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Genetics& Public Policy CENTER

U.S. Public Opinion on Uses of Genetic Information and Genetic Discrimination

Genetic testing has grown dramatically in the past decade, and increasingly is becoming an integral part of health care. Currently, genetic tests for more than 1,000 different diseases are available clinically, and several hundred more are under development. These tests can help diagnose genetic conditions and guide treatment decisions, help predict risk of future disease, inform reproductive decision making, and assist medication choices or dosing.

The growing use of genetic testing raises a number of questions about how an individual's genetic information can be used. In particular, can employers use genetic information to make hiring and firing decisions? Can insurance companies deny people coverage based on their genetic test results?

Despite widespread, longstanding agreement among American citizens and politicians that protection from genetic discrimination should be clear and consistent, an individual's genetic information is protected only by a largely untested patchwork of state and federal regulations. Many states have enacted protections against genetic discrimination in health insurance, employment, or both. However, these state laws vary widely in scope and many are untested in court. State laws fail to provide a uniform floor of protections in employment and health insurance on which Americans can rely.

Meanwhile, individual patients who could benefit from genetic testing are in some cases foregoing it out of concern over possible repercussions. A 2004 study of 470 people with a family history of colorectal cancer showed that nearly half rated their level of concern about genetic discrimination as high.[1] Those individuals with high levels of concern indicated that they would be significantly less likely to consider even meeting with a health care professional to discuss genetic testing, or to undergo testing. When people opt not to be tested, they lose the opportunity to seek monitoring and preventive care to forestall or avoid conditions for which they are at higher risk. This fear of genetic discrimination negatively affects not only patients, but also health insurers (who will pay more to treat conditions that are not caught early) and employers (when employees require more sick days and medical leave).

Moreover, the threat of discrimination hinders both genetic research and clinical practice. Linking gene variants to health outcomes often requires studies involving large numbers of people, but scientists report that many potential subjects are deterred by the fear that their information could be used against them by employers or insurers. Thus, research is impeded that would help to bring about the much-heralded era of personalized medicine.

In 2007 the Genetics and Public Policy Center surveyed 1,199 Americans over the age of 18 to measure public acceptance of the use of genetic testing for medical and non-medical purposes, to

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[1] Apse KA, et al. 2004. Perceptions of genetic discrimination among at-risk relatives of colorectal cancer patients. *Genetics in Medicine* 6:510-516.

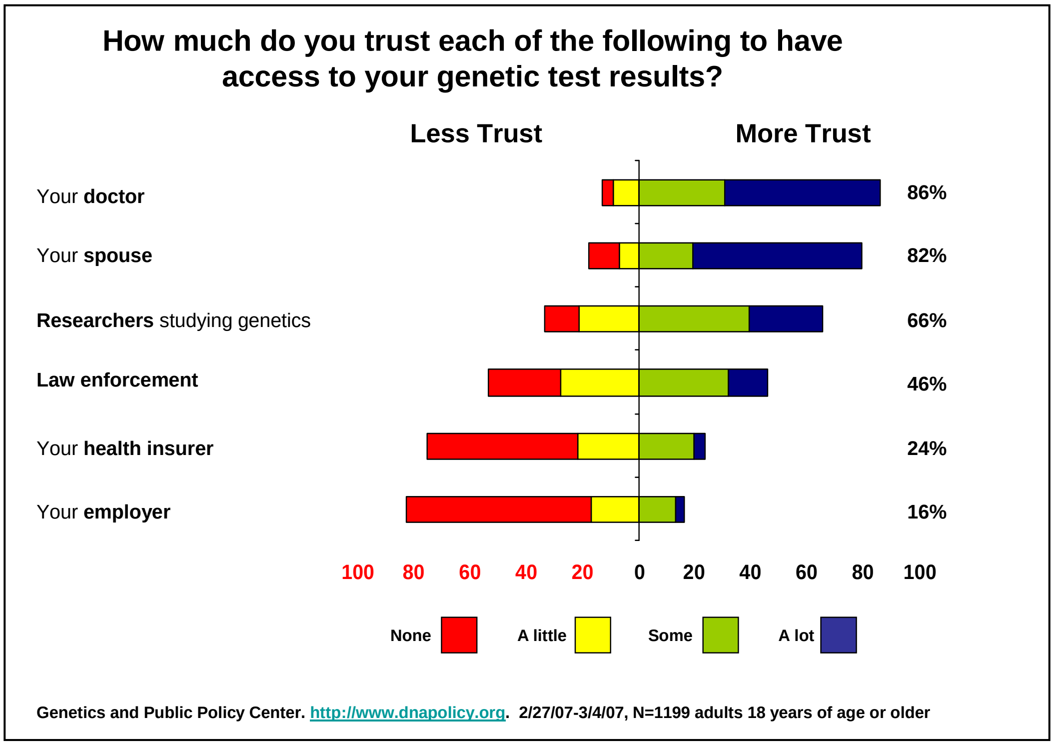
examine whom they do and do not trust with their genetic information, and gauge their support or lack thereof for laws that would protect them from some forms of genetic discrimination.

Details about the survey and participants demographics are included at the end of this report. Among the principal findings:

- The majority of Americans enthusiastically support genetic testing for research and health care, but a large majority (92%) also express concern that results of a genetic test that tells a patient whether he or she is at increased risk for a disease like cancer could be used in ways that are harmful to the person.

Table 1: Support for the uses of genetic testing	**%**
researchers, to find new ways to diagnose, prevent or treat disease:	**93**
doctors, to identify a person's risk of having a bad reaction to a particular medicine:	**93**
doctors, to identify a person's risk of a disease where treatment or medication exist:	**91**
doctors, to identify a person's risk of having a child with a serious genetic disease:	**86**
doctors, to identify a person's risk of a disease where no treatment or medication exist:	**79**
employers, to make decisions about hiring and promotion:	**19**
health insurance companies, to determine whom to insure or how much to charge:	**15**

- Majorities also said that they would trust doctors and genetic researchers to have access to genetic test results. However, only one person in four would trust health insurers, and 16% would trust employers, to have access to his or her genetic test results.



How much do you trust each of the following to have access to your genetic test results?

Genetics and Public Policy Center. http://www.dnapolicy.org. 2/27/07-3/4/07, N=1199 adults 18 years of age or older

- Nearly all Americans believe that health insurers and employers should not be able to deny or limit insurance coverage or to make decisions about hiring and promotion based on genetic test results about their risk of future disease. Three of every four Americans support a law forbidding genetic discrimination by health insurers and employers.

- Support for laws prohibiting employment and health insurance genetic discrimination was consistently strong among different groups of Americans – at least 68% of all genders, racial/ethnic groups, ages, and levels of education and household income supported laws against both types of discrimination. Support for both laws increased with education and household income.

Table 2: Uses of genetic testing results

	Yes %	No %	No Response %
Do you think an employer should be able to use a person's genetic test results about increased risk of future disease to make decisions about hiring and promotion?	6.1	93.2	0.6
Do you think there should be a law that prevents employers from using genetic test results about risk of future disease to make decisions about hiring and promotion?	76.1	22.7	1.1
Do you think health insurers should be able to use a person's genetic test results about increased risk of future disease to deny or limit insurance or charge higher prices?	5.8	93.1	1.1
Do you think there should be a law that prevents employers from using genetic test results about risk of future disease to deny or limit insurance or charge higher prices?	76.3	22.5	1.2

Conclusions

Americans clearly support the use of genetic testing to further their own health and the health of their families. The public also supports the use of genetic testing in medical research. However, this enthusiasm about genetic testing is tempered by widespread public concern and distrust about the discrimination that could result if insurers and employers access and use genetic test results. Three in four Americans support laws to ban such discrimination. Without such laws, much of the promise of the Human Genome Project to identify the causes of disease and promote public health is likely to remain unfulfilled.

Description of Survey

The 18-question survey was conducted between 2/27/07 and 3/4/07 and administered online to a random sample of U.S. adults 18 years or older. Of the 1,832 prospective participants contacted, 1,199 responded for a 65% completion rate. Based on this sample size, the maximum margin of sampling error is +/- 2.7 percentage points. In order to correct for small sampling errors, reported results are weighted with respect to U.S. benchmarks for age, gender, race/ethnicity, region, and education.