take better care of one’s health. Another 31% say this would be somewhat helpful and just 9% say it would be not too or not at all helpful.

Similarly, clear majorities support the idea of making genetic testing easily available to all who want it; four in ten strongly favor, 44% somewhat favor and 13% somewhat or strongly oppose this idea. About three in ten (29%) consider themselves likely to get tested if genetic testing were easily available; 39% are somewhat likely and 32% are not very or not at all likely to do so. Ten percent of Virginians say someone in their household has had genetic testing.

**Privacy Concerns and Factors in the Decision to Get Tested**

When asked to rate a series of factors that might influence personal decisions to get genetic testing, more people considered the privacy of the testing results to be very important than any other factor. 69% said the privacy of the testing results would be very important in their decision to get genetic testing. Another 19% said it would be important and 12% thought it would be not too or not at all important in their decision.

	Importance of... ..in your decision to get genetic testing?					
	Very important	Important	Not too important	Not at all important	Don't know	No answer
Privacy of the results	69%	19%	8%	4%	0%	0%
Family medical history	62%	29%	6%	3%	0%	1%
Availability of treatments	57%	30%	7%	4%	1%	0%
Cost of the test	52%	32%	10%	3%	1%	1%
Your current age	28%	33%	25%	11%	2%	1%

Similarly, 54% said they were very concerned, in general, about their ability to keep health and medical information private; 26% were somewhat concerned while one in five were not too or not all concerned with this. Similar portions, 58%, say they would be very concerned about keeping genetic testing results private; 24% would be somewhat concerned and 17% would be not too or not at all concerned.

### Expectations of Discrimination

There has been a lot of talk about the possibility for discrimination by insurers and employers on the basis of genetic testing information. Respondents were asked to rate how often they thought such discrimination would occur. Nearly half (48%) thought insurance companies would almost always deny people coverage because of genetic testing results. 22% thought they would do so more than half the time, 16% thought this would occur about half the time and 8% thought it would less than half the time or almost never. A similar pattern was found for beliefs about health insurance companies. 46% thought health insurance companies would deny people coverage because of genetic testing results almost always. 21% thought they would do so more than half the time, 17% thought this would occur about half the time and 10% thought it would be less than half the time or almost never. By comparison, 20% thought that employers would deny people jobs because of genetic testing results “almost always”. 21% thought employers would deny job more than half the time, 17% thought it would occur about half the time, and 10% thought it would occur less than half the time or almost never.

More optimism was expressed for how people would treat each other outside of these settings. Only 11% thought that other people would “almost always” treat you differently if they knew about your genetic testing results.

	How often do you think ...would deny people coverage/jobs because of genetic testing results?						
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer
Life insurance companies	48%	22%	16%	5%	3%	5%	2%
Health insurance companies	46%	21%	17%	7%	3%	5%	1%
Employers	20%	21%	23%	21%	10%	4%	1%

	How often do you think other people would treat you differently if they knew about your genetic testing results?						
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer
Other people	11%	13%	21%	21%	31%	2%	1%

### Trusted Groups with Genetic Testing Information

Respondents were asked how much they would trust each of five groups to safeguard their genetic testing information. More Virginians said they would trust physicians with this information than did so for laboratories, scientists doing genetic research, hospitals or health insurance companies. Fewer Virginians said they would trust health insurance companies with this information than did so for any of the other groups considered.

	How much would you trust ...to safeguard your genetic testing information?				
	A great deal	Somewhat	Not much	Not at all	Don't know
Physicians	55%	34%	5%	4%	1%
Laboratories that provide genetic testing	40%	41%	11%	7%	2%
Scientists who do genetic research	40%	40%	10%	7%	3%
Hospitals	37%	43%	12%	7%	1%
Health Insurance Companies	20%	35%	21%	22%	1%

Despite any concerns over protecting the privacy of genetic testing results and potential consequences when those results are known, support for genetic testing is clear. Asked towards the end of the survey to weigh the risks and benefits of genetic testing, 63% said the benefits outweigh the risks while a quarter said the risks outweigh the benefits.

### **Policy Needs for Privacy Protection**

Virginians expressed strong agreement with the notion that better enforcement of current laws are needed to protect the privacy of genetic testing information. Eight in ten Virginians agree with a statement to that effect; 9% disagree. 44% of Virginians agree that current laws are adequate for protecting the privacy of genetic testing information while 37% disagree and the remainder have no opinion. These results suggest that Virginians tend to support better enforcement of current laws. More people think the federal government would be best able to enforce safeguards on the privacy of genetic information compared to state or local government. Four in ten think the federal government can best enforce safeguards on privacy, 29% think state government could do this best and 22% think local government could do this best. However, two thirds of Virginians agree with the idea that “government safeguards aren’t enough; we need citizen watchdog groups to make sure that the privacy of genetic testing information is protected.” 27% disagree.

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**VCU Survey of Virginians**

November 14-25, 2003

804 Respondents

Margin of error =/± 4 percentage points

	Q1. How interested are you in keeping up with new discoveries and advances in medicine-- very interested, somewhat interested, not very interested or not interested at all?					Number of cases
	Very interested	Somewhat interested	Not very interested	Not interested at all	Don't know	
Total	46%	42%	9%	3%	0%	804

	Q2. From what you know, are most major diseases caused almost entirely by: 1) the genes we inherit, 2) our environment and living practices, or 3) some combination of genes, environment and living practices?					Number of cases
	Almost entirely by the genes we inherit	Almost entirely by our environment and living practices	Some combination of genes, environment and living practices	Don't know	No answer	
Total	4%	4%	86%	3%	2%	804

	Q3. How worried are you that medical researchers are not paying enough attention to the moral values of society-- very worried, somewhat worried, not very worried or not at all worried?						Number of cases
	Very worried	Somewhat worried	Not very worried	Not at all worried	Don't know	No answer	
Total	21%	38%	25%	13%	2%	0%	804

	Q4. Genetic testing involves a blood test to look at someone's genes or DNA to see if they have inherited a high risk of getting one or more diseases. Overall do you think genetic testing for the risk of disease is a very good idea, a good idea, a bad idea, or a very bad idea?						Number of cases
	Very good idea	Good idea	Bad idea	Very bad idea	Don't know	No answer	
Total	35%	54%	6%	2%	3%	0%	804

	Q5. Have you or anyone living in your household ever had any genetic testing?				Number of cases
	Yes	No	Don't know	No answer	
Total	10%	87%	2%	0%	804

	Q6. How helpful do you think it would be to know more about your risk for disease in order to take better care of your health-- very helpful, somewhat helpful, not too helpful, or not at all helpful?						Number of cases
	Very helpful	Somewhat Helpful	Not too helpful	Not at all helpful	Don't know	No answer	
Total	58%	31%	5%	4%	1%	1%	804

	Q7. Overall, how much would you favor or oppose making genetic testing easily available to all who want it - do you strongly favor, somewhat favor, somewhat oppose, or strongly oppose this?						Number of cases
	Strongly favor	Somewhat favor	Somewhat oppose	Strongly oppose	Don't know	No answer	
Total	40%	44%	9%	4%	2%	1%	804

	Q8. If genetic testing were easily available, how likely would you personally be to get tested -- very likely, somewhat likely, not very likely, or not at all likely?						Number of cases
	Very likely	Somewhat likely	Not very likely	Not at all likely	Don't know	No answer	
Total	29%	39%	21%	11%	1%	0%	804

If you were making a decision about whether or not to get genetic testing, please tell me how important each of the following would be in your decision. First,...

**Questions 9 to 13 asked in random order.**

	Q9. The cost of the test? (Would the cost of the test be very important, important, not too important, or not at all important in your decision to get genetic testing?)						Number of cases
	Very important	Important	Not too important	Not at all important	Don't know	No answer	
Total	52%	32%	10%	3%	1%	1%	804

	Q10. Availability of treatments for the disease being tested? (Would the availability of treatments for the disease being tested be very important, important, not too important, or not at all important in your decision to get genetic testing?)						Number of cases
	Very important	Important	Not too important	Not at all important	Don't know	No answer	
Total	57%	30%	7%	4%	1%	0%	804

	Q11. The privacy of the testing results? (Would the privacy of the testing results be very important, important, not too important, or not at all important in your decision to get genetic testing?)						Number of cases
	Very important	Important	Not too important	Not at all important	Don't know	No answer	
Total	69%	19%	8%	4%	0%	0%	804

	Q12. Your family medical history or whether anybody in your family has had the disease? (Would your family medical history be very important, important, not too important, or not at all important in your decision to get genetic testing?)						Number of cases
	Very important	Important	Not too important	Not at all important	Don't know	No answer	
Total	62%	29%	6%	3%	0%	1%	804

	Q13. Your current age? (Would your current age be very important, important, not too important, or not at all important in your decision to get genetic testing?)						Number of cases
	Very important	Important	Not too important	Not at all important	Don't know	No answer	
Total	28%	33%	25%	11%	2%	1%	804

	Q14. In general, how concerned are you about your ability to keep health and medical information private-- very concerned, somewhat concerned, not too concerned, or not at all concerned?						Number of cases
	Very concerned	Somewhat concerned	Not too concerned	Not at all concerned	Don't know	No answer	
Total	54%	26%	16%	4%	0%	0%	804

	Q15. If you had genetic testing conducted, how concerned would you be about keeping the results private-- very concerned, somewhat concerned, not too concerned, or not at all concerned?						Number of cases
	Very concerned	Somewhat concerned	Not too concerned	Not at all concerned	Don't know	No answer	
Total	58%	24%	12%	5%	0%	1%	804

**Question 16 to 18 asked in random order.**

	Q16. How often do you think <b>employers</b> would deny people jobs because of genetic testing results -- almost always, more than half the time, about half the time, less than half the time, or almost never?							Number of cases
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer	
Total	20%	21%	23%	21%	10%	4%	1%	804

	Q17. How often do you think <b>life insurance companies</b> would deny people coverage because of genetic testing results-- almost always, more than half the time, about half the time, less than half the time, or almost never?							Number of cases
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer	
Total	48%	22%	16%	5%	3%	5%	2%	804

	Q18. How often do you think <b>health insurance companies</b> would deny people coverage because of genetic testing results -- almost always, more than half the time, about half the time, less than half the time, or almost never?							Number of cases
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer	
Total	46%	21%	17%	7%	3%	5%	1%	804

	Q19. What about reactions from <b>other people</b> that you know? How often do you think <b>other people</b> would treat you differently if they knew about your genetic testing results--almost always, more than half the time, about half the time, less than half the time, or almost never?							Number of cases
	Almost always	More than half the time	About half the time	Less than half the time	Almost never	Don't know	No answer	
Total	11%	13%	21%	21%	31%	2%	1%	804

Next, for each of the following, please tell me how much you would **trust** this group of people to **safeguard your genetic testing information**-- a great deal, somewhat, not much, or not at all?  
**Questions 20 to 24 asked in random order.**

	Q20. Physicians? (How much would you trust physicians to safeguard your genetic testing information-- a great deal, somewhat, not much, or not at all?)					Number of cases
	A great deal	Somewhat	Not much	Not at all	Don't know	
Total	55%	34%	5%	4%	1%	804

	Q21. The laboratories that provide genetic testing? (How much would you trust the laboratories that provide genetic testing to safeguard your genetic testing information-- a great deal, somewhat, not much, or not at all?)						Number of cases
	A great deal	Somewhat	Not much	Not at all	Don't know	No answer	
Total	40%	41%	11%	7%	2%	0%	804

	Q22. Hospitals? (How much would you trust hospitals to safeguard your genetic testing information-- a great deal, somewhat, not much, or not at all?)						Number of cases
	A great deal	Somewhat	Not much	Not at all	Don't know	No answer	
Total	37%	43%	12%	7%	1%	1%	804

	Q23. Health insurance companies? (How much would you trust health insurance companies to safeguard your genetic testing information-- a great deal, somewhat, not much, or not at all?)						Number of cases
	A great deal	Somewhat	Not much	Not at all	Don't know	No answer	
Total	20%	35%	21%	22%	1%	0%	804

	Q24. Scientists who do genetic research? (How much would you trust scientists who do genetic research to safeguard your genetic testing information- a great deal, somewhat, not much, or not at all?)						Number of cases
	A great deal	Somewhat	Not much	Not at all	Don't know	No answer	
Total	40%	40%	10%	7%	3%	1%	804

	Q25. Overall, would you say the benefits of genetic testing outweigh the risks or do the risks outweigh the benefits?				Number of cases
	Benefits outweigh the risks	Risks outweigh the benefits	Don't know	No answer	
Total	63%	25%	9%	3%	804

Do you strongly agree, agree, disagree, or strongly disagree with each of the following statements?

	Q26. "Current laws are adequate for protecting the privacy of genetic testing information."						Number of cases
	Strongly agree	Agree	Disagree	Strongly disagree	Don't know	No answer	
Total	10%	34%	26%	11%	17%	1%	804

	Q27. "We need better enforcement of current laws to make sure that the privacy of genetic testing information is protected."						Number of cases
	Strongly agree	Agree	Disagree	Strongly disagree	Don't know	No answer	
Total	37%	43%	8%	1%	11%	0%	804

	Q28. "Government safeguards aren't enough; we need citizen watchdog groups to make sure that the privacy of genetic testing information is protected."						Number of cases
	Strongly agree	Agree	Disagree	Strongly disagree	Don't know	No answer	
Total	23%	43%	24%	3%	6%	1%	804

	Q29. Which of these three levels of government do you think could <b>best enforce</b> the safeguards protecting the privacy of patient genetic information—the federal government in Washington, state government, or local city and county governments?					Number of cases
	Federal government	State government	Local city and county government	Don't know	No answer	
Total	40%	29%	22%	5%	4%	804

### Survey Method

This survey was conducted by telephone with a randomly-selected sample of 804 adult Virginians from November 14-25, 2003. Interviewing was conducted by telephone from the facilities of the Survey and Evaluation Research Laboratory, a division of the VCU Center for Public Policy at Virginia Commonwealth University in Richmond. The interviewing was conducted by a staff of professionally trained, paid interviewers using computer-assisted telephone interviewing software.

The sample of telephone numbers was prepared by Genesys Sampling Systems of Ft. Washington, PA, and was designed so that all residential telephones, including new and unlisted numbers, had a known chance of inclusion. The cooperation rate for the survey was 34%. Using the Council of American Survey Research Organization (CASRO) response rate calculations, interviews were obtained with respondents in 28% of the known or assumed residential households in the sample.

The data were weighted to adjust for unequal probabilities of selection due to multiple telephone lines and multiple adults living in the household. In addition, the data were weighted on sex, race, age and region of residence to reflect the demographic composition of the Virginia adult population. Percentages reported in the text and tables are weighted, while the number of cases shown in the tables for various subgroups is the actual number of respondents.

Questions answered by the full sample of 804 adults are subject to a sampling error of plus or minus approximately 4 percentage points at the 95 percent level of confidence. This means that in 95 out of 100 samples like the one used here, the results obtained should be no more than 4 percentage points above or below the figure that would be obtained by interviewing all adult Virginians with telephones. Where the answers of subgroups are reported, the sampling error would be higher. Because of nonresponse (refusals to participate, etc.), standard calculations of sampling error are apt to understate the actual extent to which survey results are at variance with the true population values. Surveys are also subject to errors from sources other than sampling. While every effort is made to identify such errors, they are often difficult or impossible to measure. Readers making use of the results are urged to be mindful of the limitations inherent in survey research.