Chapter 3

Survey of the Use of Genetic Testing in the workplace

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There have been conflicting accounts of the extent of genetic testing and the use of its results. In testimony given before Congress in the fall of 1981, the corporate medical director of a large chemical company stated that except for sickle cell trait tests, his company " . . . is not conducting genetic screening of its employees, and I am not aware of any other company which is" (2). However, a series of articles in the New York Times in February 1980 alleged a widespread corporate practice of such testing on American workers (3). Furthermore, a May 1981 survey of east coast industrial physicians indicated that preemployment, preplacement, and periodic testing for sickle cell anemia, hemoglobin disease, and glucose 6-phosphate dehydrogenase (G-6-PD) deficiency was being conducted in some large east coast companies (l).

None of these or other accounts examined by OTA has been based on a rigorous, scientifically valid assessment of the use of genetic testing. Therefore, in an attempt to dispel the confusion and speculation and to provide necessary data for policy analysis, OTA surveyed major U.S. industrial companies, utilities, and unions about their use of this technology.

Purpose

The survey was designed to determine:

- the frequency of past, present, and anticipated genetic screening and cytogenetic monitoring * in the workplace and whether they had been conducted on a routine, special, or research basis;
- which tests were used and under what circumstances:
- how the results of the tests were used; and
- the criteria against which tests have been measured to determine acceptability for use.

The survey did not attempt to establish the number of workers involved in these tests: that information would have required a much more extensive effort.

"The questionnaire used the term biochemical genetic testing to refer to genetic screening and the term cytogenetic testing to refer to cytogenetic monitoring

Study design

The survey was conducted for OTA from February 25 to June 8, 1982, by the National Opinion Research Center (NORC), a nonprofit survey research corporation affiliated with the University of Chicago. NORC sent confidential questionnaires to the chief executive officers of the 500 largest U.S. industrial companies, * the chief executive officers of the 50 largest private utility companies, * * and the presidents of the 11 major unions that represent the largest numbers of employees in those companies.** * For further information on the study design and other aspects of survey methodology, see appendix A, The NORC report to OTA on the survey is in appendix B.

* Identified by Fortune 500 listing of U.S. companies engaged in manufacturing/mining; *Fortune,* vol. 103, No. 9, May 4, 1981.

•*Identified by Fortune Magazine List C; *Fortune,* vol. 103, No. 9, May 4, 1981.

* * *Identified in Dirt? ctory of National Unions and Employees Association (19791 by the US. Department of Labor.

By the June 8, 1982, cutoff date, 366 organizations had answered the questionnaire, a 65.2 percent response rate, and 26 organizations had specifically declined to do so, a 4.6 percent refusal rate. Those who declined generally gave either no reason for refusal or the reason of corporate policy not to respond to surveys. (See table 1.)

Table 1 .—Frequency of Response to Survey by 6/8/82 By Type of Response (based on 561 organizations)

Type of response	Number	Percent
Participated	366	65.2%
Refused to participate:	26	4.60/o
Policy not to reply to surveys	(10)	
Not interested, no time.	(3)	
Object to methodology	(1)	
Phone refusal—no reason	(12)	
Unknown	169	30.1%
Total	561	

SOURCE: National Opinion Research Center, survey conducted for OTA, 1982,

Results

Overall rates of testing

Of the 366 organizations responding, 6 (1,6 percent) were currently conducting genetic testing, * 17 (4.6 percent) used some of the tests in the past 12 years, 4 (1,1 percent) anticipated using the tests in the next 5 years, and 55 (15 percent) stated they would possibly use the tests in the next 5 years. Most of these organizations are in manufacturing/mining (particularly chemicals) or are utility companies. Of those organizations that have tested in the past 12 years, five are currently doing so, (See table 2.) Because the questionnaire instructed respondents to include any instance of testing, positive responses can include isolated instances of testing as well as long-term testing programs. Among the six companies currently testing, two are in the chemical industry, two are utilities, and two are in the electronics industry. Half of those that tested in the past are chemical companies. Of the four organizations that anticipate the use of genetic testing, two are conducting testing at present, one has done so in the past, and one has never had such a program. None of the four responding unions reported any testing. These results are set forth in more detail in tables 3, 4, and 5.

Types of testing: genetic screening and cytogenetic monitoring

Organizations that reported some genetic screening were asked whether they had ever tested employees for genetic traits associated with: (A) any red blood cell and serum disorders, (B) liver detoxification systems, (C) immune system markers, or (D) heterozygous chromosomal instabilities. For each of the four broad categories A through D, the questionnaire listed several examples. Of those who have ever tested, 14 of the organizations had tested in category A, 3 in category B, 5 in category C, and none in category D. Organizations that have used red blood cell and serum disorder tests, category A, often used more than one type of test. The most frequently used test in this category was that for sickle cell trait, for which 10 organizations have tested. The G-6-PD and serum alpha-1 antitrypsin deficiency tests were the second most frequently used. (See table 6 for a summary of the frequency of individual genetic screening tests.)

Table 2.—2 x 2 Contingency Table for Organizations Engaged in Genetic Testing
(past testers by current testers)

		Past testers		
		Yes	No	Total
Current testers	Yes	5	1	6
	No	12	348	360
	Total	17	349	366

SOURCE: National Opinion Research Center, survey conducted for OTA, 1982.

For each test, companies were asked about the circumstances under which the tests were done (that is, routinely, for research, or for other reasons) and the type of employee tested. Respondents generally said they tested routinely or for unspecified reasons. (See table 6.) Employees most often were selected on the basis of ethnicity and race for sickle cell trait testing and on the basis

● Genetic screening and/or cytogenetic monitoring

Table 3.—Distribution of Organizations By Type, Indicating Current, Past, and/or Future Use of Genetic Testing (based on 366 responses)

	Testing					
	Current		Past		Future	
Organization type (number of respondents)	Yes	No/NA[a]	Yes	No/NA[a]	Yes/Poss.	No/NA[a]
Manufacturing/mining companies (322)	4	318	16	306	49	273
Private utility companies (31)	2	29	1	30	9	22
Unions (5)	0	5	0	5	0	5
Unknown (8)	0	8	0	8	1	7
Total (366)	6 (1.6%)	360	17 (4.6%)	349	59 (16.1 %)	307

[a]A combination response Further breakdown is impossible since the category (current, past, future) is a summary of responses to two questions dealing with genetic screen i n g and cytogenetic mon itori ng In the case of No/NA, most responses were No, for Yes/Poss , most responses were possibly. See table 4 for further breakdown

SOURCE National Opinion Research Center, survey conducted for OTA, 1982

Table 4.—Frequency of Current, Past, and/or Future Use of Genetic Testing, By Type (based on 366 responses)

	Testing									
	Current			Past			Future			
Type of test	Yes	No	N/A	Yes	No	N/A	Yes	Poss.	No	N/A
Genetic screening	5	350	11	12	342	12	1	53	292	20
Cytogenetic monitoring	2	354	10	6	348	12	3	49	294	20

SOURCE National Opinion Research Center, survey conducted for OTA, 1982

Table 5.— Distribution of Companies by Classification,[a] Indicating Current, Past, and/or Future Use of Genetic Testing (based on 366 responses)

	Genetic testing					
	Current		Past		Future	
Main industrial classification (number of respondents)	Yes	No/NA[b]	Yes	No/NA[b]	Yes/Poss.	No/NA[b]
Chemical (37)	2	35	8	29	11	26
Utilities (33)	2	31	1	32	10	23
Petroleum (18)	0	18	0	18	4	14
Pharmaceuticals (9)	0	9	0	9	3	6
Rubbers/plastics (4)	0	4	0	4	3	1
Metals (16)	0	16	0	16	2	14
Others (249)	2[c]	247	8	241	26	223
Total (366)	(1 .6%)	360	(4.&o)	349	(16.1%)	307

[a]Main industrial classification based on the first listed response of respondent to question concerning the major Industrial classification of their company
[b]A combination response. Further breakdown Impossible since the category (current, past, future) is a summary of two questions" 1) genetic screening, 2) cytogenetic monitoring. In the case of No/NA, most responses were No; for Yes/Poss. most responses were possibly. See table 4 for further breakdown
[c]Both of these companies report electronics as their main industrial classification

SOURCE National Opinion Research Center, survey conducted for OTA, 1982.

of job category for other types of tests. No organization reported basing a genetic screening test on an employee's sex. (See table 7.)

Of the organizations that reported cytogenetic monitoring, four had tested for chromosomal aberrations and two for sister chromatid exchanges (SCE). None reported having tested for mutations by assaying either deoxyribonucleic acid (DNA) or enzymes. Most frequently, no reason was given for chromosomal aberration testing. The two companies that did SCE testing said it was for research purposes. (See table 6.) Job category was the only employee-related characteristic used to determine who would be tested. (See table 7.)

Table 6.—Genetic Testing Ever[a] Conducted By Purpose and Type of Test (based on 18 responses)

	Genetic screening						Cytogenetic monitoring	
Purpose	Sickle cell	G-6-PD	SAT	Methemoglobin reductase	Unspecified red blood cell/serum disorder	Unspecified liver detox	Unspecified immune system markers	Chromosomal aberrations	Sister chromatid exchanges
Routine	5	3	1	0	1	1	4	1	0
Research	1	0	2	1	2	1	0	1	2
Other	6	2	2	1	2	1	3	3	0
Total number of respondents utilizing test[b]	10	4	4	1	3	3	5	4	2

[a] In the past 12 years.
[b] Since categories above are not mutually exclusive, total can be less/more than sum of categories.
SOURCE: National Opinion Research Center, survey conducted for OTA, 1982.

Table 7.—Genetic Testing Ever[a] Conducted By Criteria and Type of Test (based on 18 responses)

	Genetic screening						Cytogenetic monitoring	
Criteria	Sickle cell	G-6-PD	SAT	Methemoglobin reductase	Unspecified red blood cell/serum disorder	Unspecified liver detox	Unspecified immune system markers	Chromosomal aberrations	Sister chromatid exchanges
Job category	1	2	2	0	2	1	1	2	1
Ethnicity/race	7	0	0	0	0	0	0	0	0
Sex	0	0	0	0	0	0	0	0	0
Total number of respondents utilizing test[b]	10	4	4	1	3	2	4	4	2

[a] In the past 12 years.
[b] Since categories above are not mutually exclusive, total can be less/more than sum of categories,
SOURCE: National Opinion Research Center, survey conducted for OTA, 1982,

Recipients were asked about the factors considered in the decision to implement testing and the criteria employed in selecting specific tests. Data from epidemiological studies, data from animal studies, and other reasons such as employee protection were the highest ranked factors involved in decisions to implement genetic testing for both genetic screening and cytogenetic monitoring. (See table 8.) The predictive value of a test, its specificity, scientific consensus, and other factors such as research findings were the factors cited most frequently as criteria for selecting a specific genetic test. These responses were similar for both genetic screening and cytogenetic monitoring. (See table 9.)

The types of testing carried out by current testers were compared with those of past testers. For genetic screening, current testers are using a slightly greater variety of tests (tests for red blood cell and serum disorders, liver detoxification systems, and immune system markers) than

Table 8.—Genetic Testing Ever[a] Conducted By Reasons for and Type of Testing (based on 18 responses)

	Type of testing	
Reasons for deciding to implement testing	Genetic screening	Cytogenetic monitoring
Data epidemiologic studies	6	2
Data animal studies	4	2
Legal consequences of not testing	3	0
Union employee initiative	3	0
Cost-benefit analysis	2	0
Other[b]	4	3

[a] In the past 12 years.
[b] Includes reasons related to protecting employees, research findings.
SOURCE: National Opinion Research Center, survey conducted for OTA, 1982.

Table 9.–Genetic Testing Ever[a] Conducted By Criteria for Test Selection and Type of Testing (based on 18 responses)

Criteria[b]	Type of testing: Genetic screening	Type of testing: Cytogenetic monitoring
Predictive value of test[c]	5	1
Specificity of test[d]	5	1
Scientific concensus	4	2
Sensitivity of test[e]	3	0
Cost of test	2	0
Other[f]	4	3

[a] In the past 12 years.
[b] A respondent may have based its selection for a test on one or more of the above criteria
[c] Predictive value of test: the likelihood that the disease status of the individual will be correctly Identified by the test; i e., a disease-free individual will have negative test result, a diseased individual will have positive test result
[d] Specificity of test: ability of test to correctly identify individuals without disease
[e] Sensitivity of test" ability of test to correctly identify individuals with disease
[f] Includes research findings (general).

SOURCE National Opinion Research Center, survey conducted for OTA, 1982

past testers and at a slightly higher proportion of usage. of the six current testers, five are testing for red blood cell and serum disorders, three for liver detoxification systems, and two for immune systems markers. Eight of twelve past testers had tested for red blood cell and serum disorders, none had tested for liver detoxification systems, and two had tested for immune system markers. In fact, however, because of the small numbers involved, the only notable difference between current and past testers may be the current use of tests for liver detoxification systems. In any event, testing for red blood cell and serum disorders continues to be the most frequently used test. (See table 10.)

A different pattern of use emerges for cytogenetic monitoring, Of the six current testers, one is testing for chromosomal aberrations and one is testing for sister chromatid exchanges, For the 12 past testers, 3 tested for chromosomal aberrations and 1 tested for sister chromatid exchanges. This may reflect the change in the state of the art concerning the science of sister chromatid exchanges. (See table 10.) In any event, the number of tests remain small and caution is advised in interpreting these data.

Actions taken as a result of testing

Responses concerning the way in which the results of genetic screening or cytogenetic monitoring were used varied greatly, ranging from actions involving an employee to changing or discontinuing a product. Of the 18 companies that reported taking some action, 8 reported that they had informed an employee of a potential problem. Five respondents reported transferring the "at-risk" employee. Two suggested that the employee seek another job as a result of testing. One discontinued or changed a product, The complete list of actions taken appears in table 11.

Generalizability of the survey

Can the results of this survey be generalized to the population of Fortune 500 companies, large utility companies, and major unions? An answer to this involves two additional questions: Are the responses equally distributed among the groups

Table 10.—Distribution of Type of Testing By Status of Tester (based on 18 responses)

Type of testing	Status of tester: Current N-6 Yes	No/NA	Percent using	Past N-12 Yes	No/NA	Percent using	Total
Genetic screening:							
Red blood cell and serum disorders	5	1	830/o	8	4	670/o	18
Liver detoxification systems	3	3	50 "/0	o	12	O °/o	18
Immune system markers	2	4	33%	2	10	1OO/o	18
Heterozygous chromosomal instabilities	0	6	0%	o	12	0%	18
Cytogenetic monitoring:							
Chromosomal aberrations	1	5	17 "/0	3	9	250/o	18
Sister chromatid exchange	1	5	17"/0	1	11	80/0	18
Mutations by assaying DNA	0	6	0%	0	12	O °/o	18
Mutations by assaying enzymes	0	6	0%	o	12	0%	18
Other	1	5	17 "/0	o	12	O °/o	18

SOURCE National Opinion Research Center, survey conducted for OTA, 1982

Table 11 .—Actions Taken by Respondents That Have Ever[a] Used Genetic Testing (based on 18 responses)

Type of action[b]	Number of companies
Informed employee of a potential problem	8
Transferred employee	5
Personal protection device	3
Other action	3
Suggested employee seek other job	2
Installed engineering control	2
Implemented research program	1
Discontinued/changed product	1

[a] In the past 12 years.
[b] A respondent may have taken more than one action

SOURCE: National Opinion Research Center, survey conducted for OTA, 1982.

represented in the survey? Are characteristics of the respondents different from the nonrespond - ents? These two questions are discussed in turn.

By the close of the survey, a discrepancy in response rate among the groups represented in the survey became apparent. The large corporations had the highest response rates: 68 percent for utilities and 61.5 percent for the top 200 companies in the Fortune 500 listing; the unions and small corporations had the lowest response rates: 36.4 percent for unions and 44 percent among the bottom 300 companies in the Fortune 500 listing. (See app. A.) The variation in response pattern was most probably due to the followup efforts that focused on the top 100 companies of the Fortune 500 listing and organizations in selected industrial classifications such as utilities. Thus, the results of this survey may be more applicable to the larger manufacturing/mining and utility companies than to smaller manufacturing/mining companies and unions.

Analysis of selected characteristics of respondents compared with nonrespondents is limited to the Fortune 500 companies. Respondents and nonrespondents were compared on the following characteristics: geographic location, size of organization, and type of industry. Rates of response and nonresponse did not differ greatly geographically. (See app. A.)

For size of company, however, the rate of nonresponses did differ widely from the rate of responses. For example, 53 percent of the nonrespondents were in the smallest companies, compared with 32 percent of the respondents. Again, because larger companies were used in followup efforts, the response rates may reflect these efforts. (See app. A.)

Rate of nonresponse did not vary greatly from rate of response with respect to industry classification. Eleven industries had a slightly higher rate of response than predicted. Of these industries, five (chemicals, petroleum refining, rubber and plastic products, metal manufacturing, and pharmaceuticals) were the key industries selected for followup activities and the rates from the remaining six (glass/concrete, electronics, measuring equipment, motor vehicles, aerospace, and office equipment) may be explained by such factors as the effect of followup based on size of company or chance. (See app, A.)

Thus, the results of the survey may be more representative of the larger manufacturing/mining corporations and private utility companies as identified in Fortune magazine listings; however, the respondents do not appear to differ greatly from the nonrespondents in geographic location or type of company.

Comments on survey

Respondents were encouraged to write explanatory notes or other comments on the questionnaires and on the post cards. Thirty-one respondents did so. (See app. C for complete text of comments,) Three current testers sent in comments. Two of these respondents said testing was being done for reasons of health evaluation—preplace - ment and/or routine monitoring; one respondent said that such testing should not be interpreted to mean a large-scale testing program or a problem exists.

Comments were received from two companies that had tested in the past, Both respondents referred to testing for sickle cell trait, one at the request of the State health department, and the other at the request of the employer for employees of child-bearing age as part of the company's preventive medical program.

Seven organizations that anticipate future testing but that have not conducted any testing to date provided comments. The comments ranged

from addressing animal research to questionnaire improvement to any future testing being dependent on ‘(practical utility. ”

Comments received from 19 organizations that have never tested or that do not plan to test in the future focused on three major points. The first was the genetic testing was not relevant to the products or processes to which their workers were exposed. The second was that these tests were not sufficiently developed for use. The third point was that the organization was satisfied with its current conventional industrial hygiene practice and standard medical surveillance of its workers.

Caveats

In evaluating the results of the survey, several caveats must be considered. First, since the questionnaire instructed respondents to include any instances of testing, positive responses can include isolated cases as well as long-term testing programs. Second, the questionnaire was not structured to provide information on the number of workers tested. Positive responses indicate only the existence of testing, not its extent. Third, since approximately one-third of the population did not respond and the number of organizations testing is very small, any generalizing of these results to the study population as a whole is not warranted. Fourth, the level of effort employed in completing each questionnaire is unknown. For example, holding companies which have autonomously operating subsidiaries may or may not have included the activities of those subsidiaries in their responses. Fifth, a limitation of an anonymous questionnaire is that respondents cannot be contacted about missing information or unclear responses. Approximately 3 percent of the respondents failed to answer every item in the core questions. Eight returned questionnaires did not provide enough information to allow the respondents to be classified as a Fortune 500 company or as a utility. Sixth, the use of post cards for followup has pitfalls: respondents may return post cards but not questionnaires or vice versa; NORC received 293 post cards and 366 questionnaires. This may have resulted in duplication of information or minimized the effect of followup.

Conclusions

The survey of major U.S. industrial companies, utilities, and unions has shown that genetic testing currently is being used by a few companies, that its use has declined in the past 12 years, but that it may be used by many more companies in the future. The responses cannot be generalized to the survey population or to all U.S. companies and labor unions. However, it is clear that 17 organizations have used genetic testing in the past 12 years, 5 of the 17 and 1 other currently are doing so, and 59 organizations have expressed an interest in using these tests. None of these organizations is a union. The extent of testing by these organizations is unknown.

Further, of the 18 companies that have ever conducted genetic testing in the past 12 years, more companies have conducted genetic screening (17 companies) than cytogenetic monitoring (8 companies). Tests for sickle cell trait were the most frequently used type of genetic screening and tests for chromosomal aberrations were the most frequently used type of cytogenetic monitoring. Research was the least frequently mentioned purpose for testing. Respondents generally tested routinely or for other unspecified reasons. The type of employee chosen for testing was based most often on ethnicity and race for sickle cell trait testing, and job category for other types of tests. Sex was never stated as a criterion used in determining the test of choice. Actions taken on the results of the tests ranged from informing the employee of a potential problem (eight companies) to discontinuing or changing the product (one company).

Data from epidemiological and animal studies were the most frequently cited factors in the decision to implement testing of those companies that tested. A cost-benefit analysis was the least impor-

tant factor. The predictive value and specificity of a test were the most important criteria in the selection of the specific genetic screening test, while research findings were most important in the selection of the specific cytogenetic monitoring test.

Chapter 3 references

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