

Coverage and Reimbursement

Will health insurers pay for voluntary screening and followup counseling? And will health insurance companies authorize payment for prenatal screening or testing of newborn *children*? Answers to these questions carry significant cost implications. They also will likely affect the degree to which carrier screening for cystic fibrosis (CF) becomes commonplace, since many people will be unwilling to pay out-of-pocket the costs of the assays (1). From the perspective of the commercial laboratory that provides genetic tests to medical providers and patients, the issue of reimbursement is crucial to business—current and future.

OTA asked health insurers covering individuals and medically underwritten groups about their coverage of certain genetic tests and services. Are they covered ‘at patient request,’ where there is no family history (i.e., screening)? Are they covered ‘only if medically indicated,’ where a family history exists? Or, are they “not covered”?

REIMBURSEMENT FOR GENETIC TESTS AND SERVICES

No commercial company reimburses for CF carrier tests for screening purposes. The survey also found that carrier tests for CF—as well as for Tay-Sachs and sickle cell—are not covered for any reason by 12 of 29 commercial insurers that offer individual coverage. Twelve respondents (41 percent) cover CF carrier assays if medically indicated. With respect to prenatal tests for CF, about 41 percent (12 respondents) that write individual policies reimburse for such tests when medically indicated.

For the 37 commercial companies offering medically underwritten group policies, carrier tests for CF (and, again, for sickle cell or Tay-Sachs) are not covered by any company when done solely at patient request. CF mutation analysis is covered by 24 of 37 companies if medically indicated. Ten companies offering medically underwritten group coverage do not cover any of the carrier or prenatal tests asked about in OTA’s survey. Sixty-two percent of companies (23 respondents) that offer medically underwritten group policies cover prenatal tests for CF when medically indicated (table 4-1).

Two of 25 Blue Cross and Blue Shield (BC/BS) plans offering individual coverage would reimburse CF carrier screening at patient request. Sixteen of these BC/BS plans (64 percent) cover them if they are medically indicated and seven do not cover them. Three of 25 BC/BS plans cover prenatal testing for CF at a patient’s request, seven if medically indicated, and three not at all. Of 21 BC/BS plans offering coverage to medically underwritten groups, CF carrier screening is covered at patient request by only 2 companies (10 percent), if medically indicated by 11 companies (52 percent), and not at all by 8 companies (38 percent) (table 4-1). Data on coverage for CF prenatal tests by BC/BS plans that cover medically underwritten groups are also presented in table 4-1.

For the 11 health maintenance organizations (HMOS) that offer health insurance to individuals, 1 HMO (9 percent) covers CF carrier tests at patient request and 7 HMOS (64 percent) reimburse for them if medically indicated. For the 20 HMOS that offer medically underwritten group contracts, 1 HMO (5 percent) covers CF carrier tests at patient request, 13 respondents (45 percent) reimburse for them if medically indicated, and 2 (10 percent) do not cover them at all. Table 4-1 presents these results as well as how HMOS cover prenatal tests for CF.

From OTA’s survey results, it is evident that carrier and prenatal tests often are not covered under individual and medically underwritten group policies unless they are medically necessary—i. e., unless a family history exists. Such policies can have a significant impact on both the rate at which CF carrier screening becomes routine and the ultimate utilization of CF mutation analysis.

OTA found that genetic counseling was not covered by 18 commercial companies offering individual coverage and 17 offering medically underwritten group coverage. Six commercial insurance companies offering individual policies and 16 that medically underwrite groups cover genetic counseling only if it is medically indicated. Two commercial companies offering each type of cover-

Table 4-1-Reimbursement for Genetic Tests and Genetic Counseling

Question	Respondent	At patient request	Medically indicated only	Not reversed	No response ^a
Do your standard Individual policies and medically underwritten policies provide coverage for:					
Individual policies					
Carrier tests for CF?	<i>Commercials</i>	0 (0%)	12 (41%)	12 (41%)	5 (18%)
	<i>HMOS</i>	2 (18%)	7 (64%)	0 (0%)	2 (18%)
	<i>BC/BS plans-U</i>	2 (8%)	16 (64%)	7 (28%)	0 (0%)
	<i>BC/BS plans-M</i>	0 (0%)	11 (61%)	5 (28%)	2 (11%)
Carrier tests for Tay-Sachs?	<i>Commercials</i>	0 (0%)	12 (41%)	12 (41%)	5 (18%)
	<i>HMOS</i>	2 (18%)	7 (64%)	0 (0%)	2 (18%)
	<i>BC/BS plans-U</i>	2 (8%)	16 (64%)	7 (28%)	0 (0%)
	<i>BCLBS plans-M</i>	0 (0%)	11 (61%)	5 (28%)	2 (11%)
Carrier tests for sickle Cell trait?	<i>Commercials</i>	0 (0%)	12 (41%)	12 (41%)	5 (18%)
	<i>HMOS</i>	3 (27%)	6 (55%)	0 (0%)	2 (18%)
	<i>BC/BS plans-U</i>	2 (8%)	16 (64%)	7 (28%)	0 (0%)
	<i>BC/BS plans-M</i>	0 (0%)	11 (61%)	5 (28%)	2 (11%)
Prenatal tests for CF?	<i>Commercials</i>	0 (0%)	12 (41%)	14 (48%)	3 (10%)
	<i>HMOS</i>	1 (9%)	7 (64%)	1 (9%)	2 (18%)
	<i>BC/BS plans-U</i>	3 (12%)	19 (76%)	3 (12%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (5%)	13 (73%)	2 (11%)	2 (11%)
Prenatal tests for Tay-Sachs?	<i>Commercials</i>	0 (0%)	11 (38%)	15 (52%)	3 (10%)
	<i>HMOS</i>	2 (18%)	8 (73%)	0 (0%)	1 (9%)
	<i>BCLBS plans-U</i>	3 (12%)	19 (76%)	3 (12%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (5%)	13 (73%)	2 (11%)	2 (11%)
Prenatal tests for sickle cell anemia?	<i>Commercials</i>	0 (0%)	11 (38%)	15 (52%)	3 (10%)
	<i>HMOS</i>	1 (9%)	8 (73%)	0 (0%)	2 (18%)
	<i>BC/BS plans-U</i>	3 (12%)	19 (76%)	3 (12%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (5%)	13 (73%)	2 (11%)	2 (11%)
Prenatal tests for Down syndrome?	<i>Commercials</i>	1 (4%)	10 (34%)	15 (52%)	3 (10%)
	<i>HMOS</i>	1 (9%)	9 (82%)	0 (0%)	1 (9%)
	<i>BC/BS plans-U</i>	3 (12%)	19 (76%)	3 (12%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (5%)	13 (73%)	2 (11%)	2 (11%)
Genetic counseling?	<i>Commercials</i>	2 (7%)	6 (21%)	18 (62%)	3 (10%)
	<i>HMOS</i>	1 (9%)	6 (56%)	1 (9%)	3 (9%)
	<i>BC/BS plans-U</i>	1 (4%)	9 (36%)	13 (52%)	2 (8%)
	<i>BC/BS plans-M</i>	0 (0%)	8 (44%)	8 (44%)	2 (12%)

age (individual and medically underwritten) reimburse for genetic counseling performed at patient request (table 4-1). Similar results for BC/BS plans and HMOS are also presented in table 4-1.

COVERAGE FOR CYSTIC FIBROSIS CARRIER TESTS

In contrast to questions that inquire about what the respondent's company policy would be, respondents were also asked whether they were aware if their organization had ever actually reimbursed for CF carrier tests. Regardless of the type of respondent,

CF carrier testing has been reimbursed at roughly the same frequency for all (table 4-2). For commercial insurers, 11 of the 51 respondents (22 percent) said their companies had reimbursed for such tests, and 35 respondents (69 percent) indicated their companies had not. Of the 23 HMOS that responded to the OTA survey, 7 (30 percent) had reimbursed for CF carrier testing, and 14 (61 percent) had not. Of the 29 BC/BS plans represented by the underwriter survey, 7 (24 percent) had reimbursed for CF carrier testing, and 18 (62 percent) had not. Five of the 18 (28 percent) BC/BS plans represented by a medical director survey had reimbursed for CF carrier testing, and 12 (67 percent) had not.

Table 4-I—Reimbursement for Genetic Tests and Genetic Counseling Continued

Question	Respondent	At patient request	Medically indicated only	Not covered	No response ^a
Medically underwritten groups					
Carrier tests for CF?	<i>Commercials</i>	0 (0%)	24 (65%)	10 (27%)	3 (8%)
	<i>HMOS</i>	1 (5%)	13 (65%)	2 (10%)	4 (20%)
	<i>BC/BS plans-U</i>	2 (10%)	11 (52%)	8 (38%)	0 (0%)
	<i>BC/BS plans-M</i>	0 (0%)	9 (60%)	4 (27%)	2 (13%)
Carrier tests for Tay-Sachs?	<i>Commercials</i>	0 (0%)	22 (59%)	11 (30%)	4 (11%)
	<i>HMOS</i>	1 (10%)	13 (60%)	2 (10%)	7 (20%)
	<i>BC/BS plans-U</i>	2 (10%)	11 (52%)	8 (38%)	0 (0%)
	<i>BC/BS plans-M</i>	0 (0%)	9 (60%)	4 (27%)	2 (13%)
Carrier tests for sickle cell trait?	<i>Commercials</i>	0 (0%)	23 (62%)	10 (27%)	4 (11%)
	<i>HMOS</i>	2 (10%)	12 (60%)	2 (10%)	4 (20%)
	<i>BC/BS plans-U</i>	2 (10%)	11 (52%)	8 (38%)	0 (0%)
	<i>BC/BS plans-M</i>	0 (0%)	9 (60%)	4 (27%)	2 (13%)
Prenatal tests for CF?	<i>Commercials</i>	1 (3%)	23 (62%)	10 (27%)	3 (8%)
	<i>HMOS</i>	2 (10%)	14 (70%)	0 (0%)	4 (20%)
	<i>BC/BS plans-U</i>	3 (14%)	14 (67%)	4 (19%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (7%)	11 (73%)	1 (7%)	2 (13%)
Prenatal tests for Tay-Sachs?	<i>Commercials</i>	1 (3%)	24 (65%)	10 (27%)	2 (5%)
	<i>HMOS</i>	3 (15%)	14 (70%)	0 (0%)	3 (15%)
	<i>BC/BS plans-U</i>	3 (14%)	14 (67%)	4 (19%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (7%)	11 (73%)	1 (7%)	2 (13%)
Prenatal tests for sickle cell anemia?	<i>Commercials</i>	1 (3%)	24 (65%)	10 (27%)	2 (5%)
	<i>HMOS</i>	2 (10%)	14 (70%)	0 (0%)	4 (20%)
	<i>BC/BS plans-U</i>	3 (14%)	14 (67%)	4 (19%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (7%)	11 (73%)	1 (7%)	2 (13%)
Prenatal tests for Down syndrome?	<i>Commercials</i>	2 (5%)	23 (62%)	10 (27%)	2 (5%)
	<i>HMOS</i>	2 (10%)	15 (75%)	0 (0%)	3 (15%)
	<i>BC/BS plans-U</i>	3 (14%)	14 (67%)	4 (19%)	0 (0%)
	<i>BC/BS plans-M</i>	1 (7%)	11 (73%)	1 (7%)	2 (13%)
Genetic counseling	<i>Commercials</i>	2 (5%)	16 (43%)	17 (46%)	2 (5%)
	<i>HMOS</i>	2 (10%)	12 (60%)	1 (5%)	5 (25%)
	<i>BC/BS plans-U</i>	1 (5%)	7 (33%)	12 (57%)	1 (5%)
	<i>BC/BS plans-M</i>	0 (0%)	6 (40%)	7 (47%)	2 (13%)

^a Percentages may not add to 100 due to rounding.

^bBC/BS plans represents the underwriter population and BC/BS plans-M, the medical director Population.

SOURCE: Office of Technology Assessment, 1992.

ECONOMIC ANALYSIS OF GENETIC TESTS

To determine whether insurance companies have looked into the economic implications of various genetic tests, OTA asked if companies had ever conducted an economic analysis of the costs and benefits of various testing schemes. OTA found that no commercial insurer had conducted an economic analysis of the costs and benefits of carrier or other genetic tests as part of applicant screening. In addition, no commercial company had conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered. One

commercial company reported it had done an analysis of the costs and benefits of carrier tests as part of prenatal coverage, but 48 of 51 companies had not (table 4-3).

Survey respondents from HMOS had not conducted an economic analysis of the costs and benefits of carrier testing for either applicant screening or prenatal coverage. No economic analysis had been conducted by HMOS on genetic testing for applicant screening. One company conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered.

Similar results were found for BC/BS plans. One of the 29 BC/BS plans represented by an underwriter

Table 4-2-Coverage for Cystic Fibrosis Carrier Tests

Respondent	Yes	No	No response ^a
Commercials	11 (22%)	35 (69%)	5 (9%)
HMOs	7 (30%)	14 (61%)	2 (9%)
BC/BS plans-U ^b	7 (24%)	18 (62%)	4 (14%)
BC/BS plans-M	5 (28%)	12 (67%)	1 (5%)

^aPercentages may not add to 100 due to rounding.
^bBC/BS plans-u represents the underwriter population and BC/BS plans-M, the medical director population.
 SOURCE: Office of Technology Assessment, 1992.

survey had conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered, and 1 had conducted an economic analysis of carrier testing as part of prenatal coverage. None of the BC/BS plans represented by the underwriter survey had conducted an economic analysis of carrier or genetic testing as a part of applicant screening.

One of the 18 BC/BS plans represented by the medical director survey had conducted an economic analysis of carrier testing as part of prenatal coverage. Otherwise, none of the medical directors at the responding BC/BS plans had conducted an economic analysis of carrier or genetic testing as part of applicant screening, or of genetic counseling of carriers who are covered.

PERSPECTIVES ON FUTURE REIMBURSEMENT FOR GENETIC TESTS

As new genetic tests come on line, will insurers alter their claims payment practices? When asked if they would alter claims payment practices in the next 5 years, nearly half of commercial insurers (23 of 51; 45 percent) considered it “very unlikely,” while one quarter (12; 24 percent) found it “somewhat likely”; only two companies thought it was likely (table 4-4). When commercial insurers were asked to project ahead a decade, 23 of 51 companies responded that it would be very or somewhat likely that their company would alter claims payment practices as new genetic tests came on line; 28 companies thought it would be somewhat or very unlikely.

Underwriters from 10 BC/BS plans responded it was “somewhat likely” that claims payment practices would be altered as new genetic tests came on line, 9 thought it “somewhat unlikely” and 7 thought it was “very unlikely.” More BC/BS underwriters thought it was “somewhat likely” (11 of 29) in 10 years. Six BC/BS plans represented by an underwriter survey thought it was “very likely” and seven thought it “very unlikely.”

Table 4-3-Economic Analyses of Genetic Tests and Genetic Counseling by Insurers

Question	Respondent	Yes	No	No response ^a
Has your company ever conducted an economic analysis of:				
Carrier testing as part of applicant screening?	<i>Commercials</i>	0 (0%)	50 (98%)	1 (2%)
	<i>HMOs</i>	0 (0%)	20 (87%)	3 (13%)
	<i>BC/BS plans-U^b</i>	0 (0%)	28 (94%)	1 (3%)
	<i>BC/BS plans-M</i>	0 (0%)	16 (89%)	2 (11%)
Carrier testing as part of prenatal coverage?	<i>Commercials</i>	1 (2%)	48 (94%)	2 (4%)
	<i>HMOs</i>	0 (10%)	20 (87%)	3 (13%)
	<i>BC/BS plans-U</i>	1 (13%)	27 (94%)	1 (13%)
	<i>BC/BS plans-M</i>	1 (6%)	15 (83%)	2 (11%)
Genetic testing as part of applicant screening?	<i>Commercials</i>	0 (0%)	49 (96%)	2 (4%)
	<i>HMOs</i>	0 (0%)	20 (87%)	3 (13%)
	<i>BC/BS plans-U</i>	0 (0%)	28 (97%)	1 (3%)
	<i>BC/BS plans-M</i>	0 (0%)	16 (89%)	2 (11%)
Genetic counseling of carriers who are covered?	<i>Commercials</i>	0 (0%)	49 (96%)	2 (4%)
	<i>HMOs</i>	1 (4%)	19 (83%)	3 (13%)
	<i>BC/BS plans-U</i>	1 (3%)	27 (94%)	1 (3%)
	<i>BC/BS plans-M</i>	0 (0%)	16 (89%)	2 (11%)

^aPercentages may not add to 100 due to rounding.
^bBC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.
 SOURCE: Office of Technology Assessment, 1992.

Medical directors from 4 of 18 BC/BS plans responded that it was “somewhat likely” that claims payment practices would be altered as new genetic tests came on line. However, nine medical directors from BC/BS plans thought it was “somewhat unlikely” that payment practices would be altered. In 10 years, seven underwriters from BC/BS plans thought it was “somewhat likely” and six thought it was “somewhat unlikely” (table 4-4).

Seven of 23 HMOS thought it was “very likely” or “somewhat likely” that they would alter their claims payment practices as new genetic tests came on line, nine HMOS thought it would be “very unlikely” and five responded it would be “somewhat unlikely.” In 10 years, only two HMOs thought it would be “very likely” they would alter

claims payment practices, five HMOS responded it would be ‘somewhat likely,’ eight thought it would be “somewhat unlikely” and five thought it would be “very unlikely.”

CHAPTER 4 REFERENCES

1. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening, OTA-BA-532* (Washington, DC: U.S. Government Printing Office, August 1992).
2. U.S. Congress, Office of Technology Assessment, *Genetic Counseling and Cystic Fibrosis Carrier Screening—Results of a Survey, OTA-BP-BA-97* (Washington, DC: U.S. Government Printing Office, September 1992).

Table 4-4—Projected Reimbursement Practices 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:						
Alter claims payment practices as new genetic tests come on line	<i>Commercials</i>	7 (14%)	12 (24%)	16 (31%)	16 (31%)	0 (0%)
	<i>HMOS</i>	1 (4%)	5 (22%)	9 (39%)	6 (26%)	2 (9%)
	<i>BC/BS plans-U^b</i>	1 (5%)	10 (34%)	9 (31%)	7 (24%)	2 (6%)
	<i>BC/BS plans-M</i>	1 (6%)	4 (22%)	9 (50%)	2 (11%)	2 (11%)
In the next 10 years:						
Alter claims payment practices as new genetic tests come on line	<i>Commercials</i>	7 (14%)	12 (24%)	16 (31%)	16 (31%)	0 (0%)
	<i>HMOS</i>	1 (4%)	5 (22%)	9 (26%)	6 (26%)	2 (9%)
	<i>BC/BS plans-U</i>	6 (22%)	11 (38%)	3 (10%)	7 (24%)	2 (6%)
	<i>BC/BS plans-M</i>	1 (6%)	7 (39%)	6 (33%)	2 (11%)	2 (11%)

^aPercentages may not add to 100 due to rounding.

^bBC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.