
Public Attitudes

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When the Human Genome Project officially began in 1990, the first social concern to generate widespread interest was the possibility that health insurance companies would use predictive genetic information to charge individuals higher rates or to exclude them from coverage (Murray 1992; NIH-DOE Working Group 1993). Both the public sentiment of strong opposition to such practices and the public policy response of enacting legislation prohibiting genetic discrimination in health insurance were easy to predict. Although comprehensive federal bills to prohibit genetic discrimination in health insurance have languished in Congress, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits employer-sponsored group health plans from excluding from coverage, charging higher rates, or offering different benefits to members of a group based on their genotype (HIPAA 1996). In addition, all but a few states have enacted laws prohibiting genetic discrimination in health insurance, applicable mostly to individual policies and nonemployer groups (Hall 1999; National Conference of State Legislatures 2001).

As the policy focus has shifted to the possible role of genetic information in life insurance underwriting, it is important to consider public attitudes about a range of related questions. What does the public regard as the primary social function of life insurance? What is the proper role of underwriting in general? If individuals learn that they are at a genetically increased risk of developing a serious illness in the future, would this affect their decision to purchase life insurance or the amount of coverage? If individuals are concerned about genetic discrimination in life insurance, how does the level of concern compare with other social concerns? What, if any, legislative action would be appropriate to deal with the issue?

This chapter reports some of the key findings of the first comprehensive public survey on genetic information and life insurance underwriting. In general, the data lead to the following four conclusions: (1) the public generally believes that life insurance companies would use genetic information to deny coverage or charge higher rates; (2) individuals who learned that they were at a genetically increased risk of a serious illness would be more likely to buy all forms of insurance, but especially health and disability insurance; (3) the likelihood of purchasing all forms of insurance on learning of a genetically increased risk is strongly correlated with age, with younger individuals most likely to be purchasers; and (4) support for legislative limitations on the use of genetic information by life insurers is most correlated with education level, with people with the most education supporting such measures.

Prior Research

As with the policy analysis and legislative activity, public opinion research on genetics and insurance has concentrated on health insurance. Four data sources on public attitudes regarding genetics and life insurance, however, are worth exploring: a 2002 Harris poll, two empirical research studies on adverse selection in life insurance (Zick et al. 2000; Armstrong et al. 2003) and data from an interview survey generated by our research team in 2001.

An interactive telephone survey of 1,013 adults was conducted between May 15 and 21, 2002 (Harris 2002). Among the questions asked was the following:

If you were given a genetic test which showed how likely you were to get one or more serious diseases, which of the following do you think should be allowed to see this information?

The results, originally published in the *Wall Street Journal*, were as follows:

Your regular doctor	90%
Any doctor who is helping you to prevent a disease for which the test shows you are at risk	69%
Your health insurance company which is paying the cost of this treatment or care	39%

A life insurance company from which you want to obtain life insurance	25%
Your employer who is paying for part of your health insurance	17%
Not sure/refused	5%

The question has two interesting elements. First, it asked who should be able to see the information. Although it did not ask whether insurance companies, for example, should be able to use results of the genetic tests in deciding coverage or rates, a likely interpretation by many respondents was that having access to the information could lead to some (possibly adverse) action. Second, life insurance companies are the only entities on the list that are not involved in providing or reimbursing for health services. Even with these caveats, the 25% figure is consistent with our earlier surveys reported below.

The second major piece of research attempted to measure the actions of at-risk individuals rather than general public opinion. Zick et al. studied 105 women age eighteen to fifty-five years from a large kindred who had undergone research genetic testing to determine whether they were carriers of a breast cancer mutation (BRCA 1). Of these women, twenty-eight tested positive and seventy-seven tested negative. A control group consisted of 177 women from the general population who had not had genetic testing but who had at least one first- or second-degree relative with breast or ovarian cancer. The study followed the women for one year to ascertain whether they differed in life insurance-purchasing behavior based on genetic information. In other words, would a woman's knowledge of her genetically increased risk of breast cancer lead her to purchase more life insurance or adverse selection?

The authors found no differences in the number of life insurance policies purchased or coverage levels between women in the study kindred and those from the general population. Neither family history, testing status, nor participation in prior BRCA 1 research studies had an effect on purchasing life insurance. The authors recognized, however, that the study had some clear limitations, including at least the following: (1) the Utah study population was quite homogeneous and consisted largely of active members of the Church of Jesus Christ of Latter Day Saints; (2) only twenty-eight women tested positive; and (3) the one-year follow-up period may have been too short. Nevertheless, at a minimum, the study

failed to find evidence that adverse selection in life insurance would be an immediate and widespread reaction to knowledge of a genetically increased risk of breast cancer in an at-risk family.

Third, another study assessed the effect of genetic testing for breast cancer risk on the life insurance purchasing behavior of women in a university-based breast cancer clinic from 1995 to 2000 (Armstrong et al. 2003). Surveys were mailed to 1,186 women, 926 who had participated in the clinical risk assessment program and 262 who had tested positive for a BRCA1/2 mutation through a research testing protocol. The questionnaires asked about current life insurance coverage, changes in life insurance made since going through the program, and occurrence of life insurance discrimination since participation in the risk assessment. A total of 709 questionnaires were returned, but only 636 respondents were deemed eligible for inclusion in the final study cohort.

Almost half the women expressed concern about future life insurance discrimination if they underwent genetic testing, and this fear was a leading reason for refusal to undergo testing. Despite the fear, however, there was no evidence of actual discrimination. Thirty-seven women (6%) reported changing their life insurance coverage after genetic testing or counseling, with twenty-seven increasing coverage, six decreasing or canceling coverage, and four not specifying their action. Women who increased their coverage were more likely to have tested positive for a BRCA1/2 mutation.

The study authors noted the following limitations of their research. Patients were drawn primarily from a single clinical site in Philadelphia, the sample size was small, and the survey relied on self-reports of life insurance purchasing behavior. In addition, there was no control group of women who did not enter the breast cancer risk evaluation program.

Finally, as part of research on pharmacogenomics (Rothstein 2003), we conducted a nationwide telephone interview survey of 1,796 individuals in 2001. We asked the following questions (on a rotating basis):

If your employer could get the results of a genetic test that showed whether you were more likely to get sick in the future, what impact, if any, would this have on your willingness to take the test?

If your health insurance company could get the results of a genetic test that showed whether you were more likely to get sick in the future, what impact, if any, would this have on your willingness to take the test?

If your life insurance company could get the results of a genetic test that showed whether you were more likely to get sick in the future, what impact, if any, would this have on your willingness to take the test?

Approximately 70% of respondents said that disclosing test results to a third party would make them less likely to take a genetic test. Unlike the Harris survey, responses in our survey were quite similar for employers, health insurers, and life insurers. Using multivariate analysis, we determined that being white, having a higher income, and having more education correlated with a lower likelihood of undergoing testing if results were available to employers, health insurers, or life insurers (Rothstein and Hornung 2003).

Methodology

The current survey consisted of randomly dialed telephone interviews with 2,108 individuals across the country between January 3 and April 14, 2002. The research was funded by a grant from the National Human Genome Research Institute of the National Institutes of Health. Interviews were conducted by Telesurveys Research Associates of Houston, Texas, under contract with the Institute for Bioethics, Health Policy, and Law of the University of Louisville School of Medicine.

Before conducting the interviews, sessions were held with four focus groups composed of white, African-American, Hispanic, and Asian individuals. The focus groups explored levels of awareness, knowledge, and opinions concerning genetic testing and use of genetic information in life insurance underwriting. They also provided an opportunity to assess individuals' comprehension of concepts and issues and to document the vocabulary used to describe these concepts and issues.

With the aid of focus group findings, the survey instrument was drafted by the principal investigator and survey contractor. After several revisions, the instrument was pretested in twenty interviews for length (under 15 minutes) and clarity. The final instrument was translated and back-translated by separate translators into Spanish, Mandarin and Cantonese Chinese, Vietnamese, and Korean. The research protocol and survey instrument received approval from the Human Studies Committee of the University of Louisville. All interviewees gave oral consent at the beginning of the interview.

A two-stage sampling design was created with an overall sample of 2,108, with oversampling to achieve a minimum subgroup size of 300 for whites, African-Americans, Hispanics, and Asians. The first stage consisted of a primary sample of 1,500 interviews completed by random digit dialing to all area codes in the forty-eight contiguous states, with the number interviewed in direct proportion to population. A total of 608 additional interviews were conducted to increase the sample size to a minimum of 300 for each of the four racial-ethnic groups. This was accomplished by targeted random digit dialing from area codes and telephone exchanges in which 30% or more of households were of the designated racial-ethnic group. Race and ethnicity designations were based on self-identification; respondents also could designate "other," but only a small number chose to do so. Therefore this category is not reported in findings in which race and ethnicity are reported.

This sampling design yielded both widespread geographic representation and inclusion of households with listed and unlisted telephone numbers. Furthermore, the sample of 2,108 yielded estimates with a margin of error of only 2.14% at the 95% confidence level, and 90% statistical power for detecting racial-ethnic pairwise differences of 6% at alpha equals 0.05.

The investigators recognize that Hispanics and Asians are heterogeneous groups. The preferred sampling methodology would have used oversampling to include a sufficient number of Chinese-Americans, Vietnamese-Americans, Japanese-Americans, Korean-Americans, Filipino-Americans, and other Asian subpopulations to detect important differences. Similarly, the preferred methodology would have used oversampling for Mexican-Americans, Cuban-Americans, Puerto Rican-Americans, and other Hispanic subpopulations. Native Americans also would have been included and sampled in sufficient numbers. Financial constraints, however, necessitated limiting the survey to four racial and ethnicity categories.

Telephone interviews were conducted in English, Spanish, Chinese, Vietnamese, and Korean. Up to five contact attempts were made for each telephone number at different times of day. The response rate for residential calls where the call was answered (not counting businesses, fax machines, or voice mail) was 68.3%.

The survey contained sixteen substantive questions, most with sub-parts, that asked respondents about their current life insurance coverage, their perceptions of how insurers and individuals would be likely to respond to predictive genetic information, and their opinions on public policy options to address the issue. The survey used the following fifteen demographic variables: household size, age, education, marital status, employment status, residence in urban or rural area, race-ethnicity, language spoken at home, country of birth, religion, income, prior genetic testing, health status, and gender (appendix 1.1).

Key Findings

The survey findings present a wealth of information. In this chapter, we report on the following five areas of inquiry: (1) public opinions about the expected action of life insurance companies if they have access to genetic information; (2) likely insurance-purchasing behavior of individuals who learn they are at a genetically increased risk of a serious health problem; (3) public opinions on possible regulation of use of genetic information by life insurance companies; (4) public concerns about genetic discrimination relative to other issues; and (5) public views about the need for life insurance. All data analyses were accomplished using Statistical Package for the Social Sciences (SPSS) software. Cases were weighted by age for all racial-ethnic comparisons and by race-ethnicity for all age comparisons. All other analyses used a case-weighting system to reflect both age and race-ethnicity, with sample weights adjusted to yield a total of 2,108 cases.

Expected Action of Life Insurance Companies if They Have Access to Genetic Information

Although little documented evidence of adverse treatment of individuals in employment (Miller 2000), health insurance (Hall 1999) or life insurance (Zick et al. 2000) exists to date, concern about discrimination is widespread. Such concern should not be dismissed as irrational and unworthy of consideration for two important reasons. First, the amount of predictive genetic information in medical records is expected to grow tremendously as medical applications of genetic research move

beyond rare, monogenic disorders to more common, multifactorial, chronic diseases. Second, the fear of discrimination already is causing many at-risk individuals to forgo genetic testing, thereby failing to take advantage of the opportunity for prevention and early diagnosis. Thus, there is an important population health component of concern about discrimination.

We attempted to measure public attitudes regarding the likely effects of genetic information on policy issuance and pricing by life insurance companies. We asked: “Now I would like to find out what you think life insurance companies might do if they have access to genetic information. If a life insurance company has access to the genetic information of someone applying for a life insurance policy, do you think they would be likely to” Subjects were asked to respond yes, no, or don’t know to each of the following options: refuse to sell the policy; agree to sell the policy at the regular price; agree to sell the policy at a higher price; and agree to sell the policy at a lower price; refusals also were noted.

Because life insurance is a highly competitive business and companies attempt to sell as many policies as possible (Meyer 2004), in theory, the effect of additional genetic (or other predictive medical) information would be neutral on overall availability and pricing of life insurance. Thus, for example, one could argue that for every individual whose rates were raised from standard rates on the basis of being considered at a high risk, another individual’s rates would be lowered due to assumed low risk. Even if this assumption is correct, upward and downward adjustments in price are unlikely to be made on an equal-number basis. For example, a few individuals might be offered insurance at much higher rates (or not at all), and many individuals would have the same or only slightly lower rates.

In general, the public believes that genetic information would result in life insurance companies refusing to issue policies (85.1%) or charging higher premiums (85.1%). Only 26.7% said that companies would agree to sell the policy at the regular price, and only 19.5% said that genetic information would result in the issuance of a policy at a lower price.

As shown in figure 1.1, significant differences were found across racial-ethnic groups in beliefs about what life insurance companies would do if they had access to genetic information. More than 90% of whites said that they thought companies would refuse to sell a policy and that they

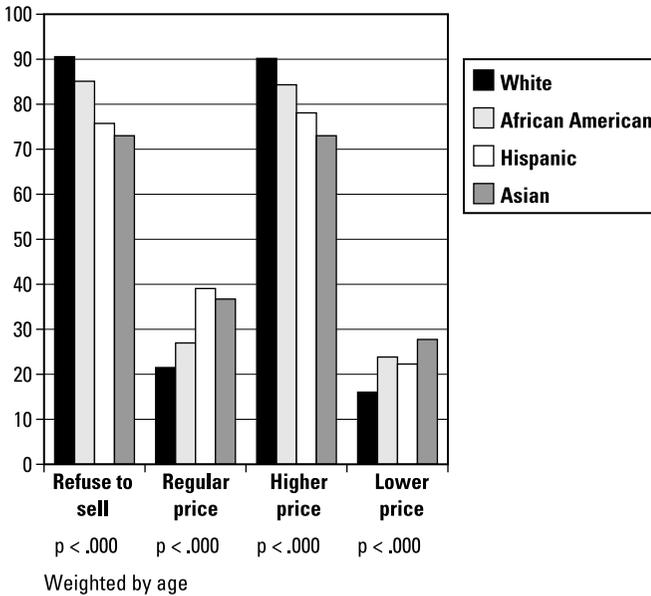


Figure 1.1

Perception of life insurers' likely response to genetic information, by race/ethnicity.

would charge a higher price, whereas only about 72% of Asians held these views. At the same time, whites were least likely to think that companies would sell a policy at the regular or lower price, whereas Asians and Hispanics were most likely to say that would be the case.

Important differences were revealed in beliefs depending on the age of the respondent (figure 1.2). The youngest and oldest respondents were least likely to believe that insurance companies would refuse to sell a policy or charge a higher price, but more than 90% of those between ages 35 and 64 years believed this would occur. At the same time, between 80% and 90% of respondents in each age group thought that insurance companies would sell policies at higher prices.

As shown in figure 1.3, the percentage of respondents who thought insurance companies would deny a policy or sell it at a higher price if they had access to genetic information increased with income. In contrast, the percentage thinking that insurance policies would be sold at the regular price decreased with income. Finally, respondents earning between \$25,000 and \$74,999 per year were least likely to believe that

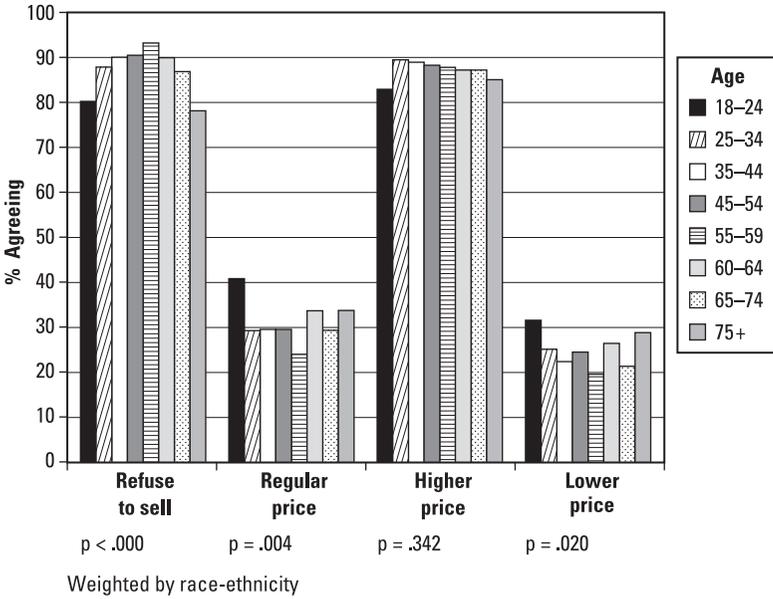


Figure 1.2 Perception of life insurers' likely response to genetic information, by age.

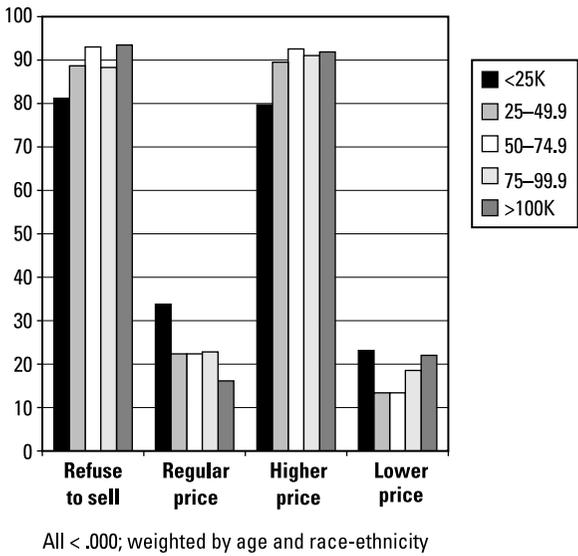


Figure 1.3 Perception of life insurers' likely response to genetic information, by income.

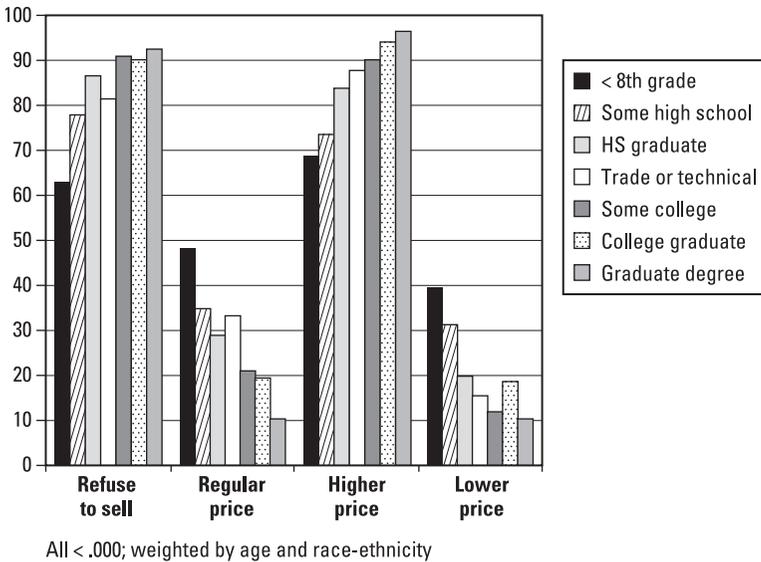


Figure 1.4

Perception of life insurers' likely response to genetic information, by education.

companies would sell policies at a reduced price if they had genetic information about applicants.

Education had the clearest relationship to what respondents believed about how life insurance companies would act if they had access to an individual's genetic information (figure 1.4). The percentage who believed that insurance companies would refuse to sell a policy and the percentage who thought companies would sell a policy at a higher price increased with years of education. Between 60% and 70% of those with less than an elementary education, but over 90% of those with a graduate degree, thought this way. As expected, the percentage who thought that an insurance company would sell a policy at the regular price or at a lower price decreased with education from a high of about 40% among those with an elementary education or less to less than 10% with a graduate degree.

Beliefs about Genetic Information about Disease and Consumers' Insurance Purchasing Behavior

The greatest threat to risk-based insurance of any type is adverse selection, defined as the likelihood that those who know they are at increased

risk will be more likely to purchase insurance and in greater amounts than those who lack such knowledge or know they are at decreased risk (Dicke 2004; Gleeson 2004; Pokorski 1995). Insurers attempt to prevent adverse selection in various ways, including the obvious example of refusing to sell flood insurance to homeowners after a hurricane has been tracked bearing down on the coast.

Adverse selection has two essential elements in the context of medical underwriting. First is asymmetry of information relevant to mortality risks. If the insurance company has the same predictive health information as the consumer, known risks can be reflected in the pricing of the product. Currently, few genetic tests are performed in routine medical practice, and they are generally limited to testing for predisposition to rare disorders among individuals with a family history of the illnesses. Because life insurance application forms ask about family health history, as to rare disorders there is unlikely to be substantial information asymmetry between the applicant and the company. The possibility of asymmetry will grow, however, as more genetic tests are performed for more common disorders in primary care settings or even by applicants themselves if home-collection genetic test kits become more widely available.

The second requirement for adverse selection is the inclination of an individual to act on the information, willingness to “game the system” by withholding information in the medical underwriting process. Virtually no empirical evidence or survey data of likely consumer behavior are available in the specific context of genetic information and life insurance. One empirical study found no evidence of adverse selection (Zick et al. 2000) and another study found some evidence of adverse selection (Armstrong et al. 2003), but both studies had serious methodological limitations.

We asked respondents if they thought that consumers would withhold unfavorable results of a genetic test from a life insurance company. Nearly one-fourth (23.1%) strongly agreed and 50% agreed, whereas only 11.3% disagreed or strongly disagreed. Almost three-quarters of the population believe that other people would withhold information from an insurance company about a genetic test that indicated that they were more likely to get a serious illness. When half of the sample was asked if they agreed or disagreed with the statement that “it would be

wrong to withhold genetic information from an insurance company,” just 50.6% agreed or strongly agreed, 25.9% disagreed, and 5.8% strongly disagreed. The other half of the sample was asked if they agreed or disagreed that it “would *not* be wrong to withhold genetic information from a life insurance company”; 37.7% disagreed or strongly disagreed, but 43.3% agreed and 10.9% strongly agreed.

To summarize these findings, respondents overwhelmingly expected consumers to withhold unfavorable results of a genetic test from life insurers. They were more closely divided on the issue of whether it would be wrong to do so, with results varying on whether the question was asked in the affirmative or negative.

We attempted to obtain additional insights into the prospects of adverse selection in life insurance based on genetic information by asking a question that placed life insurance in the context of other forms of insurance. We asked the following:

I am going to read a list of different types of insurance and ask you to tell me whether you would be likely or unlikely to buy each type if a medical test indicated you were at an increased risk of getting a serious disease. First, if a medical test indicated that you, personally, had an increased chance of getting cancer or heart disease in the next ten years, would you be likely or unlikely to (buy/buy more) . . .

- A. Health insurance?
- B. Life insurance?
- C. Long-term care or nursing home insurance?
- D. Disability insurance that would pay a portion of your wages if you could not work due to accident or illness?

Before stating the responses, a few words of explanation. We believed it was necessary to give an example of some common, serious illnesses so that all respondents would use a similar definition of “serious illness.” We chose cancer and heart disease, the former because it is an area where several genetic tests already are in use and the latter because it is the most common cause of mortality. We included the ten-year figure so that all respondents would be applying the same time horizon. Based on results of focus groups, we thought it necessary to add brief explanations of long-term care and disability insurance, but did not think it necessary to explain health or life insurance. The order in which insurance products were mentioned was rotated. Finally, the answer options for each question were likely, unlikely, and unsure; refusals also were noted.

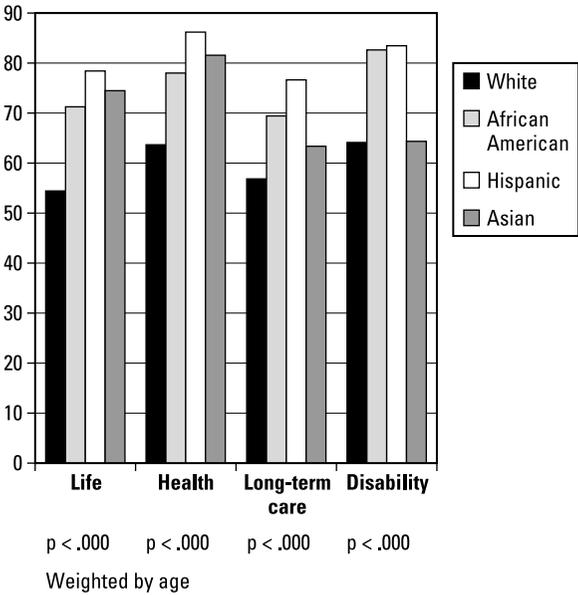


Figure 1.5

Likelihood of buying life insurance if medical test indicated increased 10-year risk of cancer or heart disease, by race/ethnicity.

Overall, respondents indicated an interest in purchasing all forms of insurance, with the following specific percentages: health 70.6%; disability 70.3%; long-term care 62.8%; and life 61.1%. Although the question did not ask whether respondents would also refuse to divulge to the insurance company that they had undergone testing, the answers shed light on this point. Figure 1.5 presents responses according to race-ethnicity. Hispanics were most likely to respond that they would buy or buy more insurance if they had information about an increased risk of illness (88.6% health, 85.5% disability, 80.5% life, 78.8% long-term care) and whites were least likely to do so (health 65.5%, life 56%, long-term care 58.3%, disability 65.8%). The high percentage of Hispanic respondents may be explained by the fact that they were the group least likely to have life insurance in the first place, only 45.0%, compared with 77.9% for African-Americans, 75.6% for whites, and 47.5% for Asians.

Perhaps surprising, in light of the role of predictive information affecting insurance-purchasing behavior, figure 1.6 indicates that the likeli-

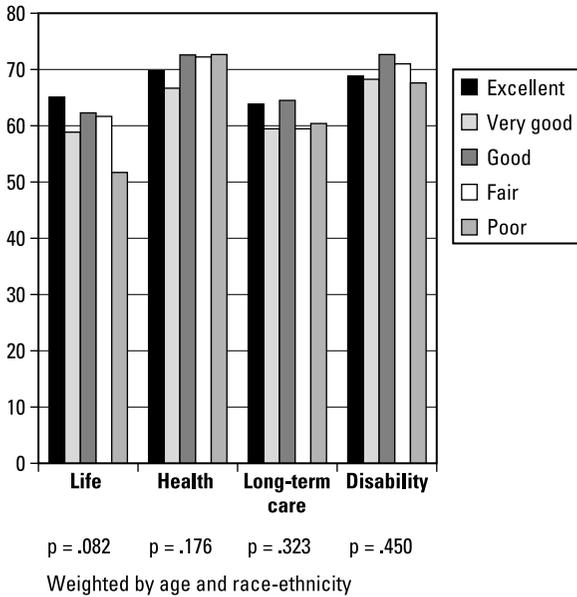


Figure 1.6

Likelihood of buying life insurance if medical test indicated increased 10-year risk of cancer or heart disease, by health status.

hood of an individual buying insurance is not affected by current health status. Similarly, neither education nor income was a significant predictor of likelihood to buy or buy more insurance. Figure 1.7, however, indicates a strong association between age and likelihood of buying life, health, and disability insurance, with younger individuals much more likely to buy or buy more insurance. On the one hand, this may not be viewed as great a risk of adverse selection because younger individuals are less likely to have insurance at the outset, and the amount they would purchase is likely to be lower because they generally have lower incomes and fewer assets. On the other hand, the result may be viewed as a substantial risk of adverse selection because younger people pay much lower premiums for life insurance because of their lower mortality risk, and premature death in this cohort would result in a substantial loss in expected years of life. The percentage saying they would be likely to buy any type of insurance did not differ according to either education or income.

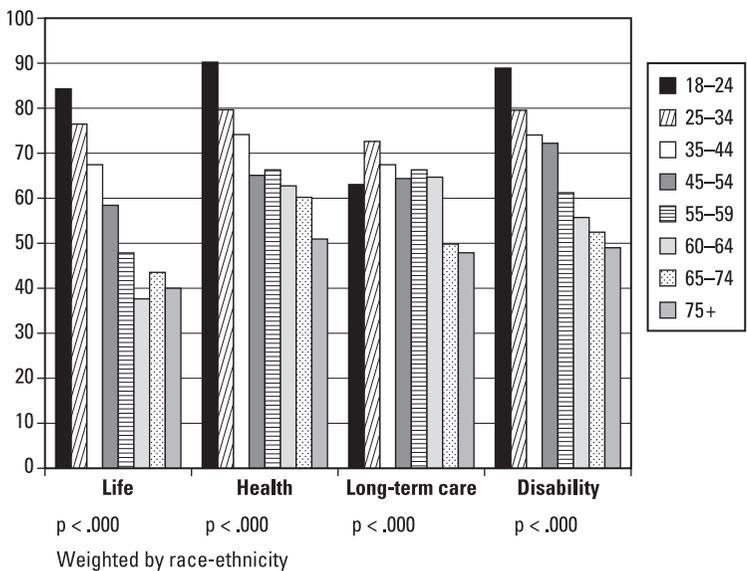


Figure 1.7
Likelihood of buying life insurance if medical test indicated increased 10-year risk of cancer or heart disease, by age.

Opinions on Possible Regulation of Life Insurers’ Use of Genetic Information

Elected officials, executives of the life insurance industry, academics, consumer advocates, and numerous other individuals have begun searching for an appropriate response to the issue of genetic information and life insurance underwriting. We attempted to identify public opinion about various policy options. The immediate options available to life insurance companies are to acquire relevant genetic information from an applicant’s medical record, or to require someone applying for a policy to take a specific genetic test or a battery of tests to determine risk of life-threatening disease. To explore beliefs about what the population thinks is appropriate genetic information that an insurance company should be allowed to obtain, we asked:

Now I am going to read some general statements about life insurance and genetic testing and ask whether you agree, disagree, or have no opinion. The first is . . .

A. Life insurance companies should be allowed to require all applicants to take a genetic test.

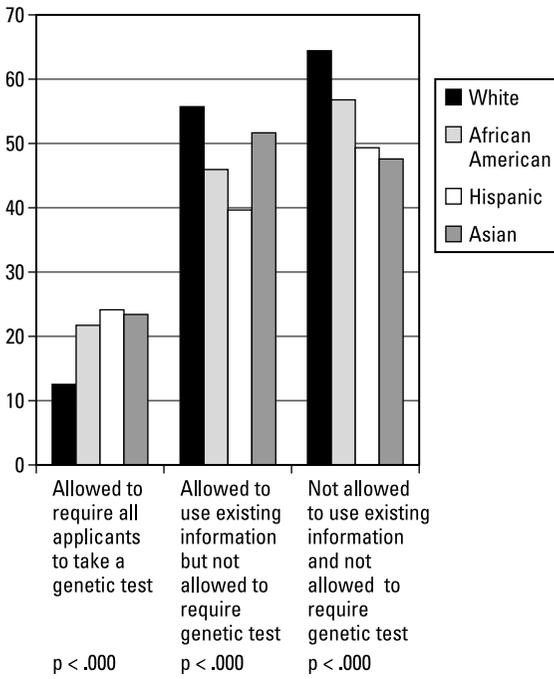


Figure 1.8

Preference for regulation of life insurers' use of genetic information, by race/ethnicity.

B. Life insurance companies should not be allowed to use either the results of genetic tests or other genetic information.

C. Life insurance companies should be able to use genetic information from existing medical records, but they should not be allowed to require applicants to take a genetic test.

The order in which the three parts of the question were asked was rotated. The answer options were agree, no opinion, disagree, and unsure; refusals also were noted.

Most respondents (60.8%) said that life insurance companies should not be permitted to use *either* the results of genetic tests or other genetic information. Most (53.2%) said that companies should be able to use genetic information from existing medical records, but they should not be allowed to require applicants to take a genetic test. Only 15.4% agreed with the statement that companies should be allowed to require all applicants to take a genetic test. As shown in figure 1.8, whites

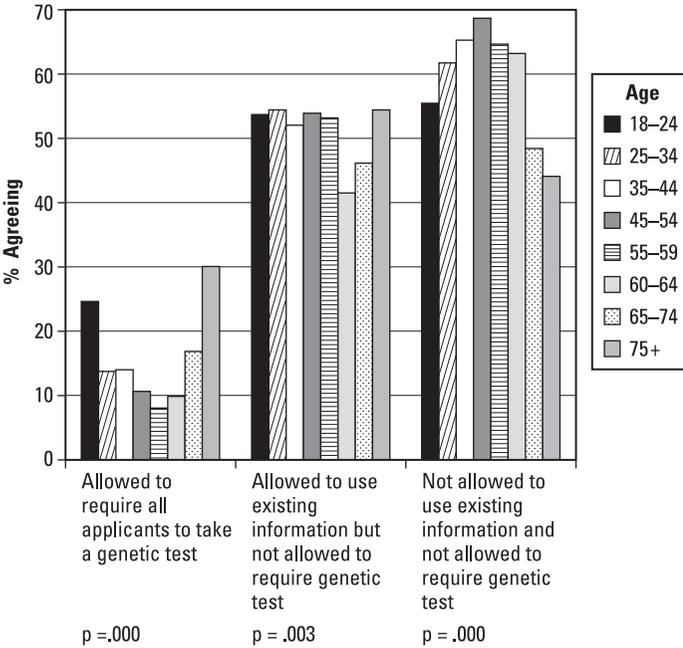


Figure 1.9
 Preference for regulation of life insurers' use of genetic information, by age.

(12.4%) were least likely to say that companies should be allowed to require applicants to take a genetic test and most likely (55.6%) to say that companies should be allowed to use existing information.

Figure 1.9 reveals the effect of age on the answers. Between 25% and 30% of respondents less than twenty-four and over seventy-five years of age were most likely to approve of required genetic testing. Socioeconomic status characteristics also appear to be important determinants of attitudes. More than 20% of the lowest-income group said that insurance companies ought to be allowed to require applicants to have a genetic test, but only about 8% of the highest-income group had that opinion (figure 1.10). Similarly, between 25% and 30% of respondents who did not complete high school approved of life insurance companies requiring genetic tests, compared with less than 10% of respondents who had a college or graduate degree (figure 1.11). When it came to using existing genetic information from an applicant's medical record, clear differences of opinion were seen by education, but less clear differences

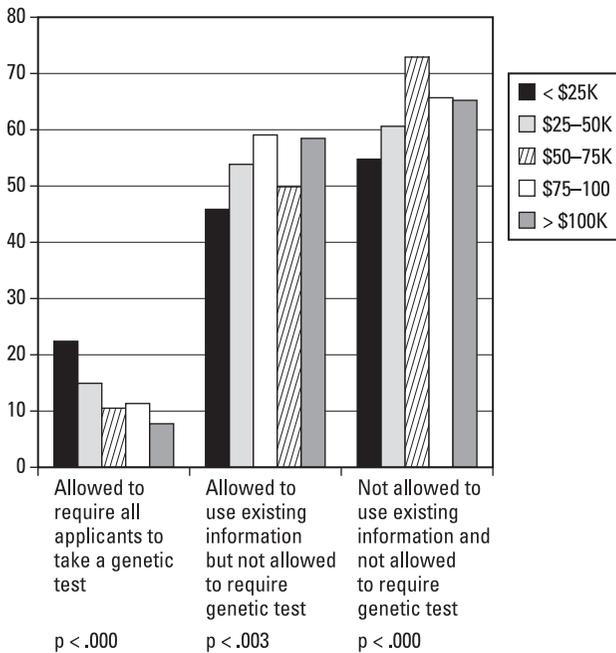


Figure 1.10

Preference for regulation of life insurers' use of genetic information, by income.

by economic status. Respondents with the least education were least likely to say that companies ought to be allowed to use existing information. In contrast, groups with the highest education were twice as likely to allow companies access to existing information.

What is interesting to note is that the lowest-education group, those with less than an elementary education and who presumably had the least understanding of genetic testing and genetic information and what they can be used for, did not seem to distinguish between the implications of requiring a test and using existing information. However, as education level increased, respondents were more likely to oppose required genetic tests but would permit use of genetic information that might already exist.

Figure 1.12 provides counterintuitive results. We asked individuals if they ever had a genetic test, and those who had *not* had a genetic test were most likely to oppose allowing life insurance companies to require such tests. Although it is not clear what is responsible for this result, it

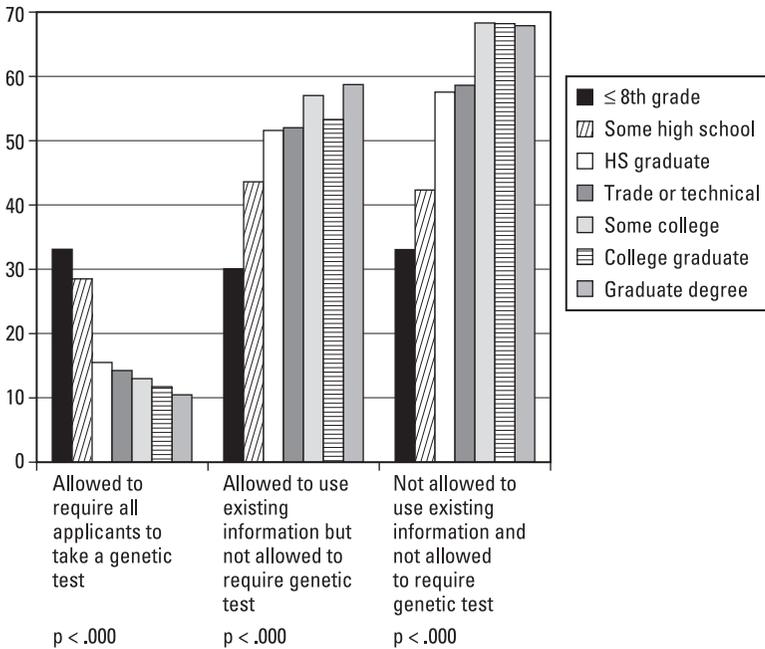


Figure 1.11
 Preference for regulation of life insurers' use of genetic information, by education.

may be that it reflects negative test results or individuals who had declined testing because of possible nonmedical uses of the information. It also should be noted that only 8.1% of respondents reported having had a genetic test.

Concerns about Genetic Discrimination Relative to Other Issues

In our earlier interview survey on public attitudes toward pharmacogenomics we learned that the public is concerned about the possibility of genetic discrimination (Rothstein and Hornung 2003). Although this finding is consistent with numerous studies, it does not measure the degree of concern about genetic discrimination relative to other matters. We tried to address this issue in the current study. As the first part of a question, we asked the following:

Are you concerned that, as scientists learn more about genetics, there is likely to be genetic discrimination or making decisions against a person based on his or her genetic information rather than their actual health?

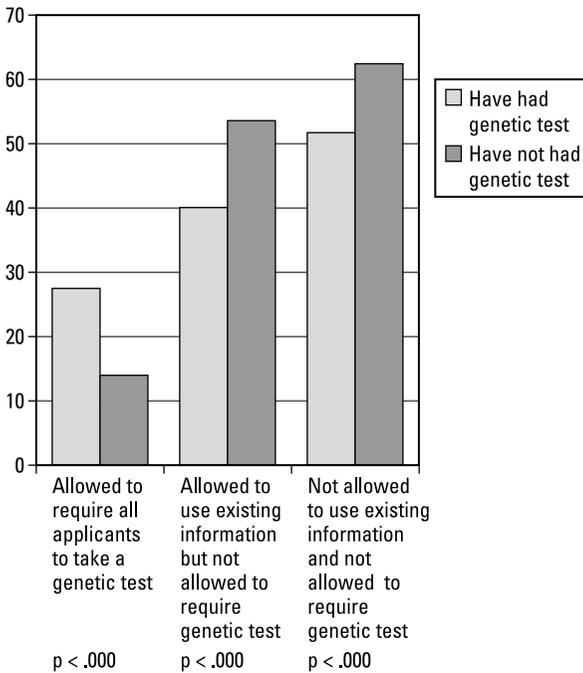


Figure 1.12

Preference for regulation of life insurers' use of genetic information, by whether they have had a genetic test.

Not surprising, 83.1% of respondents answered yes. In part two of the question, we asked those who answered yes the following:

I am going to read a list of other issues and ask you to tell me whether you feel each one is a bigger concern or a smaller concern than genetic discrimination. If you feel any of the issues and genetic discrimination are equal concerns, please tell me that. First, ...

We gave them a list of seven concerns that we asked in rotating order: cloning, crime, the economy, the environment, access to health care, taxes, and terrorism (figure 1.13). About five times more respondents rated terrorism, crime, access to health care, and the economy as causing more concern than rated genetic discrimination a concern. The environment was a more important concern than genetic discrimination by a margin of about three to one, and taxes by a margin of two point five to one. Even cloning, which had the lowest level of concern of the comparison issues, was more a concern than genetic discrimination by a margin of four to three.

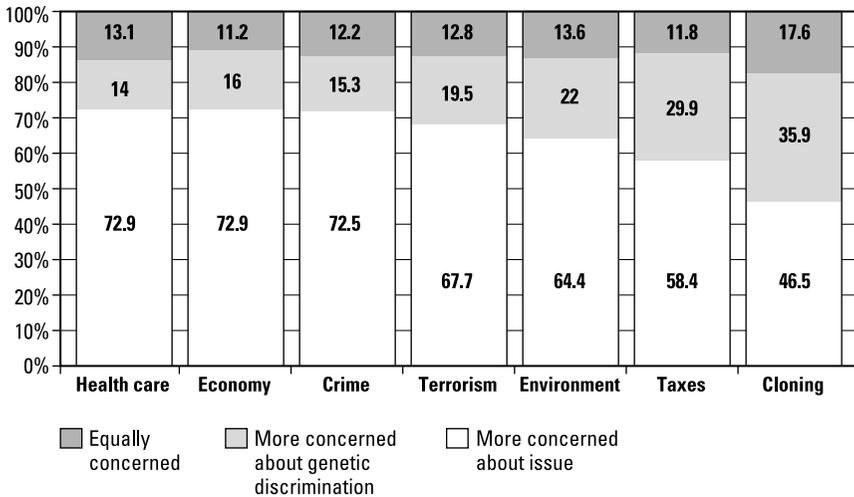


Figure 1.13
Concern about genetic discrimination relative to other issues.

Thus, genetic discrimination, although reported as a concern by 83.1% of respondents, was less a concern than any of the other items on the list. It should be noted that we asked about genetic discrimination in general, which could include employment, health insurance, and other forms of discrimination.

The Need for Life Insurance

A major policy question for possible regulation of the use of genetic information in life insurance (and a recurring theme in several of the chapters that follow) is whether access to life insurance should be considered an economic issue or a civil rights issue. If the former, insurance companies should be given wide latitude in deciding what information to consider in underwriting. If the latter, restricting insurer prerogatives (with the effect of low-risk individuals subsidizing high-risk individuals) may be necessary to promote other social policies. As described below, the survey data also may shed some light on public views on this question.

We asked the following:

Now I am going to read some statements about insurance and ask you to tell me whether you strongly agree, agree, have no opinion, disagree, or strongly disagree with each one. The first statement is . . .

- A. Everyone needs health insurance.
- B. Everyone has a right to health insurance.
- C. Everyone needs life insurance.
- D. Everyone has a right to life insurance.

The questions were block rotated (A and B, C and D). Because there is no legal right either to health or life insurance, we assumed that questions B and D were viewed by respondents as “Everyone should have a right to health/life insurance.”

Of our respondents, 91.2% said that everyone needs health insurance and 90.6% said that everyone has a right to it. These data were in line with expectations. Furthermore, 69.2% said that everyone needs life insurance. This was in line with expectations (70% of households have life insurance), in that depending on age, health, family status, and financial status, a substantial minority of respondents might not believe that everyone needs life insurance. On the second part of the question, however, instead of a comparable response, as was the case with the question on health insurance, 82.6% of respondents said that everyone has a right to life insurance. Overall, 62.2% agreed with both statements—that everyone needs and should have a right to life insurance.

A wide range of demographic factors can be detected from these responses. Those who regarded life insurance as both a need and a right had fewer years of education, tended to be African-American or Hispanic, were Catholic, and had total family incomes under \$25,000 per year. About 20% believed that everyone needs life insurance, but that it is not a right. These individuals were likely to have college or postgraduate education, be older and widowed, be white or Asian, and have an annual income over \$100,000. A little less than 7% did not feel that everyone needs life insurance, but that they should have a right to it. They were likely to be retired and to have incomes above \$75,000 per year. Finally, about 10% of respondents did not think that everyone needs life insurance and did not believe that everyone should have the right to it. These individuals completed the most education, were more likely to be white, and to have incomes above \$50,000.

How does one account for this disparity? Consistent responses regarding health insurance were not repeated for life insurance. A substantial number of respondents had different opinions about whether access to life insurance is an economic issue (need insurance), a civil rights issue

(have a right to insurance), both, or neither. The remaining chapters address both aspects of life insurance, and the recommendations in chapter 11 focus on these concerns.

Conclusion

The interview survey provides a detailed look at public attitudes about the use of genetic information in life insurance underwriting. The following conclusions can be drawn from the data: (1) most people expect life insurers to use genetic information to deny coverage or increase rates; (2) those who learn that they are at an increased risk of having a serious illness are most concerned about obtaining health and disability insurance; (3) age is the most significant factor affecting the likelihood of purchasing insurance after learning about an increased health risk; (4) most individuals are opposed to life insurers requiring applicants to take a genetic test as a condition of obtaining a policy; and (5) whereas overwhelming concern was expressed about genetic discrimination, it is considerably behind all other social issues we probed.

References

- Armstrong, K., "Life Insurance and Breast Cancer Risk Assessment: Adverse Selection, Genetic Testing Decisions, and Discrimination," *Am. J. Med. Genet.* 120A: 359–364 (2003).
- Dicke, A. A., "The Economics of Risk Selection in Life Insurance," in *Genetics and Life Insurance: Medical Underwriting and Social Policy*, M. A. Rothstein, ed. Cambridge: MIT Press (2004).
- Gleeson, R., "Medical Underwriting for Life Insurance," in *Genetics and Life Insurance: Medical Underwriting and Social Policy*, M. A. Rothstein, ed. Cambridge: MIT Press (2004).
- Hall, M., "Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information," *Jurimetrics J.*, 40: 93–125 (1999).
- Harris Interactive, "Americans Say They'd Use Genetic Testing for Diseases," *Wall St. J.*, June 5, 2002.
- Health Insurance Portability and Accountability Act, 42 U.S.C. §§300gg-300gg-2 (1996).
- Meyer, R., "Genetics and Life Insurance: The Insurer Perspective," in *Genetics and Life Insurance: Medical Underwriting and Social Policy*, M. A. Rothstein, ed. Cambridge: MIT Press (2004).

Miller, P., "Is there a Pink Slip in My Genes? Genetic Discrimination in the Workplace," *J. Health Care Law & Policy* 3: 225–245 (2000).

Murray, T., "Genetics and the Moral Mission of Health Insurance," *Hastings Center Rep.*, 22(6): 12–17 (1992).

National Conference of State Legislatures, Denver and Washington, D.C.: National Conference of State Legislatures, *Genetics Policy Report: Insurance Issues* (2001).

NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, *Genetic Information and Health Insurance, Report of the Task Force on Genetic Information and Insurance* (1993).

Pokorski, R., "Genetic Information and Life Insurance," *Nature* 376: 13–16 (1995).

Rothstein, M. A. ed., *Pharmacogenomics: Social, Ethical, and Clinical Dimensions*. Hoboken, N.J.: John Wiley & Sons (2003).

Rothstein, M. A. and C. A. Hornung, "Public Attitudes About Pharmacogenomics," in *Pharmacogenomics: Social, Ethical, and Clinical Dimensions*," M. A. Rothstein ed. Hoboken, N.J.: John Wiley & Sons (2003).

Zick, C. et al., "Genetic Testing, Adverse Selection, and the Demand for Life Insurance," *Am. J. Med. Genet.* 93: 29–50 (2000).