



MICHIGAN BRFSS SURVEILLANCE BRIEF

A NEWSLETTER FROM THE CHRONIC DISEASE EPIDEMIOLOGY UNIT, MDCH

Genetic Testing and Genetic Non-Discrimination Laws

Background. Genetic testing has grown dramatically in the past decade, and is becoming an integral part of health care.¹ Genetic tests can help diagnose genetic conditions; many of which are hereditary, meaning they are passed down from parent to child. The results of genetic tests can often help guide treatment decisions, predict future disease risk, inform reproductive decision making, and assist in medication selection or dosing.¹ Fears of potential genetic discrimination have been raised for the past decade and anxieties about discrimination can profoundly affect individuals' health decisions and behaviors.²

In 2000, the state of Michigan passed legislation to prevent genetic discrimination by health insurers and employers.^{3,4} In 2008, federal legislation was passed known as the Genetic Information Nondiscrimination Act of 2008, or GINA, that protects Americans from being treated unfairly because of differences in their genetic code that may affect their future health.⁵ GINA prevents health insurers from denying coverage or adjusting premiums based on a genetic test result, and prohibits insurers from requesting that an individual undergo genetic testing for any reason. Similarly, the law prevents employers from using genetic information to make hiring, firing, or promotion decisions.⁵

Currently, there is no federal or Michigan legislation that prevents genetic discrimination in life insurance. Life insurance is often privatized and companies vary widely on coverage criteria. The Michigan Department of Community Health (MDCH) Genomics and Genetic Disorders Section often receives questions from the public and professionals regarding genetic discrimination. Based on these questions, the fear of genetic discrimination from employers, health insurers, and/or life insurers seems to exist despite the implementation of GINA in recent years.

Methods. The MDCH Genomics and Genetic Disorders Section, in cooperative agreement with the Centers for Disease Control and Prevention (CDC) Office of Public Health Genomics, provided financial support for the addition of four questions to the 2010 Michigan Behavioral Risk Factor Survey (MiBRFS) related to genetic testing and genetic discrimination (Figure 1). These questions, asked of adults ages 18 and above, were used to assess 1) public awareness of GINA, 2) the public's view on the necessity of laws which prevent life insurance genetic discrimination, and 3) public interest in having a genetic test for disease risk. Population demographics for adults were examined to investigate potential differences between these populations. Other state-added questions on family history collection and practices were examined in relation to these questions.

Figure 1. State-added Questions on Genetic Testing and Genetic Discrimination, 2010 MiBRFS

1. A genetic test looks at a person's blood or saliva to find differences in genes that might cause disease in the future. How interested are you in having a genetic test that could tell you about your chances of developing a disease?
2. How concerned are you that life insurance companies might use genetic test results to determine life insurance coverage and costs?
3. How important do you think it is to have laws that prevent genetic test results from being used to determine life insurance coverage and costs?
4. Have you heard about laws that prevent genetic test results from being used to determine health insurance coverage and costs? One such law is called GINA, or the Genetic Information Non-discrimination Act.

Table 1. Awareness of Laws That Prevent Genetic Test Results from Being Used to Determine Health Insurance Coverage and Costs, 2010 MiBRFS

	%	95% CI
Total	13.3	(11.6-15.2)
Age		
18 - 24	15.2	(8.9-24.8)
25 - 34	14.1	(8.7-22.3)
35 - 44	9.4	(6.5-13.4)
45 - 54	14.2	(11.0-18.2)
55 - 64	15.3	(12.3-18.8)
65 - 74	13.4	(10.4-17.2)
75 +	14.8	(11.3-19.1)
Gender		
Male	13.9	(11.4-16.7)
Female	12.8	(10.6-15.3)
Race		
White	13.1	(11.3-15.1)
Black	17.0	(12.1-23.2)
Other	12.2	(6.8-20.9)
Education		
Less than high school	11.1	(5.4-21.3)
High school graduate	7.4	(5.6-9.7)
Some college	14.9	(11.7-18.7)
College graduate	17.1	(14.1-20.7)
Household Income		
< \$20,000	16.6	(12.1-22.4)
\$20,000 - \$34,999	10.1	(7.3-13.7)
\$35,000 - \$49,999	13.7	(9.7-19.1)
\$50,000 - \$74,999	13.6	(9.5-19.3)
\$75,000 +	14.2	(11.1-18.0)

MiBRFSS News

- The 2010 Michigan BRFS Annual Report is near completion and will be available on the Michigan BRFSS website (www.michigan.gov/brfs) in the near future. An email notice will be sent out to the Michigan BRFSS distribution list once the 2010 annual report is available for download.
- The most up-to-date health estimates from the Michigan BRFSS can be found on the Michigan BRFSS website.
- Did you miss an issue of *Michigan BRFSS Surveillance Brief*? Back issues are also available on our website.

Results. In 2010, an estimated 13.3% of Michigan adults reported being aware of a law that prevents genetic test results from being used to determine health care coverage (Table 1). Aware adults were more likely to have a higher education level. Adults who reported having collected a family health history were significantly more likely to have heard of this law (18.9%) than those who had not collected their family history (11.0%) (data not shown).

When asked if they thought these laws were important to prevent genetic test results from being used to determine life insurance coverage and costs, 84.8% thought it was very or somewhat important (Table 2). These adults were most likely to be younger and female.

Again, family history was associated with increased importance. Adults who thought family history was important were significantly more likely to think these laws were important (85.8%) compared to those who didn't think family history was important to their health (64.2%).

Conclusions. Genetic testing, although not indicated for all people, can provide life-saving test results that guide medical management and increased disease surveillance options. Although federal law exists to protect people from discrimination based on genetic test results, fear of discrimination still exists in those facing genetic testing.² A recent study found that wide and profound confusion about health insurance still exists along with misunderstandings and confusion about protective laws such as GINA.²

Our findings show that only 13.3% of the Michigan public are aware that their genetic information is protected under federal law, even though the law has been in place for over 3 years. This finding suggests that more public education is needed surrounding genetic discrimination protections and genetic test result use. In addition, educational efforts should focus on underserved populations with lower literacy levels as those who were aware of protective laws were more likely to have a higher education level; a finding consistent with prior studies on awareness of genetic testing.⁶

We also recommend continued promotion of family health history collection among providers and the public, as those individuals who deem family history important and have collected their own family health history were more aware of other genetic topics such as GINA. Finally, 84.8% of individuals think it is very or somewhat important to have a law that protects them from life insurance discrimination as well, suggesting a need within the genetics and legislative communities for increased protections relative to life insurance.

References

- ¹ Genetic Privacy and Discrimination, Genetics and Public Policy Center, retrieved September 2011 from <http://www.dnapolicy.org/policy.privacy.php>.
- ² Klitzman, R. Views of Discrimination Among Individuals Confronting Genetic Disease. *J Genet Counsel* (2010):19(1):68-83.
- ³ Public Act 26 of 2000, Amendment to section 401 of The Nonprofit Health Care Corporation Reform Act of 1980, 2000.
- ⁴ Public Act 32 of 2000, Amendment to sections 201 and 202 of the Persons with Disabilities Civil Rights Act of 1976, 2000.
- ⁵ Genetic Information Non-Discrimination Act of 2008, H.R. 493, 110th Cong. 2007-2008.
- ⁶ Wideroff, et. al, Awareness of Genetic Testing for Increased Cancer Risk in the Year 2000 National Health Interview Survey. *Community Genet* (2003); 6:147-156.

Table 2. Level of Importance for Laws that Prevent Genetic Test Results from Being Used to Determine Life Insurance Coverage and Costs, 2010 MiBRFS

	Very/Somewhat Important		Not very/Not at all Important	
	%	95% CI	%	95% CI
Total	84.8	(82.8-86.6)	15.2	(13.4-17.2)
Age				
18 - 24	81.4	(70.6-88.8)	18.6	(11.2-29.4)
25 - 34	89.2	(82.1-93.7)	10.8	(6.3-17.9)
35 - 44	87.6	(82.8-91.1)	12.4	(8.9-17.2)
45 - 54	88.5	(84.7-91.5)	11.5	(8.5-15.3)
55 - 64	86.3	(82.7-89.2)	13.7	(10.8-17.3)
65 - 74	78.3	(74.1-82.1)	21.7	(17.9-25.9)
75 +	69.5	(64.0-74.5)	30.5	(25.5-36.0)
Gender				
Male	81.3	(77.8-84.3)	18.7	(15.7-22.2)
Female	88.1	(85.9-89.9)	11.9	(10.1-14.1)
Race				
White	84.4	(82.1-86.4)	15.6	(13.6-17.9)
Black	85.5	(80.6-89.4)	14.5	(10.6-19.4)
Other	90.8	(82.7-95.4)	9.2	(4.6-17.3)
Education				
Less than HS	79.3	(68.7-87.1)	20.7	(12.9-31.3)
HS graduate	83.8	(80.0-87.1)	16.2	(12.9-20.0)
Some college	85.6	(82.0-88.6)	14.4	(11.4-18.0)
College graduate	85.8	(82.2-88.7)	14.2	(11.3-17.8)
Household Income				
< \$20,000	79.1	(73.0-84.2)	20.9	(15.8-27.0)
\$20,000 - \$ 34,999	81.5	(76.5-85.6)	18.5	(14.4-23.5)
\$35,000 - \$49,999	90.0	(83.9-94.0)	10.0	(6.0-16.1)
\$50,000 - \$74,999	87.1	(82.5-90.7)	12.9	(9.3-17.5)
\$75,000 +	87.8	(84.0-90.8)	12.2	(9.2-16.0)

The Michigan Behavioral Risk Factor Surveillance System (MiBRFSS)

The MiBRFSS comprises annual, statewide telephone surveys of Michigan adults aged 18 years and older and is part of the national BRFSS coordinated by the CDC. The annual Michigan Behavioral Risk Factor Surveys (MiBRFS) follow the CDC BRFSS protocol and use the standardized English core questionnaire that focuses on various behaviors, medical conditions, and preventive health care practices related to the leading causes of mortality, morbidity, and disability. Interviews are conducted across each calendar year. Data are weighted to adjust for the probabilities of selection and a poststratification weighting factor that adjusts for the sex, age, and race distribution of the adult Michigan population. All analyses are performed using SAS-callable SUDAAN[®] to account for the complex sampling design.

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