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A Survey of Medical Directors of Life Insurance Companies Concerning Use of Genetic Information

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Summary

Rapid advances in our ability to test persons presymptomatically for genetic diseases have generated increasing concern that genetic information will be abused by insurance companies. Reasoning that the insurance companies may have the strongest interest in using genetic data and that the medical directors of those companies with responsibility for rating applicants would be a good source of information on the use of such data, we conducted a large survey of medical directors of North American life insurance companies. We received responses from 27 medical directors. Our results suggest that (1) few insurers perform genetic tests on applicants, but most are interested in accessing genetic test information about applicants that already exists; (2) the degree of insurers' interest in using genetic test results may depend on the face amount of the policy applied for and on the specificity and sensitivity of the test; (3) many companies employ underwriting guidelines with respect to certain genetic conditions but may not always have specific actuarial data in house to support their rating decisions; (4) a considerable degree of subjectivity is involved in most insurers' rating decisions; and (5) some of the medical directors who responded to our survey are not fully informed about certain basic principles of medical genetics.

Introduction

Rapid advances in our ability to test persons presymptomatically for genetic diseases have generated increasing concern that genetic information will be abused in nonclinical contexts—particularly by insurance companies (Billings et al. 1992). The potential for abuse may be greatest in the area of life insurance, which, unlike health insurance, is generally purchased by individuals rather than acquired as a benefit of employment. Thus, while all insurers could have some interest in obtaining genetic information, life insurers presumably have the strongest incentive to use genetic data to rate individual applicants.

Some fear that genetic discrimination in insurance is becoming widespread (Billings et al. 1992), while others question how often it occurs (Hook 1992; Lowden 1992). A survey of state insurance commissioners that we conducted in late 1991 uncovered little evidence to suggest that those charged with ensuring that the law is observed as it relates to life insurance practices in the 50 states perceive that genetic testing *currently* poses a significant threat to consumers or that many consumers are *presently* filing complaints with commissioners about insurers' use of genetic data in underwriting (McEwen et al. 1992). Nevertheless, we reasoned that it would be instructive to compare the perceptions of the insurance commissioners with the views and practices of those in the industry who may influence how applicants are rated. We therefore conducted a survey of medical directors of life insurance companies throughout the United States and Canada.

Material and Methods

We developed a survey instrument based on conversations with geneticists and persons working in the insurance industry and after a review of the relevant literature. A survey-design expert reviewed drafts of the survey instrument. We used a 13-page questionnaire

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Table 1

Medical Directors' Use of Medical History

What methods does your company use to obtain medical information for underwriting life insurance policies? Assume the applicant is 35 years old. If you circle YES for a particular method, please circle the policy type(s) and amount(s) for which you use the method.

			$100,000		$500,000	
	YES	NO	Term	Whole	Term	Whole
a. Ask questions of the applicant regarding his or her medical history	☐	☐	☐	☐	☐	☐
b. Ask questions of the applicant regarding his or her family history	☐	☐	☐	☐	☐	☐
c. Review the applicant's medical records	☐	☐	☐	☐	☐	☐
d. Require an examination by a nurse or paramedic	☐	☐	☐	☐	☐	☐
e. Require an examination by a physician	☐	☐	☐	☐	☐	☐
f. Use a reference laboratory (e.g., Home Office Reference Lab [HORL]) to perform tests on the applicant	☐	☐	☐	☐	☐	☐
Other (please specify): _____						

containing 25 closed-ended questions, a number of which were further subdivided. The questionnaire took respondents an estimated 25 min to complete. Recipients of the questionnaire were assured confidentiality.

The substance of several of the survey questions is reproduced in the tables accompanying the text. The questionnaire was designed to elicit information about the following topics: (1) the extent of genetic and other information about life insurance applicants that life insurance companies currently collect, the types of laboratory tests that they perform, and the way that they use the data obtained; (2) the extent to which companies currently have underwriting guidelines or actuarial data relating to particular genetic or genetically influenced conditions; (3) the extent to which companies would be interested in using predictive tests for various genetic and other conditions in their underwriting, if such tests were available; (4) the procedures that companies use to ensure the confidentiality of medical information and to communicate test results to applicants; (5) the extent of companies' involvement in legislative activities regarding the use of genetic data; and (6) the professional backgrounds and general level of knowledge about genetics that medical directors of life insurance companies have. In preparing the survey instrument, we reviewed the life insurance application forms that a number of companies currently use, to learn the types of family history and related information that they elicit from applicants.

We mailed the survey questionnaire to 177 medical directors of life insurance companies throughout the United States and Canada. Recipients were selected at random from a list of the medical directors of all North American companies. We sent the questionnaire to every fourth medical director whose name appeared on the list. We sent out the initial questionnaire in May 1992 and conducted a follow-up mailing 1 mo later.

Results

Forty medical directors responded to our survey. This number, however, includes six responses from medical directors who expressly declined to fill out the questionnaire, for reasons further discussed below, and seven other responses from those affiliated with companies that currently sell only health or disability insurance or that are reinsurers and thus do not sell life insurance directly to the public. We did not include these responses in our tabulations, because many of them were incomplete or were otherwise completed in a manner that made them difficult to interpret. Thus, we considered 27 responses in reporting our final results.

Although this rate of response did enable us to discern some general patterns, it is not high enough to permit a meaningful statistical analysis. We make no claim that the 27 formal responses that we received represent the approaches that most life insurance com-

Table 2

Medical Directors' Use of Family History

What questions regarding family history does your company ask of applicants for life insurance policies? Assume the applicant is 35 years old. If you circle YES for a particular method, please circle the policy type(s) and amount(s) for which you ask the question.

			$100,000		$500,000	
	YES	NO	Term	Whole	Term	Whole
a. Age at death of the applicant's mother and father	☐	☐	☐	☐	☐	☐
b. Cause of death of the applicant's mother and father	☐	☐	☐	☐	☐	☐
c. Age at death of the applicant's siblings	☐	☐	☐	☐	☐	☐
d. Cause of death of the applicant's siblings	☐	☐	☐	☐	☐	☐
e. Institutionalization of the applicant's parents or siblings for mental illness	☐	☐	☐	☐	☐	☐
f. Institutionalization of the applicant's extended family members for mental illness	☐	☐	☐	☐	☐	☐
g. Institutionalization of the applicant's siblings for mental retardation	☐	☐	☐	☐	☐	☐
h. Institutionalization of the applicant's extended family members for mental retardation	☐	☐	☐	☐	☐	☐
i. Presence of serious genetic diseases in the applicant's extended family	☐	☐	☐	☐	☐	☐
j. Other (please specify): _____						

panies take to the use of genetic data. Nevertheless, the responses of these medical directors represent a fraction of the industry that we estimate as collectively insuring many millions of citizens. For this reason, and because this survey is, to our knowledge, the first of its type, we believe that it provides a reference point for further research and analysis.

Medical and Family History Information Elicited

All of the survey respondents indicated that the life insurance companies that they work for routinely ask insurance applicants questions about both their medical and family history, although some stated that the precise nature of the questions that they asked would vary depending on several factors, including the nature of the product applied for, the applicant's sex, and the face amount of the policy. In general, however, respondents indicated that their companies elicit medical and family history information regardless of the policy amount in question ($100,000 or $500,000) and regardless of whether the applicant has applied for a *term life* or *whole life* policy. Whole life policies provide lifetime benefits that extend beyond 1 policy year, have a level premium schedule, and over time accumulate cash value against which the insured can withdraw or borrow. Term life policies, by contrast, provide coverage only for a specified or limited period of time (although they are generally renewable) and have no cash surrender value or cash loan value.

All respondents also indicated that their companies independently review applicants' existing medical records, although some stated that this is done only on a selected basis, depending on the nature and completeness of the answers that an applicant has provided about his or her medical history. In addition, some respondents reported that their companies would require a medical records review only if the applicant were applying for a term life, rather than a whole life, policy; in fewer instances, respondents indicated that they would review medical records only when the applicant had applied for a whole life policy.

The great majority of respondents indicated that their companies also require applicants to be examined by a nurse or paramedic—particularly at the higher ($500,000 or greater) policy levels. About half stated that they require an examination by a physician, but most appear to require a physician's examination only at the higher ($500,000 or greater) policy levels. All respondents stated that their companies use the services of a reference laboratory, such as the Home Office Ref-

Table 3

Medical Directors' Use of Laboratory Tests

What laboratory tests does your company require as a condition for issuing life insurance policies? Assume the applicant is 35 years old. If you circle YES for a particular test, please circle the policy type(s) and amount(s) for which you require the test.

			$100,000		$500,000	
	YES	NO	Term	Whole	Term	Whole
a. Serum cholesterol	☐	☐	☐	☐	☐	☐
b. High-density lipoprotein (HDL)	☐	☐	☐	☐	☐	☐
c. Electrocardiogram	☐	☐	☐	☐	☐	☐
d. Blood pressure	☐	☐	☐	☐	☐	☐
e. Hematocrit	☐	☐	☐	☐	☐	☐
f. Electrolytes	☐	☐	☐	☐	☐	☐
g. Urine test for sugar	☐	☐	☐	☐	☐	☐
h. Urine test for cocaine	☐	☐	☐	☐	☐	☐
i. Urine test for cotenine	☐	☐	☐	☐	☐	☐
j. Liver function tests	☐	☐	☐	☐	☐	☐
k. HIV test	☐	☐	☐	☐	☐	☐
Other (please specify): _____						

erence Laboratory Inc. or Clinical Reference Laboratory Inc., to perform laboratory tests on applicants.

We were interested to know what elements of an applicant's family history insurers considered. The vast majority of respondents indicated that, regardless of the policy type or amount applied for, their companies inquire into the age at death of the applicant's parents and the cause of the parents' death. A lesser number, but still a majority, inquire into the age at death of the applicant's siblings and/or the cause of the applicant's siblings' deaths. By contrast, very few companies appear to ask questions about the institutionalization, for mental illness or mental retardation, of an applicants' parents, siblings, or extended family members. One respondent, affiliated with a Canadian company, stated that the family-history questions that his company asks are limited by government regulation. The survey responses regarding the range of family questions that life insurers ask were confirmed by our independent review of the actual application forms that a number of companies use.

Laboratory Tests Required and Procedures for Dissemination of Test Results

The vast majority of the respondents indicated that their companies require, as a condition for issuing either a term or a whole life insurance policy of $500,000 or more, that the applicant submit to a blood pressure test; blood tests to measure serum cholesterol, high-density lipoprotein (HDL), liver function, and HIV status; urine tests for the presence of sugar; and urine (or saliva) tests for the presence of cocaine and cotenine (a metabolite of nicotine). A lesser number, but still a substantial majority, stated that their companies require these same tests even at a lower ($100,000) policy level. About half required an electrocardiogram, but only at the $500,000 policy level or higher. However, almost none stated that their companies test electrolytes or hematocrit, even for applicants at the higher policy levels.

Almost all respondents stated that their companies inform applicants from whom they obtain blood or urine samples about the nature of the laboratory tests that will be run by using the samples. They stated that this is typically done by way of an information sheet prepared either by the company, the testing laboratory, or both.

All respondents stated that, when applicants are denied insurance based on a laboratory test result (other than a positive HIV test result), their companies will release the actual test result, as opposed to merely the fact of insurance denial. The manner in which this information is relayed to the applicant varies widely. The responses indicated that some companies send the results to the applicant's physician; others send them directly to the applicant, but usually only after an information request form, provided to the applicant through the insurance agent, is furnished to the company. Still

Table 4

Existence of Underwriting Guidelines and Actuarial Data

Does your company have underwriting guidelines or actuarial data relating to any of the following conditions or diseases? Please circle one answer in each column.

	Underwriting Guidelines			Actuarial Data		
	Yes	No	Don't Know	Yes	No	Don't Know
a. Smoking history	☐	☐	☐	☐	☐	☐
b. Coronary artery disease	☐	☐	☐	☐	☐	☐
c. Achondroplasia	☐	☐	☐	☐	☐	☐
d. Lung cancer	☐	☐	☐	☐	☐	☐
e. Hemochromatosis	☐	☐	☐	☐	☐	☐
f. Familial colon cancer	☐	☐	☐	☐	☐	☐
g. Nonfamilial colon cancer	☐	☐	☐	☐	☐	☐
h. Familial breast cancer	☐	☐	☐	☐	☐	☐
i. Nonfamilial breast cancer	☐	☐	☐	☐	☐	☐
j. Lymphoma	☐	☐	☐	☐	☐	☐
k. Marfan syndrome	☐	☐	☐	☐	☐	☐
l. Emphysema	☐	☐	☐	☐	☐	☐
m. Cirrhosis of the liver	☐	☐	☐	☐	☐	☐
n. Huntington disease	☐	☐	☐	☐	☐	☐
o. Hypertension	☐	☐	☐	☐	☐	☐
p. Neurofibromatosis	☐	☐	☐	☐	☐	☐
q. Schizophrenia	☐	☐	☐	☐	☐	☐
r. Adult polycystic kidney disease	☐	☐	☐	☐	☐	☐

other companies send test results directly to the agent or use a combination of other communication methods. Some, but not all, respondents indicated that results can be released only when the applicant signs a form authorizing, in writing, release of the information. Almost all stated that their companies have a standard protocol relating to the confidentiality of applicants' medical records, but fewer stated that this protocol was available in writing.

Existence of Underwriting Guidelines and Corresponding Actuarial Data

Almost without exception, the respondents indicated that their companies have established underwriting guidelines (compiled in underwriting manuals) with respect to a wide variety of both genetically and nongenetically influenced diseases or conditions. These conditions include smoking history, lung cancer, emphysema, lymphoma, cirrhosis of the liver, coronary artery disease, hypertension, schizophrenia, familial and nonfamilial colon and breast cancers, Huntington disease, Marfan syndrome, hemochromatosis, neurofibromatosis, and adult polycystic kidney disease. Of 18 conditions about which we inquired, there was only 1, achondroplasia, for which a substantial number of respondents said that their companies did not have underwriting guidelines; but, even in this case, more than half stated that they had relevant underwriting guidelines.

Few respondents, however, indicated that their companies have their own actuarial data (statistical data that indicate the life expectancy of persons at various ages who have particular conditions) to support their underwriting guidelines with respect to these same conditions; this tended to be particularly so with regard to those conditions that have a more obvious genetic component. Just under half reported that their companies have actuarial data relating to smoking history and hypertension; one-fourth to one-third stated that they have data relating to lung cancer, emphysema, lymphoma, cirrhosis of the liver, and nonfamilial colon and breast cancer; and less than one-fourth said that they have data relating to achondroplasia, neurofibromatosis, hemochromatosis, Marfan syndrome, Huntington disease, adult polycystic kidney disease, schizophrenia, and familial colon and breast cancers. More than one-third of respondents answered that they did not know whether their companies had actuarial data available to support any of their underwriting guidelines with respect to the listed conditions. To the extent that such

Table 5

Case Studies

Please read the following brief case studies and indicate, for each one, whether or not you would recommend that your life insurance company (1) decline to insure the individual described or (2) charge that individual a higher than standard premium. Please circle one answer for each option.

	Options	Yes	No	Don't Know
a. A 23-year-old single, white woman with spina bifida (a congenital defect of the lower spine that renders her unable to walk without crutches and to have bladder problems) applies for a $250,000 whole life policy.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐
b. A 34-year-old white man whose father died of Huntington disease (an adult-onset, incurable, progressive fatal disease of the nervous system) applies for a $250,000 whole life policy. He is at 50% risk for having the gene but has no symptoms. Although a test is available, he prefers not to take it.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐
c. A 22-year-old white, married, childless man with cystic fibrosis (a genetically caused lung disease with a median life expectancy of 28 years) applies for a $250,000 whole life policy.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐
d. A 30-year-old white, married, childless woman whose mother and maternal aunt both died of breast cancer before age 45 years applies for a $250,000 whole life policy.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐
e. A 50-year-old white, married, childless man whose parents both died of coronary artery disease in their 50s applies for a $250,000 whole life policy.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐
f. A 27-year-old single, black, woman with sickle cell anemia (a genetically determined blood disorder that is burdensome but compatible with a life span up to about 50 years) applies for a $250,000 whole life policy.	Decline: Higher Premium:	☐ ☐	☐ ☐	☐ ☐

data were in their possession, most respondents indicated that the data were supplied by reinsurers rather than generated by the life insurance company itself. The majority stated that they reconsider the types of information on which they base their underwriting decisions, every 1–2 years or more or on an as-needed basis when new medical developments occur.

Approaches to Rating Applicants with Selected Genetic Conditions

The respondents were asked to read a series of case studies involving various genetic conditions and to indicate for each one whether they would recommend that their company decline to insure the individual described or charge that individual a higher than standard premium. For each case study, respondents were asked to assume that the individual in question had applied for a $250,000 whole life policy.

Respondents were first asked to consider the situation of a 23-year-old single white woman with spina bifida (described as a congenital defect of the lower spine, which rendered her unable to walk without crutches and to have bladder problems). Most respondents stated that they would not recommend that the company decline coverage altogether, but more than two-thirds said that they would recommend charging the applicant a higher premium.

Respondents next were asked to consider the case of a 34-year-old white man whose father had died of Huntington disease (described as an adult-onset, incurable, progressive fatal disease of the nervous system). Respondents were told that this individual was at 50% risk for having the gene that causes the disease, that he had no symptoms, and that he preferred not to take the available test to determine whether he had the gene. Here, more than half the respondents indicated that they would recommend denial of coverage; almost all the rest would recommend charging a higher premium.

Responding to other case studies, almost two-thirds of the respondents indicated that they would recommend that their company decline coverage to a 27-year-old single black woman with sickle cell anemia (described as a genetically determined blood disorder that is burdensome but compatible with a life span up to

Table 6

Interest in the Use of Predictive Tests

Assume that a highly accurate, attractively priced test were available for predicting which people have either twofold or 10-fold increased risk of developing each of the following conditions within the next 10 years. Please indicate for each test whether or not you would recommend that your company require a life insurance applicant to take the test for rating purposes. Assume the applicant is 35 years old.

	Twofold Increase		10-Fold Increase	
	Yes	No	Yes	No
a. Coronary artery disease	☐	☐	☐	☐
b. Breast cancer	☐	☐	☐	☐
c. Alzheimer disease	☐	☐	☐	☐
d. Colon cancer	☐	☐	☐	☐
e. Renal failure	☐	☐	☐	☐
f. Adult-onset diabetes	☐	☐	☐	☐
g. Emphysema	☐	☐	☐	☐

about 50 years). More than three-fourths stated that they would recommend that the company decline coverage to a 22-year-old white, married, childless man with cystic fibrosis (described as a genetically caused lung disease compatible with a median life expectancy of 28 years).

Few respondents indicated that they would recommend either increasing the premium charged or denying coverage in two other hypothetical situations. When asked about a 30-year-old white, married, childless woman whose mother and maternal aunt both had died of breast cancer before age 45 years, only 1 respondent of the 27 indicated that he would recommend that his company decline coverage, and only 6 stated that they would recommend charging a higher premium. Likewise, when asked about the case of a 50-year-old white, married, childless man whose parents both had died of coronary artery disease in their 60s, only 2 of 27 respondents stated that they would recommend declining coverage, and only 5 stated that they would recommend increasing the premium.

Some of the responses to the case studies were qualified with comments that suggest that a number of additional variables would significantly influence many companies' decisions about whether to refuse coverage or charge a higher premium in any particular case. These variables include (1) the precise nature of the presenting problem, (2) the course of the disease to date, (3) the regularity of medical follow-ups, and (4) the presence or absence of other risk factors. However, one respondent stated flatly that, if the applicant were age 35 years, for example, the presence of any condition that would be expected to be fatal in the next 20 years would make him or her uninsurable. To issue a whole life policy, most companies, according to this respondent, would require at least 30 years expectation of life.

Interest in Using Genetic or Other Predictive Tests, Perceptions of Adverse Selection, and Industry Involvement in Regulatory Activity

The respondents were asked to assume that highly accurate, attractively priced tests were available for indicating which people have an increased risk of developing, within 10 years, any of the following conditions (none of which was identified as having a particular "genetic" basis): coronary artery disease, breast cancer,

Table 7

Interest in the Use of Genetic Tests

Assume that a highly accurate, attractively priced test were available for determining which people carry a gene that causes each of the following conditions. Please indicate whether or not you would recommend that your company require a life insurance applicant to take the test as a condition for obtaining any of the following whole life policies. Assume the applicant is 35 years old. If you circle YES for a particular test, please circle the policy amount(s) for which you would require the test.

	Yes	No	$100,000	$500,000+
a. Coronary artery disease	☐	☐	☐	☐
b. Lung cancer	☐	☐	☐	☐
c. Hemochromatosis	☐	☐	☐	☐
d. Familial colon cancer	☐	☐	☐	☐
e. Family breast cancer	☐	☐	☐	☐
f. Lymphoma	☐	☐	☐	☐
g. Marfan syndrome	☐	☐	☐	☐
h. Emphysema	☐	☐	☐	☐
i. Cirrhosis of the liver	☐	☐	☐	☐
j. Huntington disease	☐	☐	☐	☐
k. Hypertension	☐	☐	☐	☐
l. Neurofibromatosis	☐	☐	☐	☐
m. Schizophrenia	☐	☐	☐	☐
n. Adult polycystic kidney disease	☐	☐	☐	☐

Table 8

Medical Director's Knowledge of Genetics

We would like to know your general familiarity with genetics. Please answer spontaneously, to the best of your ability. Please circle *one*.

A certain genetic disease has affected a grandfather, a mother, and a daughter over three generations in a family. Its pattern of inheritance is most likely:	Autosomal recessive	Autosomal dominant	Sex-linked recessive	New mutation
Cystic fibrosis affects about 1:2,500 white children in the United States. What proportion of white people carry the gene for cystic fibrosis?	1 in 4	1 in 25	1 in 100	1 in 2,500
Duchenne muscular dystrophy affects boys almost exclusively. This is because:	Their leg muscles develop later in gestation	Female hormones counteract the problem gene	Girls have a protective X chromosome	Affected girls die before birth

	True	False
a. Genes are composed of chromosomes	☐	☐
b. DNA is composed of four to eight types of nucleotides	☐	☐
c. Most genetic diseases primarily affect the blood	☐	☐
d. Humans have 46 chromosomes	☐	☐
e. Men are genetically different from women because men lack a Y chromosome	☐	☐
f. Sickle cell anemia is most common in people of Chinese origin	☐	☐
g. Prenatal testing is available for Tay-Sachs disease	☐	☐
h. Down syndrome affects primarily females	☐	☐

colon cancer, Alzheimer disease, renal failure, adult-onset diabetes, and emphysema. Respondents were asked to indicate, for each test, whether they would recommend that their company require a hypothetical 35-year-old life insurance applicant to take the test for rating purposes. Here, the responses varied, depending on the hypothesized predictive power of the test in question, although they did not vary significantly between diseases. For example, asked to assume that the test were able accurately to predict a *twofold* increased risk of developing each disease, only about one-fourth to one-third of the respondents indicated that they would recommend requiring the test. However, if the test were able accurately to predict those persons with a *10-fold* increased risk, more than three-fourths stated that they would recommend it to their companies.

Respondents were next asked to assume that a highly accurate, attractively priced test were available for determining which people carry genes that cause any of a series of conditions, including coronary artery disease, lung cancer, hemochromatosis, familial breast and colon cancers, lymphoma, Marfan syndrome, emphysema, cirrhosis of the liver, Huntington disease, hypertension, neurofibromatosis, schizophrenia, and adult polycystic kidney disease. Respondents were asked to indicate whether they would recommend that their company require a 35-year-old applicant to take such a test to obtain coverage. Most of the responses did not vary greatly from condition to condition, but here, for each of the conditions in question, the responses were split approximately equally. About half the respondents stated that they would recommend requiring the test, and half stated that they would not. Those who would recommend using one test generally would recommend using all, but would do so only at the higher ($500,000 or greater) policy levels. One respondent noted that most of the genetic conditions hypothesized are too rare to warrant routine testing in the absence of any family history of the disease; this respondent did not, however, indicate what approach he would take when there *was* a relevant family history.

Regarding both the genetic and nongenetic predictive tests, several of the respondents specifically pointed out that whether they would recommend a particular test would *not* rest exclusively on its availability and cost. One, for example, noted that his company

would be most likely to test for conditions that are untreatable, have high fatality rates, and cause premature death—specifically citing Huntington disease, by way of illustration. By contrast, this respondent would not recommend testing for "easily treatable" conditions such as hypertension and hemochromatosis. Noting, for example, that coronary artery disease, at least in the elderly, is relatively common, this respondent stated that his company would not be interested in wide-scale testing or screening that would excessively fragment the company's pool of "standard" insureds.

In addition, two medical directors who declined formally to participate in the survey but who wrote extended letters in which they described their general approaches to genetic information indicated that, before deciding whether to require a particular genetic (or other) test in a given case, they would need to know the sensitivity and specificity of the test and the prior probability assumptions for each combination of applicant, condition, and test. In deciding whether to recommend a test for screening purposes, they would weigh the test's predictive value against its cost and consider both the implications for longevity that are associated with the impairment at issue and the clinical use and acceptance of the testing procedure. One medical director who responded only by letter also noted that each of the disorders hypothesized in the question on genetic testing has considerable variability (heterogeneity, different inheritance patterns, different mortality impact, variable penetrance, and variable expressivity) and that some of the conditions are disease producing while others are merely disease predisposing.

The two medical directors who responded by letter also pointed out that there is a difference between *ordering* a test and *having access* to test information that already exists, such as when a physician has obtained it to investigate a clinical concern. Both indicated that they generally would independently want to review and assess any such *existing* data. One stated that his company was "most likely to begin to use genetic tests in selected situations when the tests are being used clinically so that we have access to the same information as the applicant to limit the potential for [adverse selection]" (the practice of buying insurance coverage in anticipation of developing a particular disease, without informing the company of the increased risk).

When asked about how widespread they perceived that the problem of adverse selection in life insurance is, almost half the respondents expressed the belief that more than 10% of all applicants for life insurance engage in this practice. One-fifth said that they thought that as many as 15% or more do this. Several respondents noted that the expected percentage of those practicing adverse selection would depend on the product, the method of marketing, and the targeted population; one noted specifically the high incidence of adverse selection among applicants who smoke and fail to report their smoking status.

Two of the 27 respondents stated that their companies had proposed laws to regulate the use of medical information in life insurance underwriting, 10 stated that they had opposed such laws, and 7 stated that they had supported such laws. More than one-third of the respondents did not know whether their companies had ever proposed, opposed, or supported any such laws.

Medical Directors' Professional Backgrounds and Knowledge of Genetics

Respondents were asked a series of questions designed to reveal their company's size, their own professional backgrounds, and the general level of their understanding of genetics. Although many respondents declined to respond to questions about their companies' annual sales volume or number of policies sold, among those who did provide this information, the 1990 sales volumes ranged from a low of about $30 million to a high of $4 billion; the number of life insurance policies sold ranged from 204 to 1 million.

Three-fourths of the respondents indicated that they had held the position of medical director in their company for more than 5 years; half of the positions were listed as full time, half as part time. Less than one-fourth had completed a fellowship in life insurance medicine. About three-fourths of the respondents listed their primary area of medical specialization as internal medicine, general or family practice, or insurance medicine; other identified specialties included pediatrics, surgery, hematology, nephrology, pulmonary medicine, clinical physiology, and critical care. None of the respondents listed genetics as his or her area of specialization. No significant differences were observed in any of the survey response patterns, either between respondents with different professional backgrounds or lengths of experience or between full-time and part-time respondents.

Responding to a series of multiple-choice and true-false questions about genetics, respondents, with very few exceptions, appeared to be able to identify a particular pattern of inheritance as autosomal dominant; knew that humans have 46 chromosomes; understood that men have a Y chromosome; knew that most ge-

netic diseases do not primarily affect the blood; and were aware that prenatal testing is available for Tay-Sachs disease. However, more than one in four indicated that they believed that genes are composed of chromosomes rather than the other way around, and almost one in five stated that they thought Down syndrome affects primarily females. Only half knew that DNA is composed of four types of nucleotides, and only half, told that cystic fibrosis affects about 1 in 2,500 white children in the United States, were able correctly to compute the proportion of white people (1 in 25) who carry the gene for cystic fibrosis. In addition, three respondents indicated that the reason that Duchenne muscular dystrophy affects boys almost exclusively is that (*a*) female hormones counteract the problem gene or (*b*) affected girls die before birth, and one thought that sickle cell anemia is most common in people of Chinese origin.

Discussion

Level of Participation

One interesting finding is the fact that so few medical directors responded to our survey. In addition to the large number who simply did not reply, we received letters from six medical directors who expressly declined to fill out the questionnaire. Despite the fact that we pledged to keep their responses confidential, several medical directors wrote that they felt that their responses would be inappropriate because they had no idea of our intent in collection or plan for use or because they considered the information sought in the questionnaire to be confidential. One wrote that he doubted that our survey would yield meaningful results —given the newness of genetic testing technology and associated uncertainty surrounding the practice, combined with significant variations in industry-wide underwriting practices. This same medical director acknowledged, however, that the industry has been "unusually proactive" in the area of genetic testing.

Treatment of Medical and Family History Information

The survey responses that we did receive, coupled with our independent review of the application forms that a number of different life insurers use, confirmed our hypothesis that many life insurance companies already use "genetic" information in making their underwriting decisions, even if they do not perform or require "genetic testing" as such. This information takes the form of family historical data and routine laboratory test results. Regarding family history, most seem to be more interested in the existence of physical conditions that run in an applicant's family than in the presence of mental illness or mental retardation. Most insurers also routinely require applicants to submit to a wide variety of laboratory tests that, while not traditionally viewed as "genetic," can provide information about conditions that in some cases have a genetic component (e.g., coronary artery disease).

It is not surprising that, the higher the face amount of the policy applied for, the greater the interest that companies seem to have in obtaining detailed medical information about the applicant. However, a number of companies appear to employ more stringent underwriting requirements (e.g., reviews of the applicant's existing medical records) when issuing term life policies than when issuing whole life policies. This may be because the respondents perceived the risk of adverse selection to be higher among term life applicants than among whole life applicants.

While most companies appear to gather the same general types of information from applicants, the responses reveal a *lack* of uniformity as to the procedures used to (1) ensure the confidentiality of medical information and (2) disseminate laboratory test results. Not all respondents stated that their companies have reduced their confidentiality protocols to writing, and not all respondents indicated that their companies require a release from applicants before they will communicate test results to insurance agents or others. These findings suggest that, in some companies, a gap may exist that could lead to the improper dissemination of private information about applicants to third parties. While such practices are not necessarily unlawful, they may raise serious ethical concerns.

Predictive Testing and Adverse Selection

As noted above, the majority of the respondents favored recommending that their companies require predictive testing for a variety of diseases or conditions that do *not* tend to be viewed as classically genetic (e.g., coronary artery disease, renal failure, and adult-onset diabetes). Respondents indicated that they would be particularly interested in recommending such testing if a test were developed that could determine a *greatly* (10-fold) increased risk of developing the condition in question. In light of this acknowledgment that they are interested in predictive testing for nongenetic conditions, it is somewhat surprising that considerably fewer (only about half) indicated that they would recommend requiring predictive tests for *genetic* conditions. This disparity might indicate that some were unwilling to

disclose an interest in using genetic testing unlike other, perhaps less controversial types of testing. Alternatively, it may suggest merely (as one respondent noted) that many respondents felt that most of the genetic conditions hypothesized in the question on genetic testing are too rare to justify routine testing in the absence of a relevant family history. It seems reasonable to expect, however, that there might be a higher level of interest in genetic testing—particularly for applicants who seek large policies—in situations where a particular genetic condition appears to run in an applicant's family. Fully one-half of the respondents indicated that, assuming the availability of a test with high sensitivity and specificity and general clinical acceptance, they would be interested in using genetic testing in at least some situations.

In addition, the responses leave little doubt that most medical directors, including those who would not necessarily recommend *performing* genetic tests on applicants, are interested in *accessing* genetic test data that applicants have already obtained on their own. The reason for this is presumably to minimize the potential for adverse selection—a risk that many of the respondents perceive as substantial. One-half of the respondents indicated a belief that more than 1 in 10 life insurance applicants practice adverse selection. Because little reliable data exist on the *actual* incidence of adverse selection by applicants for life insurance, it is difficult to determine the extent to which this belief is supportable (Clifford and Iuculano 1987; Hiam 1987–88). It seems reasonable to assume that there may be less of an incentive for adverse selection in life insurance than in disability insurance. Reinsurers may also have a greater incentive than life insurers in obtaining genetic test information, because they play an important role in insuring those at higher risk on the basis of either the face value of the policy or an applicant's medical history.

Underwriting Guidelines, Actuarial Data, and Approaches to Rating Applicants

As noted, with the exception of underwriting guidelines for achondroplasia, the majority of respondents acknowledged that their companies employ underwriting guidelines with respect to a wide range of both genetic and nongenetic conditions. Significantly, however, the responses indicate that few medical directors are aware of the existence, within their companies, of specific actuarial data corresponding to any of these same conditions—and, in particular, the classically genetic conditions. It appears that little reliable actuarial data relative to the life expectancy associated with many genetic conditions have yet been compiled. For many inherited diseases, only reports in the scientific literature can be used to calculate morbidity and mortality risks, because few companies have a sufficient caseload to develop actuarial data in house. Nevertheless, the respondents' acknowledgment that their companies have little hard actuarial data of their own to support their underwriting guidelines concerning genetic conditions is striking, because some states (although only a few at present) have already enacted laws that prohibit insurers from discriminating against applicants on the basis of a genetic condition in the absence of specific actuarial justification for treating them differently (McEwen and Reilly 1992). In addition, all states have unfair-insurance-practices laws that generally prohibit differentiating between applicants of the same age and with equal expectancy of life. Without good actuarial data on certain specific conditions or diseases, it is difficult to discern the basis for the underwriting decisions that most respondents stated that their companies would make. As some of the respondents noted, however, while life insurance companies typically do not generate their own actuarial data, such data (at least with regard to some of the more common conditions) may be available from large reinsurance companies. Another data source is the Society of Actuaries, which collects information from large numbers of insurance companies (Lew and Gajewski 1991).

The respondents' reactions to the six "case studies" regarding whether they would recommend declining coverage or charging a higher premium to applicants who either had or were at risk of developing certain genetic or genetically influenced conditions (i.e., spina bifida, sickle cell anemia, cystic fibrosis, Huntington disease, familial coronary artery disease, and familial breast cancer) were instructive, particularly when they are compared with the responses of state insurance commissioners to an analogous set of questions that we asked in our earlier study (McEwen et al. 1992). It is interesting that the responses of the insurance commissioners in the earlier survey indicated that, at least in a number of states, life insurance companies *might not be permitted,* under existing law or practice, to deny coverage or charge a higher premium to the applicants in at least some of the hypothetical situations. By contrast, the medical director respondents generally appeared to *assume* that either course of action would be permissible, with the only question being *which of the two* options—declination of coverage or increasing the premium—they would recommend that their companies

exercise. This suggests that some medical directors may not have considered the limits of their companies' latitude in denying coverage or rating applicants.

The medical directors' responses to the six case studies also demonstrate the considerable degree of subjectivity that is involved in most insurers' rating decisions. To the extent that the views of medical directors determine or influence companies' ultimate decisions on the issuance of insurance, little uniformity of approach appears to exist among insurers. This finding may merely reflect the reality that insurance companies, who frequently service different types of clients facing different types of risks, vary in their approches to medical impairments generally. One company may be prepared to take a greater risk than another with full knowledge of the usual clinical history for that disorder. For example, some insurers will insure renal transplant patients with low ratings while others will deny them coverage years after they have received a graft from a compatible relative (J. A. Lowden, personal communication). It is also possible that the competition in the industry, suggested by the diversity of responses, may in some cases act as a safeguard to prevent unfair discrimination or "redlining." Because of the variation in practices, an applicant, with the assistance of his or her agent, may currently be able to "shop" for the best deal. The vast majority of people who apply for life insurance do, in fact, receive it, although some may have to look harder than others.

Even within certain companies, however, some of the approaches to the case studies in the survey seem difficult to reconcile. For example, as noted, more than two-thirds of the respondents indicated that they would recommend charging a higher premium to the hypothetical 23-year-old applicant with spina bifida, even though little evidence exists that a young adult with a low spinal lesion will die prematurely from complications of that disease. Similarly, almost two-thirds indicated that they would recommend the denial of coverage to a 27-year-old black person with sickle cell anemia, even though the disease is compatible with a life span of about 50 years.

The finding that more than three-fourths of the respondents would recommend refusing coverage to a 22-year-old person with cystic fibrosis—a disease with a median life expectancy of 28 years—is not surprising, given that the hypothesized applicant would be expected to live only a few years. This finding is also consonant with the finding, in our survey of insurance commissioners, that indicated that most states would permit companies in their states to deny a policy to such an individual (McEwen et al. 1992). On the other hand, in the case of the 34-year-old individual at 50% risk for Huntington disease who preferred not to take the available predictive test, almost all the medical director respondents stated that they would recommend either the denial of coverage or the charging of a higher premium—presumably on the basis that a 50% risk is too great a probability to be ignored. This finding, however, contrasts with the finding, in the survey of insurance commissioners, that more than one-third were unsure whether the law would *permit* insurers in their state to take *either* course of action.

Very few of the medical director respondents indicated that they would recommend that their companies decline coverage or increase the premium with respect to the hypothesized applicants at risk for premature death from familial coronary artery disease or breast cancer. This finding is consistent with the finding, in our survey of state insurance commissioners, that few commissioners' offices believe that the law in their state would permit differential treatment in either of these two situations (McEwen et al. 1992). The rationale for the reluctance of the respondents, in either this or the earlier survey, to treat (or allow the treatment of) those at risk for these two diseases as stringently as those either with or at risk for other, more classically "genetic" conditions is unclear. It may reflect a perception that these diseases, being relatively common in the general population, are not truly "genetic," so that a family history of them is an insufficiently reliable predictor of longevity. The finding may also reflect a desire on the part of some companies to avoid overly fragmenting their pool of "standard" insureds.

As previously discussed, some of the subjectivity in the responses to the case studies may merely reflect the fact that different companies look at risk in different ways. However, some of the incongruity in approach may also be attributable to a less than full appreciation of basic principles of genetics. The respondents' answers to the "knowledge" questions in the survey suggest that, while most have a good basic understanding of the science, a number do not. As noted, none of the respondents listed genetics as his or her primary area of specialization. In light of the increasingly important role that genetics is likely to play in predictive medicine in the coming years, it will be helpful to increase the level of knowledge of these professionals—an effort that is already underway.

In sum, the results of our survey suggest that (1) while few life insurance companies perform genetic tests on applicants, most are interested in accessing genetic test

information about applicants that already exists; (2) the degree of life insurers' interest in using genetic test results may depend on the face amount of the policy applied for and on the specificity and sensitivity of the test in question; (3) many companies employ underwriting guidelines with respect to a variety of genetic conditions but do not always have their own detailed actuarial data on those conditions to support their rating decisions; (4) a considerable degree of subjectivity is involved in most insurers' rating decisions; and (5) some of the medical directors are not fully informed about certain basic principles of medical genetics. While we acknowledge the limitations of the survey that are due to the small number of responses, we believe that the study represents a useful starting point for further empirical research and for the future development of an informed public policy.

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