Chapter 5
General Attitudes Toward Genetic Tests and Information

Besides current or anticipated reimbursement practices for genetic tests, OTA also asked several questions to gauge health insurers' general attitudes toward genetic tests and genetic information. This chapter reports results from these questions. Additionally, general attitudes of respondents can be gleaned from the verbatim comments offered by some respondents, presented in appendix B.

IMPACT OF GENETIC TESTS ON BUSINESS PRACTICES

As genetic tests become widely available, one important consideration for insurers will be the financial impact such tests might have on their business. OTA asked survey participants about whether they believed certain scenarios involving the availability of genetic tests would lead to a negative financial impact for their company.

The majority of commercial insurers (30 of 51; 59 percent) said a negative financial impact would not occur if genetic tests were widely available to the medical community. A majority of chief underwriters at Blue Cross and Blue Shield (BC/BS) plans (20 of 29; 69 percent) responded similarly, as did 6 of 18 medical directors at BC/BS plans (33 percent). Respondents from health maintenance organizations (HMOS), however, were equally divided in their opinions of whether widespread availability of genetic tests to the medical provider community would result in a negative financial impact for their HMOS (table 5-l).

In contrast, table 5-1 shows that a clear majority of respondents from commercial insurers, BC/BS plans, and HMOS thought a negative financial impact would likely occur if genetic tests were widely available, but had constraints on insurers' access to the results. Similarly, a majority of survey respondents from all populations clearly thought a negative financial impact would result for their companies if the availability of genetic tests resulted in adverse claims or underwriting results due to adverse selection (table 5-l). A handful of respondents among the total survey population also wrote in that a negative financial impact also would be likely if genetic tests became mandated benefits for which they would not ordinarily have reimbursed.

ATTITUDES TOWARD GENETIC INFORMATION

As discussed in chapter 3, health insurers that offer individual or medically underwritten group policies clearly weigh several factors in determining both insurability and rating. Included among the factors that respondents considered "very impor-

table 5-1—impact of Genetic Tests on Insurers

Question	Respondent	Yes	No	No response[a]
Under what conditions would a negative financial impact be likely to occur for your company (check all that apply):				
Widespread availability of genetic tests to the medical provider community.	*Commercials*	19 (37%)	30 (59%)	2 (4%)
	HMOS	10 (44%)	10 (44%)	3 (13%)
	BC/BSplans-U[b]	7 (24%)	20 (69%)	*2 (7%)*
	BC/BS plans-M	6 (33%)	11 (61%)	1 (6%)
Widespread avdlability of genetic tests with constraints on insurers' access to results.	*Commercials*	34 (67%)	15 (29%)	2 (4%)
	HMOS	16 (70%)	4 (17%)	3 (13%)
	BC/BS plans-U	17 (59%)	10 (35%)	2 (7%)
	BC/BS plans-M	11 (61%)	6 (33%)	1 (6%)
Adverse claims or underwriting results from antiselection.	*Comrnercials*	47 (92%)	2 (4%)	2 (4%)
	HMOS	18 (78%)	2 (9%)	3 (13%)
	BC/BS plans-U	27 (93%)	0 (0%)	2 (7%)
	BC/BS plans-M	16 (89%)	1 (6%)	1 (6%)

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

Table 5-2-Genetic Information as Medical Information or Preexisting Conditions

Question	Respondent	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly	No response[a]
Genetic information is no different than other types of medical information	*Commercials*	17 (33%)	10 (20%)	12 (23%)	10 (20%)	2 (4%)
	HMOs	7 (30%)	6 (26%)	5 (22%)	3 (13%)	2 (9%)
	BC/BS plans-U[b]	6 (21%)	14 (48%)	6 (21%)	1 (3%)	2 (7%)
	BC/BS plans-M	5 (28%)	5 (28%)	4 (22%)	2 (11%)	2 (11%)
Genetic conditions such as cystic fibrosis or Huntington disease are preexisting conditions	*Commercials*	14 (28%)	9 (18%)	17 (33%)	8 (16%)	3 (6%)
	HMOs	12 (52%)	8 (35%)	1 (4%)	0 (0%)	2 (9%)
	BC/BS plans-U	8 (28%)	7 (24%)	8 (28%)	5 (17%)	1 (3%)
	BC/BS plans-M	10 (56%)	2 (11%)	3 (17%)	1 (6%)	2 (11%)
Carrier status for genetic conditions such as cystic fibrosis or Tay-Sachs are preexisting conditions	*Commercials*	8 (16%)	12 (24%)	16 (31%)	13 (25%)	2 (4%)
	HMOs	5 (22%)	12 (52%)	0 (0%)	4 (17%)	2 (9%)
	BC/BS plans-M	4 (14%)	6 (21%)	7 (24%)	9 (31%)	3 (10%)
	BC/BS plans-U	7 (39%)	3 (17%)	2 (11%)	4 (22%)	2 (11%)

a percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the chief underwriter population and BC/BS plans-M, the medical director population.
SOURCE: Office of Technology Assessment, 1992.

Table 5-3-General Attitudes of Insurers Toward Genetic Information and Genetic Tests

Statement	Respondent	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly	No response[a]
An insurer should have the option of determining how to use genetic information in determining risks.	*Commercials*	19 (37%)	19 (37%)	9 (22%)	3 (6%)	1 (2%)
	HMOs	2 (9%)	15 (65%)	4 (17%)	0 (0%)	2 (9%)
	BC/BS plans-U[b]	9 (31%)	15 (52%)	4 (14%)	0 (0%)	1 (3%)
	BC/BS plans-M	8 (44%)	6 (33%)	0 (0%)	3 (17%)	1 (6%)
It's fair for insurers to use genetic tests to identify individuals with increased risk of genetic disease.	*Commercials*	11 (22%)	23 (45%)	11 (22%)	4 (8%)	2 (4%)
	HMOs	3 (13%)	14 (61%)	2 (9%)	2 (9%)	2 (9%)
	BC/BS plans-U	4 (14%)	17 (59%)	4 (14%)	2 (7%)	2 (7%)
	BC/BS plans-M	0 (0%)	11 (61%)	2 (11%)	4 (22%)	1 (6%)

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.
SOURCE: Office of Technology Assessment, 1992.

tant' or "important,' were personal medical history of significant conditions, family medical history of significant conditions, and carrier risk for genetic disease-although the importance respondents placed on any single factor varied. Many, in fact, considered certain factors unimportant or never used them in decisionmaking.

Overall, how do health insurers view genetic information, regardless of the source (i.e., a positive test or elevated risk for carrier status or disease because of a known family history)? Results from OTA's survey found a majority of respondents, both as an aggregate population and as individual subsets, agreed with the statement, ''Genetic information is no different than other types of medical information" (table 5-2). Underscoring this finding are results that the majority of health insurers, collectively, agree ''strongly' or "somewhat" that genetic conditions such as cystic fibrosis (CF) or Huntington disease are preexisting conditions, but that carrier status for diseases such as Tay-Sachs or CF is not a preexisting condition (table 5-2).

Third-party payers already use genetic information in making decisions about individual policies or medically underwritten groups, and health insurers clearly believe it is fair for them to have access to information known to the applicant. Survey respondents were asked whether 'an insurer should have the option of determining how to use genetic information in determiningg risks." A majority of all respondents agreed strongly or somewhat with this statement (table 5-3).

OTA also sought the reactions of commercial insurers, HMOS, and BC/BS plans to a hypothetical situation based on a real life case. Respondents were asked to indicate whether they "agree" strongly, "

''agree somewhat,'' "disagree somewhat," or "disagree strongly,' with:

> Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decides to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the CF-related costs for the child.

For commercial vendors, three medical directors (6 percent) agreed strongly or somewhat. Thirteen individuals (25 percent) in this population disagreed somewhat and 34 (67 percent) disagreed strongly. Among medical directors at HMOS, 3 respondents (13 percent) agree to some extent, but 18 respondents (78 percent) disagreed, 15 (65 percent) of them strongly. For chief underwriters of BC/BS plans, six respondents agreed (21 percent), either strongly or somewhat. Eight BC/BS chief underwriters (28 percent) indicated they disagreed somewhat, and 14 (48 percent) disagreed strongly. Among medical directors of BC/BS plans, 1 (6 percent) agreed strongly, 1 (6 percent) agreed somewhat, and 15 (84 percent) disagreed strongly or somewhat.

USE OF GENETIC TESTS

Health insurers do not *need* genetic tests to find out genetic information. Currently, it is less expensive to ask a question or request medical records, and applicants disclose genetic information as part of the battery of questions they respond to in personal and family history inquiries. OTA is unaware of any insurer who currently underwrites individual or medically underwritten groups and requires carrier or presymptomatic tests (e.g., for Huntington or adult polycystic kidney diseases) (1,2), although OTA's survey findings indicate that insurers generally believe that it is fair for them to use genetic tests to identify those at increased risk of disease, and that they should decide how to use that information in risk classification (table 5-3). Thus, what about the possibility of requiring genetic tests as a condition of coverage in the future?

Even a decade from now, OTA's survey found that the majority of respondents do not expect to require genetic tests of applicants-whether or not they have a family history of serious genetic conditions-nor do they anticipate requiring carrier assays. Requiring carrier screening as a condition of consideration for insurance is viewed as even more remote than mandating genetic assays for those who have family histories of serious disorders (table 5-4).

For example, OTA found that a minority of commercial insurers who responded believe it will be "very likely" (2 respondents; 4 percent) or "somewhat likely" (17 respondents; 33 percent) that in 10 years they will require genetic testing for applicants who have a family history of serious conditions. No BC/BS chief underwriter considered it ''very likely' that its plan would require genetic testing in the next decade for applicants who had family histories of serious disorders. Medical directors at BC/BS plans were of a similar opinion: No medical director viewed mandatory genetic testing of applicants with family histories as very likely before the turn of the century (table 5-4).

Of medical directors at HMOS, 3 of 23 (13 percent) thought their HMO would require applicants to have a genetic test if a family history of a serious disorder existed, and 5 others (22 percent) said they considered it "somewhat likely " tests would be required in this manner-again, in the next 10 years. A similar distribution of responses was revealed when respondents were queried about requiring carrier tests for applicants at risk of passing on serious genetic conditions to their offspring (table 5-4).

Few respondents believe their company will require genetic tests in either 5 or 10 years, but what about optional testing? Commercial health insurers and BC/BS plans do not anticipate that optional testing or screening will be part of their company's policy in 5 or 10 years. It is interesting to note that a majority of HMO-based medical directors who responded to OTA's survey said they considered it "very likely' or ''somewhat" **likely that their HMO** would offer optional genetic testing and carrier testing in 10 years (12 respondents; 52 percent) (table 5-4). The difference in response between the HMO population versus the commercial insurers and BC/BS plans could reflect HMOS' longer standing history with and emphasis on managed and preventive care.

Thus, over the next decade, OTA's survey indicates the vast majority of health insurers that offer individual coverage or medically underwrite groups do not anticipate requiring applicants to undergo genetic screening for disease, predisposition, or carrier status. Thus, whether or not genetic information is available to health insurers hinges on whether

Table 5-4-Projected Use of Genetic Tests by Insurers in 5 and 10 Years

Question	Respondent	Very likely	Somewhat likely	Somewhat unlikely	Very unlikely	No response[a]
How likely do you think it is that your company/HMO will in the next 5 years:						
Require genetic testing for applicants with family histories of serious conditions?	*Commercials*	1 (2%)	3 (6%)	16 (31%)	31 (61%)	0 (0%)
	HMOs	1 (4%)	4 (17%)	7 (39%)	9 (39%)	2 (9%)
	BC/BS plans-U[b]	0 (0%)	1 (3%)	11 (38%)	15 (52%)	2 (7%)
	BC/BS plans-M	0 (0%)	2 (11%)	5 (28%)	10 (56%)	1 (6%)
Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring?	*Commercials*	2 (4%)	13 (25%)	35 (69%)	1 (2%)	0 (0%)
	HMOs	2 (9%)	3 (13%)	5 (22%)	11 (48%)	2 (9%)
	BC/BS plans-U	0 (0%)	1 (3%)	12 (41%)	14 (48%)	2 (7%)
	BC/BS plans-M	0 (0%)	1 (6%)	6 (33%)	10 (56%)	1 (6%)
Require genetic testing for applicants with no known risk of genetic disease?	*Commercials*	0 (0%)	0 (0%)	4 (8%)	47 (92%)	0 (0%)
	HMOs	1 (4%)	0 (0%)	2 (9%)	18 (78%)	2 (9%)
	BC/BS plans-U	0 (0%)	1 (3%)	6 (21%)	20 (69%)	2 (7%)
	BC/BS plans-M	0 (0%)	0 (0%)	3 (17%)	14 (78%)	1 (6%)
Offer optional genetic testing and carrier testing?	*Commercials*	0 (0%)	3 (6%)	18 (35%)	30 (59%)	0 (0%)
	HMOs	4 (17%)	6 (26%)	6 (26%)	5 (22%)	2 (9%)
	BC/BS plans-U	1 (3%)	5 (17%)	9 (31%)	12 (41%)	2 (9%)
	BC/BS plans-M	1 (6%)	1 (6%)	7 (39%)	7 (39%)	2 (11%)
How likely do you think it is that your company/HMO will in the next 10 years:						
Require genetic testing for applicants with familiy histories of serious conditions?	*Commercials*	2 (4%)	17 (33%)	14 (28%)	18 (35%)	0 (0%)
	HMOs	3 (13%)	5 (22%)	9 (39%)	3 (13%)	3 (13%)
	BC/BS plans-U	0 (0%)	10 (34%)	8 (28%)	9 (31%)	2 (7%)
	BC/BS plans-M	0 (0%)	3 (17%)	6 (33%)	8 (44%)	1 (6%)
Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring?	*Commercials*	1 (2%)	13 (25%)	16 (31%)	21 (41%)	0 (0%)
	HMOs	3 (13%)	4 (17%)	9 (39%)	4 (17%)	3 (13%)
	BC/BS plans-U	0 (0%)	9 (31%)	9 (31%)	9 (31%)	2 (7%)
	BC/BS plans-M	0 (0%)	3 (17%)	6 (33%)	8 (44%)	1 (6%)
Require genetic testing for appicants with no known risk of genetic disease?	*Commercials*	0 (0%)	4 (8%)	8 (16%)	39 (76%)	0 (0%)
	HMOs	1 (4%)	0 (0%)	6 (26%)	13 (57%)	3 (13%)
	BC/BS plans-U	0 (0%)	3 (10%)	9 (31%)	15 (52%)	2 (7%)
	BC/BS plans-M	0 (0%)	1 (6%)	3 (17%)	13 (72%)	1 (6%)
Offer optional genetic testing and carrier testing?	*Commercials*	0 (0%)	12 (24%)	17 (33%)	22 (43%)	0 (0%)
	HMOs	5 (22%)	7 (30%)	6 (26%)	2 (9%)	3 (13%)
	BC/BS plans-U	3 (10%)	10 (34%)	5 (17%)	9 (31%)	2 (7%)
	BC/BS plans-M	2 (11%)	3 (16%)	4 (22%)	7 (39%)	2 (11%)

[a] Percentages may not add to 100 due to rounding.
[b] BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.
SOURCE: Office of Technology Assessment, 1992.

individuals who seek personal policies, or are part of medically underwritten groups, become aware of their genetic status because of general family history, because they have sought a genetic test because of family history, or because they have been screened in some other context (2). Even then, a majority of respondents to OTA's survey reported they thought it "somewhat unlikely" or "very unlikely" that they would be using genetic *information* for underwriting (table 5-5).

CHAPTER 5 REFERENCES

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Table 5-5-Projected Use of Genetic Information by Insurers In 5 and 10 Years

Question	Respondent	Very likely	Somewhat likely	Somewhat unlikely	Very unlikely	No responsea
How likely do you think It is that your company/HMO will In the next 5 years:						
Use information derived from genetic tests for underwriting?	*Commercials*	7 (14%)	12 (24%)	16 (31%)	16 (31%)	0 (0%)
	HMOs	1 (4%)	5 (22%)	9 (26%)	6 (26%)	2 (9%)
	BC/BS plans-U[b]	3 (10%)	8 (28%)	10 (34%)	6 (21%)	2 (7%)
	BC/BS plans-M	1 (6%)	2 (11%)	7 (39%)	7 (39%)	1 (6%)
In the next 10 years:						
Use information derived from genetic tests for underwriting?	*Commercials*	12 (24%)	20 (39%)	11 (22%)	7 (14%)	1 (2%)
	HMOs	3 (13%)	6 (26%)	8 (35%)	3 (13%)	3 (13%)
	BC/BS plans-U	5 (17%)	13 (45%)	3 (10%)	6 (21%)	2 (7%)
	BC/BS plans-M	1 (6%)	5 (28%)	6 (33%)	5 (28%)	1 (6%)

[a] Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.