

Public Awareness of Genetic Nondiscrimination Laws in Four States and Perceived Importance of Life Insurance Protections

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Abstract Genetic testing has grown dramatically in the past decade and is becoming an integral part of health care. Genetic nondiscrimination laws have been passed in many states, and the Genetic Information Nondiscrimination Act (GINA) was passed at the federal level in 2008. These laws generally protect individuals from discrimination by health insurers or employers based on genetic information, including test results. In 2010, Connecticut, Michigan, Ohio, and Oregon added four questions to their Behavioral Risk Factor Surveillance System (BRFSS) survey to assess interest in genetic testing, awareness of genetic nondiscrimination laws, concern about genetic discrimination in determining life insurance eligibility and cost, and perceived importance of

genetic nondiscrimination laws that address life insurance. Survey results showed that awareness of genetic nondiscrimination laws was low (less than 20 % of the adult population), while perceived importance of these types of laws was high (over 80 % of respondents rated them as very or somewhat important). Over two-thirds of respondents indicated they were very or somewhat concerned about life insurance companies using genetic test results to determine life insurance coverage and costs. Results indicate a need for more public education to raise awareness of protections provided through current genetic nondiscrimination laws. The high rate of concern about life insurance discrimination indicates an additional need for continued dialogue regarding the extent of legal protections in genetic nondiscrimination laws.

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Introduction

Opportunities to use genetic information to inform health care decisions have grown considerably over the past decade, yet reported barriers to participation in genetic testing threaten to diminish the full potential for health impact. Fear of discrimination in insurance and employment have been common themes identified in research studies as barriers to genetic testing in clinical and research settings (Allain et al. 2012; Iverson et al. 2013), despite limited evidence of genetic discrimination in practice (Joly et al. 2013b; Otlowski et al. 2012). By early 2008, 32 states had enacted legislation providing varying levels of protection from genetic discrimination (National Conference of State Legislatures 2008). However, there was no national minimum standard of protection aside from some nondiscrimination provisions included in the Health Insurance Portability and Accountability Act

(HIPAA) of 1996, which apply only to employer-based and commercially-issued group health insurance (Health and Human Services [HHS] 2009; National Human Genome Research Institute 2012). To address fears of genetic discrimination and provide uniform basic protections for genetic information, the United States Congress passed the Genetic Information Nondiscrimination Act of 2008, also known as GINA, which prohibits health insurers and employers from using genetic information to make health insurance coverage or employment decisions (GINA 2008). All entities covered by GINA in the United States must meet its minimum requirements, but such entities must also comply with any additional state requirements when they are more protective than GINA (HHS 2009).

Under GINA, health insurers and employers may not request, require, or purchase genetic information about an individual or the individual's family members. Health insurers and health plan administrators cannot use genetic information to determine coverage, adjust premiums, or impose preexisting condition exclusions. Employers cannot use genetic information to make decisions regarding hiring, firing, promotion, or other terms of employment (GINA 2008; HHS 2009).

GINA defines "genetic information" as an individual's genetic tests, the genetic tests of that individual's family members, and the manifestation of a genetic disease or disorder in an individual's family members. The definition of "genetic information" includes information related to genetic services requested or received by an individual, such as counseling, testing, or education, as well as participation in clinical research that includes genetic services. "Family member" includes any first- through fourth-degree relatives of the individual, and also includes the fetus of a pregnant individual or an embryo held by an individual using assisted reproductive technology. GINA defines "genetic test" as an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes. The definition of "genetic test" does not include "analysis of proteins or metabolites that does not detect genotypes, mutations or chromosomal changes" or "analysis directly related to a manifested disease, disorder or pathological condition that could be reasonably detected by a health care professional with appropriate training and expertise in the field of medicine involved." (GINA 2008)

Despite the many protections GINA offers, it does have exceptions and limitations. For instance, GINA provisions do not apply to life, disability, or long-term care insurance, and GINA does not mandate health insurance coverage for any genetic services. Additionally, while GINA prohibits health insurers from determining individual eligibility or rates based on the manifestation of genetic diseases in an individual's *family members*, it does not prohibit eligibility or premium rate decisions based on manifestation of a disease or disorder of the enrolled *individual*. Finally, while GINA prohibits

health insurance eligibility and premium decisions based on genetic information, it does not prohibit the use of genetic test information in health insurance reimbursement decisions (GINA 2008; HHS 2009). The recent Patient Protection and Affordable Care Act of 2010 (ACA 2010) enhances consumer protections in the private health insurance market and complements some of the provisions of GINA (U.S. Congressional Research Service. *The Genetic Information Nondiscrimination Act of 2011*). The law prohibits issuers of health insurance from discriminating against patients with genetic diseases by refusing coverage because of preexisting conditions. The ACA further prohibits the adjustment of premiums for patients with genetic diseases.

Many states, including Connecticut, Michigan, Ohio and Oregon, had some legal protections in place to prevent genetic discrimination prior to GINA. The legal provisions varied and, in many cases, were not as detailed or comprehensive as the provisions in GINA. However, in some instances, state law had additional provisions not addressed in GINA. Table 1 summarizes the genetic non-discrimination laws in each state, which pre-dated GINA, and shows the areas where GINA strengthens the states' legal protections.

Connecticut law, like GINA, prohibits health insurers from determining eligibility and risk classification based on genetic information. Connecticut law also prohibits employers from requesting or requiring genetic information about an employee or family member, and they cannot use that information for hiring, firing, assignment, promotion, or compensation decisions. While GINA only applies to employers with 15 or more employees, Connecticut law applies to employers with three or more employees (Connecticut General Statute [CGS] 46a-60). Connecticut law defines genetic information broadly, as "information about genes, gene products or inherited characteristics that may derive from an individual or family member" (CGS 38a-816, CGS 46a-60). It does not specifically define "family member", "genetic testing" or "genetic services" and does not specifically protect against misuse of family health history, but these are defined through GINA. While Connecticut law does not prohibit insurers from requesting or requiring genetic testing as a condition of enrollment, this is prohibited under GINA (Table 1).

Michigan law prohibits health insurers from requiring genetic testing before issuing, renewing, or continuing coverage (Michigan Compiled Law [MCL] 550.1401), as does GINA. It also prohibits health insurers from disclosing if a genetic test has been conducted, as well as the results of any test or other genetic information. Employers cannot require genetic testing as a condition of employment, or use genetic information to discriminate against an employee (MCL 37.1201). Michigan law defines "genetic information" as "information about a gene, gene product, or inherited characteristic derived from a genetic test", and "genetic test" is defined as an analysis of human DNA, RNA, chromosomes, metabolites and proteins

Table 1 Summary of current legal genetic nondiscrimination and genetic privacy protections, United States, Connecticut, Michigan, Ohio, and Oregon

	National	Connecticut	Michigan	Ohio	Oregon
Protections provided nationally by GINA and HIPAA					
Health insurers may not establish rules for eligibility based on genetic information	GINA	§§ 38a-816, 38a-476		§§ 1751.65, 3901.491, 3901.501	§ 746.135
Health insurers may not require genetic tests/genetic information	GINA		§§ 550.1401	§§ 1751.65, 3901.491, 3901.501	§ 746.135
Health insurers may not use genetic information for risk selection or risk classification purposes	GINA	§§ 38a-816, 38a-476		§§ 1751.65, 3901.491, 3901.501	§§ 743.730, 746.135
Health insurers may not disclose individually identifiable genetic information	HIPAA		§§ 550.1401		§§ 192.531 to 192.549, 746.135
Specific penalties for genetic privacy violations	GINA				§192.531 to 192.549
Prohibits employers from requesting, requiring, or purchasing genetic information about an employee or family member	GINA	§ 46a-60	MCLA 37.1201		§§ 659a.300, 659a.303
Prohibits use of genetic information in hiring, firing, job assignments, compensation, and promotions	GINA	§ 46a-60	MCLA 37.1201		§ 659a.303
Definition of genetic information explicitly includes family medical history	GINA		MCLA 37.1201		explicitly <i>excluded</i> in § 192.531 to 192.549
Definition of genetic information explicitly excludes routine tests	GINA		§§ 550.1401, MCLA 37.1201		
Definition of genetic information as associated with a disease	GINA		§§ 550.1401, MCLA 37.1201	§ 1751.64	
Definition of genetic information explicitly includes carrier status	GINA			§ 1751.64	
Additional protections provided by state legislation					
Individual may inspect, request correction of and obtain genetic information from individual's records					§ 192.531 to 192.549
Consent required to perform/require presymptomatic or predictive genetic test			§ 333.17020, § 333.17520		
Consent required to obtain, access, retain or disclose individually identifiable genetic information					§ 192.531 to 192.549
Scope of legal protections					
Employment	GINA	§ 46a-60	MCLA 37.1201		§§ 659a.300, 659a.303
Health insurance	GINA, HIPAA	§§ 38a-816, 38a-476	§§ 550.1401	§§ 1751.65, 3901.491, 3901.501	§§ 743.730, 746.135, 192.531 to 192.549
Disability insurance					§ 746.135
Life insurance					§ 746.135
Long-term care insurance					§ 746.135

in a clinical setting to detect heritable disease-related genotypes and phenotypes (MCL 550.1401). “A genetic test must be generally accepted in the scientific and medical communities as being specifically determinative for the presence, absence, or mutation of a gene or chromosome in order to qualify under this definition” (MCL 550.1401). Like GINA, Michigan does not include routine physical exams or analyses of body fluids unless they are specifically conducted to detect gene or chromosome presence, absence or mutation. Michigan law does not define “genetic services,” and it does not explicitly include family health history or carrier status in the definition of genetic information under MCL 550.1401, but these definitions and inclusions are covered under GINA.

Like GINA, it does include family health history in its protections of employees in MCL 37.1201. Michigan requires healthcare providers to obtain written informed consent from an individual prior to pre-symptomatic or predictive genetic testing (MCL 333.17020), and this is an area where Michigan law is more prescriptive than GINA (Table 1).

Under Ohio law and GINA, health insurers may not require genetic testing as a precondition for coverage, and cannot use genetic information to determine eligibility and rates. Like GINA, Ohio defines genetic information as associated with disease and includes carrier status. Ohio law does not explicitly include family health history (Ohio Revised Code [ORC] 1751.65, ORC 3901.491), but this inclusion of family health

history is provided through GINA. Likewise, Ohio law does not cover employment discrimination related to genetic information, but GINA covers this gap (Table 1).

Oregon was the first state in the country with a comprehensive genetic privacy law, enacted in 1995. Oregon law prohibits misuse of genetic information in clinical, research, employment, and health insurance settings and limits disclosure. Healthcare providers must obtain informed consent from an individual prior to any genetic testing ([Oregon Revised Statute \[ORS\] 192.535](#)). Oregon law defines genetic information more narrowly than GINA, as information obtained from a genetic test about an individual or the individual's blood relatives, and the law explicitly excludes family history. However, GINA's broader definitions and inclusions supersede Oregon law. Oregon goes beyond GINA by requiring individual consent before a covered entity can obtain, retain, or disclose individually identifiable genetic information, and allowing an individual to inspect, request correction of, and obtain their genetic records ([ORS 192.531 to 192.549](#), [ORS 746.135](#)). The Oregon law also requires patient notification and the opportunity to opt-out of possible anonymous or coded use of genetic information by the covered entity or a third-party ([ORS 192.531 to 192.549](#)). Like GINA, Oregon law prohibits employers from obtaining, seeking to obtain, or using genetic information for employment decisions ([ORC 659a.303](#)). Unlike GINA and the other three states' laws, [ORS 746.135](#) does cover disability, life and long-term care insurance, and statute language refers generally to "any policy of insurance" ([ORS 746.135](#)) (Table 1).

According to a recent national survey, only 16 % of Americans are aware of any laws that protect the privacy of their genetic information (Cogent Research 2010). To explore public awareness and perceived importance of genetic nondiscrimination laws in Connecticut, Michigan, Ohio, and Oregon, survey questions were added to the 2010 Behavioral Risk Factor Surveillance System (BRFSS) survey administered by these four states.

Methods

The BRFSS collects information about health conditions, risk behaviors, and healthcare access and utilization in the United States using a random-digit-dialed telephone survey of the non-institutionalized population aged 18 years or older from each state. Response rates in 2010 were 47.5 % for Connecticut, 56.9 % for Michigan, 52.8 % for Ohio, and 39.1 % for Oregon (Centers for Disease Control and Prevention 2010). In 2010, Connecticut, Michigan, Ohio, and Oregon added four questions to their state BRFSS survey related to genetic testing and genetic discrimination (Table 2). These questions were used to assess the public's interest in genetic testing, their awareness of genetic nondiscrimination

laws, and their perception of laws that prevent the use of genetic information in determining life insurance eligibility and costs. Study covariates included the following sociodemographic variables: age group, sex, race/ethnicity, education level, and household income category. Interest in genetic testing was also included as a covariate (Tables 3 & 4).

Each state analyzed its own data. Oregon used Stata version 13.1 (StataCorp LP, College Station, TX), Michigan used SAS-Callable SUDAAN, Release 11.0.0 (Research Triangle Institute, Research Triangle Park, NC), Ohio used SAS, Release 9.2 (SAS Institute, Cary, NC), and Connecticut used SAS, Release 9.3 (SAS Institute, Cary, NC). Sample data were weighted to reflect the demographic characteristics of the adult population in each of the states. The unweighted counts of survey question respondents are reported in Tables 2, 3 and 4. Pearson chi-square tests were used to look for statistically significant variation by sociodemographic categories within each state. Confidence intervals were also used to determine significant differences between sociodemographic categories in each state, and these were also used for cross-state comparisons. Statistical analyses were not adjusted for multiple comparisons.

The human research protection offices at the Centers for Disease Control and Prevention, Oregon Public Health Division, Connecticut Department of Public Health, Michigan Department of Community Health, and Ohio Department of Health's Institutional Review Board have determined that the BRFSS survey is exempt from institutional review.

Results

In 2010, less than 20 % of adult respondents had heard about genetic nondiscrimination laws such as GINA, with awareness ranging from 13.3 % of adult respondents in Michigan to 19.1 % in Oregon (Tables 2 & 3). Despite any statistically significant variation in awareness by sociodemographic characteristics, awareness remained low across all sociodemographic groups in all four states. In all four states, there was significant variation in awareness by education. College graduates had the highest percentage of awareness of nondiscrimination laws in all four states, yet awareness in this group was still less than 26 % (Table 3).

There was statistically significant variation by income in every state except Michigan. In Connecticut and Oregon, households with incomes of \$75,000 or more per year were significantly more likely than those in the lowest income category (less than \$25,000 per year) to have heard of genetic nondiscrimination laws. For those in the highest income category in these three states, awareness ranged from 16.7 % in Ohio to 26.4 % in Oregon (Table 3). Most respondents, even in the highest income category, were unaware of genetic nondiscrimination laws.

Awareness was low irrespective of age group. Only Connecticut had significant variation in awareness of

Table 2 Genetic testing questions from 2010 BRFSS and percent responding “yes” or “very/somewhat”

	Connecticut	Michigan	Ohio	Oregon
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 chance of developing a disease?	<i>n</i> =6,331 46.4 (44.5–48.3)	<i>n</i> =2,768 52.4 (49.7–55.0)	<i>n</i> =6,034 39.5 (37.7–41.3)	<i>n</i> =2,327 49.0 (46.2–51.7)
How concerned are you that life insurance companies might use genetic test results to determine life insurance coverage and costs?	<i>n</i> =6,257 69.5 (67.7–71.3)	<i>n</i> =2,736 76.6 (74.2–78.9)	<i>n</i> =5,973 66.7 (65.0–68.4)	<i>n</i> =2,306 71.7 (69.1–74.1)
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?	<i>n</i> =6,109 84.8 (83.4–86.2)	<i>n</i> =2,691 84.8 (82.8–86.6)	<i>n</i> =5,807 81.9 (80.5–83.3)	<i>n</i> =2,241 83.7 (81.6–85.6)
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 Nondiscrimination Act.	<i>n</i> =6,226 15.6 (14.2–17.0)	<i>n</i> =2,713 13.3 (11.6–15.2)	<i>n</i> =5,988 14.5 (13.2–15.7)	<i>n</i> =2,294 19.1 (17.0–21.3)

Table 3 Percent aware of genetic nondiscrimination laws, 2010 BRFSS

	Connecticut <i>n</i> =6,226 % (95 % CI)	Michigan <i>n</i> =2,713 % (95 % CI)	Ohio <i>n</i> =5,988 % (95 % CI)	Oregon <i>n</i> =2,294 % (95 % CI)
Total	15.6 (14.2–17.0)	13.3 (11.6–15.2)	14.5 (13.2–15.7)	19.1 (17.0–21.3)
Age group	<i>p</i> =0.0005	<i>p</i> =0.3691	<i>p</i> =0.0791	<i>p</i> =0.2055
18–44	13.5 (11.0–16.0)	12.0 (9.2–15.4)	13.1 (11.0–15.3)	20.7 (16.9–25.1)
45–64	19.0 (16.9–21.0)	14.8 (12.5–17.4)	15.5 (13.7–17.2)	18.4 (15.9–21.3)
65+	14.1 (12.3–16.0)	14.8 (11.6–16.8)	16.2 (14.1–18.2)	16.2 (13.7–19.2)
Gender	<i>p</i> =0.0352	<i>p</i> =0.5404	<i>p</i> =0.6592	<i>p</i> =0.0778
Male	17.1 (14.8–19.5)	13.9 (11.4–16.7)	14.8 (12.8–16.8)	21.0 (17.7–24.8)
Female	14.1 (12.5–15.7)	12.8 (10.6–15.3)	14.2 (12.7–15.7)	17.2 (14.7–19.9)
Race and ethnicity	<i>p</i> =0.0476	<i>p</i> =0.5182	<i>p</i> =0.0132	<i>p</i> =0.3645
White non-Hispanic	16.2 (14.6–17.8)	13.0 (11.2–15.1)	14.2 (12.9–15.5)	19.4 (17.1–21.9)
Black non-Hispanic	8.0 (4.5–11.5)	17.0 (12.1–23.3)	18.2 (13.5–22.8)	^b
Hispanic	12.7 (8.0–17.5)	^b	7.6 (1.8–13.4)	^b
Other ^a	16.7 (10.0–23.4)	10.7 (5.5–19.6)	15.2 (8.7–21.6)	21.4 (15.1–29.4)
Education	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> =0.0001	<i>p</i> <0.0001
High school or less	10.0 (8.0–12.1)	8.0 (6.2–10.4)	11.6 (9.8–13.3)	11.0 (8.1–14.9)
Some college	12.2 (9.8–14.7)	14.9 (11.7–18.7)	14.0 (11.7–16.4)	19.7 (15.9–24.1)
College graduate	20.7 (18.4–23.1)	17.1 (14.1–20.7)	18.0 (15.7–20.3)	25.4 (21.8–29.2)
Household income	<i>p</i> <0.0001	<i>p</i> =0.4249	<i>p</i> =0.0249	<i>p</i> =0.0004
<\$25,000	9.4 (6.9–11.8)	15.3 (11.8–19.7)	13.9 (11.4–16.3)	15.7 (12.0–20.2)
\$25,000–\$49,999	13.5 (10.6–16.4)	11.4 (8.6–14.8)	15.2 (12.5–17.9)	14.8 (11.4–19.2)
\$50,000–\$74,999	16.0 (12.4–20.0)	13.6 (9.5–19.3)	12.7 (9.8–15.6)	21.5 (16.4–27.7)
\$75,000+	19.3 (16.8–21.7)	14.2 (11.1–18.0)	16.7 (14.0–19.3)	26.4 (21.9–31.4)
Interest in genetic testing	<i>p</i> =0.2218	<i>p</i> =0.0658	<i>p</i> =0.7367	<i>p</i> =0.1780
Very/somewhat interested	16.6 (14.3–18.9)	14.9 (12.5–17.6)	14.2 (12.2–16.1)	20.6 (17.5–24.1)
Not very/not at all interested	14.8 (13.1–16.5)	11.6 (9.4–14.2)	14.6 (13.0–16.2)	17.6 (14.9–20.7)

^a Includes respondents with other or unknown race or ethnicity, and respondents identifying as two or more races^b Insufficient number of respondents, percentage not calculated

Table 4 Percent that view laws preventing genetic tests results from being used to determine life insurance coverage and costs as somewhat or very important, 2010 BRFSS

	Connecticut <i>n</i> =6,109 % (95 % CI)	Michigan <i>n</i> =2,691 % (95 % CI)	Ohio <i>n</i> =5,807 % (95 % CI)	Oregon <i>n</i> =2,241 % (95 % CI)
Total	84.8 (83.4–86.2)	84.8 (82.8–86.6)	81.9 (80.5–83.3)	83.7 (81.6–85.6)
Age group	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
18–44	85.8 (83.2–88.3)	86.4 (82.6–89.4)	84.7 (82.2–87.2)	87.6 (83.5–90.8)
45–64	88.2 (86.6–89.8)	87.8 (85.3–90.0)	84.1 (82.3–85.9)	85.6 (82.9–88.0)
65+	76.0 (73.7–78.3)	74.4 (71.0–77.5)	69.9 (67.2–72.5)	69.4 (65.8–72.8)
Gender	<i>p</i> =0.0022	<i>p</i> =0.0005	<i>p</i> =0.0027	<i>p</i> =0.0280
Male	82.6 (80.3–84.9)	81.3 (77.8–84.3)	79.7 (77.3–82.1)	81.4 (77.9–84.5)
Female	86.8 (85.2–88.4)	88.1 (85.9–89.9)	84.0 (82.4–85.5)	85.9 (83.3–88.1)
Race and ethnicity	<i>p</i> =0.8438	<i>p</i> =0.5091	<i>p</i> =0.3077	<i>p</i> =0.4498
White non-Hispanic	85.1 (83.6–86.6)	84.5 (82.2–86.5)	81.6 (80.0–83.1)	84.5 (82.3–86.5)
Black non-Hispanic	82.9 (76.6–89.3)	85.1 (80.0–89.1)	86.2 (82.4–89.9)	81.9 (39.1–96.9)
Hispanic	84.7 (79.6–89.8)	^b	84.2 (74.9–93.5)	82.5 (67.7–91.4)
Other ^a	82.9 (76.7–89.2)	90.2 (81.3–95.1)	82.1 (74.1–90.1)	78.2 (70.1–84.6)
Education	<i>p</i> <0.0001	<i>p</i> =0.4373	<i>p</i> =0.0001	<i>p</i> =0.0134
High school or less	80.4 (77.6–83.2)	83.0 (79.4–86.1)	76.3 (73.8–78.8)	81.8 (77.9–85.1)
Some college	83.8 (80.9–86.6)	85.6 (82.0–88.6)	83.7 (80.9–86.4)	80.9 (76.3–84.9)
College graduate	88.1 (86.3–90.0)	85.8 (82.2–88.7)	86.5 (84.4–88.5)	87.6 (84.6–90.0)
Household income	<i>p</i> <0.0001	<i>p</i> =0.0132	<i>p</i> =0.0001	<i>p</i> =0.1085
<\$25,000	73.8 (68.8–78.7)	78.7 (73.6–83.1)	76.2 (72.8–79.5)	83.3 (78.8–87.0)
\$25,000–\$49,999	80.9 (77.4–84.4)	87.3 (83.5–90.3)	82.5 (79.8–85.2)	81.7 (77.0–85.6)
\$50,000–\$74,999	88.3 (85.3–91.3)	87.1 (82.5–90.7)	87.8 (84.8–90.7)	86.3 (81.0–90.3)
\$75,000+	88.4 (86.4–90.4)	87.8 (84.0–90.8)	85.5 (82.9–88.2)	87.8 (83.9–90.9)
Interest in genetic testing	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> =0.0001	<i>p</i> <0.0001
Very/somewhat interested	90.4 (88.5–92.2)	89.1 (86.4–91.3)	90.4 (88.5–92.2)	90.4 (87.7–92.5)
Not very/not at all interested	79.9 (77.9–81.9)	80.2 (77.1–83.0)	76.5 (74.6–78.5)	77.2 (73.9–80.2)

^a Includes respondents with other or unknown race or ethnicity, and respondents identifying as two or more races

^b Insufficient number of respondents, percentage not calculated

genetic nondiscrimination laws by age, with those ages 45 through 64 years having the highest percentage of awareness (19.0 %), significantly higher than both the 18–44 years age group (13.5 %) and the age 65 years and older age group (14.1 %). None of the other states had this distribution of awareness among the three age groups, nor were any of the other states' differences by age significant (Table 3).

No consistent patterns were seen by race or ethnicity among the four states. Two states, Connecticut and Ohio, had significant variation of awareness by race and ethnicity, although each state had different distributions among the four race categories. In Connecticut, non-Hispanic whites were significantly more likely to be aware of genetic nondiscrimination than non-Hispanic

blacks (16.2 % versus 8.0 %). In Ohio, non-Hispanic blacks had the highest percentage of respondents reporting awareness of these laws, and the percentage of blacks was significantly higher than the percentage of Hispanics (18.2 % versus 7.6 %). Non-Hispanic blacks also had the highest percentage of awareness in Michigan, but there was no significant difference between this and the other race categories in Michigan.

There was no significant variation in awareness based on respondent interest in having a genetic test for any of the four states.

Irrespective of the state they lived in, most respondents were either somewhat or very concerned that life insurance companies might use genetic test results to determine

coverage and costs, ranging from 66.7 % in Ohio to 76.6 % in Michigan (Table 2). An even greater percentage of respondents believed it was somewhat or very important to have laws that prevent genetic test results from being used to determine life insurance coverage and costs, ranging from 81.9 % in Ohio to 84.8 % in Connecticut and Michigan (Tables 2 & 4).

For all four states, the percentage of respondents who felt it was somewhat or very important to have these laws was significantly higher for those under age 65 years compared with those over age 65 years. In addition, higher percentages of females than males viewed life insurance nondiscrimination laws as somewhat or very important (Table 4).

Perceived importance of life insurance nondiscrimination laws varied significantly by level of education in three of the four states (Connecticut, Ohio, and Oregon). In these three states, a significantly higher percentage of college graduates ranked these laws as somewhat or very important compared to those with high school education or less. The percentage of college graduates in these three states rating life insurance nondiscrimination laws as somewhat or very important ranged from 86.5 % in Ohio to 88.1 % in Connecticut; among those with a high school education or less, the percentage ranged from 76.3 % in Ohio to 81.8 % in Connecticut.

There was also significant variation by income level in perceived importance of these laws in three of the four states. In Connecticut, Michigan, and Ohio, a significantly higher percentage of respondents in households earning \$50,000 or more per year felt that life insurance genetic discrimination laws were somewhat or very important compared to those in the lowest income category (less than \$25,000 per year). In these three states, the percent of respondents in the highest income category who felt these laws were at least somewhat important ranged from 85.5 % in Ohio to 88.4 % in Connecticut, while the percent of respondents in the lowest income category ranged from 73.8 % in Connecticut to 78.7 % in Michigan.

Finally, perceived importance of laws preventing genetic discrimination in life insurance varied significantly by the respondents' interest in having a genetic test to determine their disease risk in the future. A significantly higher percentage of those who were somewhat or very interested in having a genetic test viewed these laws as important (89.1 % in Michigan, 90.4 % in the other three states) compared to those less interested in having a genetic test (ranging from 76.5 % in Ohio to 80.2 % in Michigan). Despite this difference, legal protections for life insurance were important to a majority of respondents in both interest categories.

Discussion

Evidence-based guidelines supporting the use of genetic testing in defined clinical settings are increasingly becoming available (Clyne et al. 2014). Practice guidelines are in place

to guide medical professionals in referring patients to certified genetic counselors and other genetic specialists who can help patients make informed testing decisions, interpret test results, and share information about state and federal genetic nondiscrimination laws. Indeed, recent studies suggest a major shift in genetics specialists' perspectives on genetic discrimination and clinical practices reflecting their general awareness of existing legislative protections (Matloff et al. 2013; Huizenga et al. 2010); whereas Laedtke et al. (2012) found that family physician awareness and knowledge of GINA was limited more than a year after its passage, with fewer than half reporting awareness of GINA. Genetic counseling and testing could lead to life-saving treatments for people who meet increased risk guidelines, yet concern about genetic discrimination could be a barrier in some instances (Allain et al. 2012). While state and federal laws are in place to provide protection against discrimination, the 2010 BRFSS found that over 80 % of respondents were unaware of these genetic nondiscrimination laws. In all four states, awareness levels were even lower among those with less education; and for three out of four states, lower incomes were also associated with lower awareness.

Our results are similar to the results of another survey where 85 % of genetic counseling clients were unaware of GINA (Parmarti 2011). In a different survey of people with Huntington's disease, their family members, and caregivers, conducted during an overlapping period to our study (July 2009–June 2010), greater awareness was found among this group (41.2 %); however, less than half of those aware could correctly identify GINA's provisions (Dorsey et al. 2013), suggesting that we might expect far fewer people in our study than reflected by reported awareness to understand the protections of GINA. A survey of individuals at risk for or affected by hereditary breast and ovarian cancer by Allain et al. (2012), which was also conducted in a period overlapping our study (August 2009–December 2010), found that 52.3 % of respondents were worried about life insurance discrimination when they first considered genetic testing, and 54.3 % of respondents who had genetic testing were unaware of GINA prior to the survey. Again, awareness is higher among this selected group as compared to the current population-based study, but concern about genetic discrimination in life insurance is somewhat lower.

A significantly higher percentage of respondents in Oregon reported awareness of genetic nondiscrimination laws than in any of the other three states. One possible reason for this may be that Oregon's genetic nondiscrimination law was one of the first in the nation, first enacted in 1995 (ORS 192.531 to 192.549). Similar differences were found by Kolor et al. (2012) when comparing the percentage of adults aware of direct-to-consumer personal genomic tests in Oregon, Connecticut, and Michigan: 29.1 %, 22.9 %, and 15.8 %, respectively.

A 2012 survey found that 13 U.S. states regulate genetic information in life insurance (Disability Rights Legal and Cancer Legal Resource Center 2012a, b). With the exception of Oregon law, GINA and the other three states' genetic nondiscrimination laws do not have provisions for discrimination in life, long-term care, or disability insurance. Most respondents from all states were either somewhat or very concerned that life insurance companies might use genetic test results to determine coverage and costs, ranging from 66.7% in Ohio to 76.6% in Michigan. Moreover, the majority of respondents in all four states (81.9%-84.8%) perceived legal protections from genetic discrimination in life insurance as very or somewhat important. Respondents who were female, less than 65 years old, and somewhat or very interested in receiving a genetic test had the highest percentages reporting that these laws are at least somewhat important. Because older adults either already own life insurance policies or find it too expensive to buy, they could perceive life insurance nondiscrimination laws as less important than younger adults. In three of the four states, high household income and higher education were also associated with higher perceived importance. However, despite these demographic differences, a majority of respondents in all groups, even those with the lowest percentages, believed that life insurance genetic nondiscrimination was somewhat or very important. No demographic category in any state had less than 69% of respondents viewing these legal protections as somewhat or very important.

Notably, significant differences in perceived importance of life insurance non-discrimination laws were not observed in the current study across the racial and ethnic groups examined. Previous studies have found disparities in use of genetic tests and participation in genetic research in certain racial and ethnic groups, and reported barriers include fear of discrimination (Simon and Petrucelli 2009; Sheppard et al. 2013; Nwulia et al. 2011). Our findings were mixed in regard to awareness of nondiscrimination laws. In Ohio, non-Hispanic black respondents had the highest awareness, and the percentage was significantly higher than the percentage for Hispanic respondents. In Connecticut, non-Hispanic black respondents had the lowest awareness, significantly lower than the percentage for non-Hispanic white respondents. In Michigan, non-Hispanic black respondents reported the highest level of awareness, but the percentage was not statistically different from the other groups.

The percentage of respondents who were somewhat or very interested in receiving a genetic test ranged from 39.5% in Ohio to 52.4% in Michigan. Many of these people may have been uninterested for reasons other than worry about genetic discrimination, but over three-fourths of those not interested in genetic testing still viewed nondiscrimination laws as important. Concern over genetic discrimination, whether it is in health insurance, employment, life insurance, or other arenas, could impact health care decisions and health outcomes.

Limitations of this study include differences in the sociodemographic characteristics of the populations in each state, as well as differences in state survey methodology. Additionally, the survey utilized residential landline phone numbers, so respondents without access to a working residential landline telephone were not included. The study did not include evaluation of the health literacy and numeracy of our survey population. The data collected are based on self-reported information, which may be inaccurate if respondents misinterpreted the questions. Lastly, the study assessed awareness of GINA, but did not evaluate knowledge of the specific protections and limitations of GINA.

Despite these limitations, the results indicate that more policies, processes, and education are needed to raise awareness of protections in place for genetic information in the employment, research, healthcare, and health insurance arenas. GINA and other state genetic nondiscrimination laws have yet to calm anxiety over genetic discrimination in the U.S., as most respondents were unaware of genetic nondiscrimination laws and had high levels of concern over life insurance genetic discrimination. Recent studies suggest that concerns regarding genetic discrimination in health insurance and employment persist in the post-GINA era (Shostak et al. 2011; Laedtke et al. 2012; Bernhardt et al. 2011). This suggests a continued need for educational efforts, although there is some evidence indicating those concerns are waning among patients and healthcare providers (Ready et al. 2011; Matloff et al. 2013; Huizenga et al. 2010).

Building awareness of the protections offered by these laws may encourage more people to undergo appropriate and potentially life-saving genetic counseling and testing. These efforts may be particularly important for those with lower levels of formal education and lower incomes, as these groups are even less aware of genetic discrimination legal protections than the general public and may therefore be less likely to get appropriate genetic counseling or testing. There is a continued need for public health and genetic specialists to develop new methods for reaching out to populations and individuals with less formal education and lower incomes, as they may not have access to the same communication devices and networks utilized by those with higher levels of education and income.

The high rate of concern about life insurance discrimination and the high rate of perceived importance of laws protecting against life insurance discrimination also point to the need for continued dialogue about legal protections in this and other insurance areas. A multidisciplinary group convened in 2012 examined whether predictive risk assessment based on genomic data should be used for life insurance underwriting (Joly et al. 2013a). In their action items, the group acknowledges that "there is at present insufficient benefit to warrant the addition of predictive genomic data to actuarial risk stratification models;" however, they also encouraged research by insurance companies "on ways to

include genomic data to their models and the implication for customer's insurability," and propose actions that insurers and others could take to "alleviate concerns over the use of genomic information in life insurance." The group also supported explicit policies and international consensus against requesting genomic research results from life insurance applicants.

Recent reviews of genetic discrimination in general, and in life insurance specifically, concluded that the available evidence clearly documents examples of individual cases of genetic discrimination (Joly et al. 2013b; Otlowski et al. 2012; Barlow-Stewart et al. 2009). However, Joly et al. (2013b) concluded that the evidence for genetic discrimination in life insurance has important limitations that make it difficult to justify policy action on its own, highlighting the importance of additional factors as considerations in policymaking, such as concerns about potential genetic discrimination in life insurance among patients, research participants, healthcare providers, and the general public, as barriers to patient care and research (Ader et al. 2009; Haga et al. 2011).

We found that 39.5 % to 52.4 % of respondents were interested in having a genetic test that could tell them about their risk of having a genetic disease. Despite this moderate level of interest, previous studies have shown that few people have used genetic testing services, even among those who meet evidence-based genetic testing guidelines (Quillin et al. 2014; Levy et al. 2009). This limited real-world experience with genetic testing, coupled with respondents' low awareness of genetic discrimination laws, may reflect a concern with genetic discrimination that is presently largely rhetorical for most respondents. As genetic testing technology advances and becomes more accessible to a larger portion of the population, people may become more personally concerned with the possibility of genetic discrimination. Genetic specialists and privacy lawyers can encourage dialogue and awareness of the scope and limitations of our existing legal protections now, rather than simply reacting to problems as they arise in the future, which may help ensure a more rational policy landscape in a rapidly changing field.

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Conflict of Interest The authors declare no conflicts of interest.

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