

Appendix C

Survey Instruments

As part of the 1992 assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA surveyed commercial health insurers that offer policies to individuals or medically underwritten groups, Blue Cross and Blue Shield plans, and selected health maintenance organizations. The instruments were tailored slightly for

each population, but the substance for all three questionnaires was unchanged. The following are reproductions of the survey questionnaires. For Blue Cross and Blue Shield plans, identical surveys were sent separately to chief underwriters and medical directors, but only the former is reproduced.

CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

SURVEY OF HEALTH INSURERS' ATTITUDES AND PRACTICES
REGARDING GENETIC TESTING FOR CYSTIC FIBROSIS

Aim: MEDICAL DIRECTOR

Please Respond by July 15, 1991

The Congressional Office of Technology Assessment (OTA) is contacting health insurers who offer individual coverage in a national survey of attitudes and practices regarding cystic fibrosis screening. This questionnaire has been directed to you as the person in your organization whose responsibilities include medical decisionmaking. We request your assistance in answering some questions about genetic testing and medical decisionmaking in your company. If you are not the Medical Director, we would appreciate it if you would please forward the questionnaire to the appropriate person.

For the purposes of this survey, OTA has adopted the following definitions:

By carrier testing we mean testing an unaffected individual to reveal the possibility that off-spring may have a serious chronic condition or disease (e.g., cystic fibrosis or sickle cell disease).

By we mean testing applicants or policyholders for certain inherited characteristics either presymptomatically to reveal future serious chronic disease (e.g., for Huntington's disease or for risk oriented Purpo_ses (e.9., predisposition to heart disease).

This is an important study that has been requested by the U.S. Congress, and is designed to represent the attitudes and practices of health insurers. We need to know how insurers view the technologies of genetic testing in terms of their current and future applications in health insurance.

Please read each question and mark the space that most nearly corresponds to your answer. Please feel free to qualify your answers. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions. The survey responses will be kept strictly anonymous as well as confidential.

PLEASE NOTE: This survey focuses on two health insurance ovulations-(1) Individuals who seek insurance independently and without any association with an empl oyer or membership group of any kind; and (2) underwritten groups ~ i.e., those groups whose members must be medically underwritten.

Conversions should be excluded from your responses. In addition, we prefer that you exclude Medigap insurance from your responses. If because of reporting or other reasons, you must include Medigap policies, please check the box below:

YES, Medigap policies and statistics are included in our responses to this survey.

Do you offer coverage for either individuals or medically underwritten groups?

Yes _____ (1)
 No _____ (2)

IF YOU ARE NOT OFFERING EITHER OF THESE TYPES OF COVERAGE, THIS COMPLETES YOUR SURVEY. THANK YOU VERY MUCH. PLEASE RETURN IT IN THE PRE-ADDRESSED POST-PAID ENVELOPE.

SECTION 1: INDIVIDUAL AND GROUP STATISTICS

| | Individual Policies | Medically Underwritten Groups |
|---|------------------------|-------------------------------------|
| 1. What is the approximate number of persons that you currently insure through: | _____ | _____ |
| 2. What is the approximate number of applications received by your company per year for coverage under: | _____ | _____ |
| 3. What portion of those applications are: | | |
| a. Accepted at standard rates | _____ % | _____ % |
| b. Covered with an exclusion waiver, but standard premium | _____ % | _____ % |
| c. Covered with a rated premium, but not exclusion waiver | _____ % | _____ % |
| d. Covered with an exclusion waiver and a rated premium | _____ % | _____ % |
| e. Declined by your company | _____ % | _____ % |
| f. Other (SPECIFY) | _____ % | _____ % |
| _____ | _____ % | _____ % |
| _____ | _____ % | _____ % |
| TOTAL | 100% | 100% |

SECTION 11: UNDERWRITING PRACTICES

4. For each category of coverage, please estimate the proportion of all health insurance applicants from whom you require:

| | Individual Policies | Medically Underwritten Groups |
|------------------------------|------------------------|-------------------------------------|
| a. A personal health history | _____ % | _____ % |
| b. A family health history | _____ % | _____ % |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

- spouse (1)
- Parents (2)
- Grandparents (3)
- Siblings (4)
- Children (5)
- Other (SPECify) _____ (6)

c. An attending physician statement (APS) _____ % _____ %

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK AU THAT APPLY.

- Any Significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- An significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)

d. Physical exam: _____ % _____ %

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK AU THAT APPLY.

- Any significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- Any significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)
- Any significant diagnosis or symptoms identified in APS (6)

e. Blood or urine screens: _____ % _____ %

5. For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

1 = *Very important*; 2 = *Important*; 3 = *Unimportant*; 4 = *Never Used*

| | Individual Policies | Medically Underwritten Groups |
|---|------------------------|-------------------------------------|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. Lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of <i>significant conditions</i> | _____ | _____ |
| h. Family medical history of <i>significant conditions</i> | _____ | _____ |
| i. Genetic predisposition to <i>significant conditions</i> | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

6. How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the following conditions in an examination(s) or application:

1 = *Accepted with standard rates*; 2 = *Accepted with exclusion waiver at standard rates*;
 3 = *Accepted with exclusion waiver at rated premium*;
 4 = *Accepted without exclusion waiver but at rated premium*; 5 = *Declined*

| | individual Policies | Medically Underwritten Groups |
|----------------------------|------------------------|-------------------------------------|
| a. Hypertension | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ |
| d. Hemophilia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |

SECTION III: GENETIC CONDITIONS

7. Does your company specifically inquire, for each category of coverage, about the following conditions in the application for health insurance in the personal history, family history, or neither

1 = *Personal history only*; 2 = *Family history*; 3 = *Neither*

| | Individual Policies | Medically Underwritten Groups |
|--|------------------------|-------------------------------------|
| a Hemophilia | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Huntington's disease | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ |
| e- Cystic fibrosis | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ |

8. For individual policy applicants only how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

1 = *Accepted with standard rates*; 2 = *Accepted with exclusion waiver at standard rates*;
 3 = *Accepted with exclusion waiver at rated premium*;
 4 = *Accepted without exclusion waiver but at rated premium*; 5 = *Declined*

| | individual Policies |
|--|------------------------|
| a Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

9. For individual policy applicants *only* how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

- 1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
 3 = Accepted with exclusion waiver at rated premium;
 4 = Accepted without exclusion waiver but at **rated** premium; 5 = Declined

| | Individual Policies |
|--|------------------------|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

10. Do your standard individual policies and medically underwritten policies provide coverage for:

- 1 = At patient request; 2 = Only if medically indicated; 3 = Not covered

| | Individual Policies | Medically Underwritten Groups |
|----------------------------|------------------------|-------------------------------------|
| Carrier tests for | | |
| a. Cystic fibrosis | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Sickle cell trait | _____ | _____ |
| Prenatal tests for: | | |
| d. Cystic fibrosis | _____ | _____ |
| e. Tay-Sachs | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |
| g. Down Syndrome | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ |
| Genetic counseling | _____ | _____ |

ii. How would individual policies and medically underwritten policies normally be affected by the following findings:

1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
 3 = Accepted with exclusion waiver at rated premium;
 4 = Accepted without exclusion waiver but rated premium; 5 = Declined

| | Individual Policies | Medically Underwritten Groups |
|---|------------------------|-------------------------------------|
| a. Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ |

SECTION IV: GENERAL ATTITUDES

12. To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?
 Yes _____ (1)
 No _____ (2)

13. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|-----|----|
| a Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

14. Under what conditions would a negative financial impact be likely to occur for your company:
 (CHECK AU THAT APPLY)

- a Widespread availability of genetic tests to the medical/provider community _____ (1)
- b. Widespread availability of genetic tests with constraints on insurers' access to the results _____ (2)
- c. Adverse claims or underwriting results from antiselection _____ (3)
- d. Other (SPECIFY) _____ (4)

15. How likely do you think it is that your company will:

| | very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|---|----------------|--------------------|----------------------|------------------|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |
| In the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

16. Please indicate whether you:

| | Agree strongly | Agree somewhat | Disagree Somewhat | Disagree Strongly |
|---|----------------|----------------|-------------------|-------------------|
| a. It's fair for insurers to use genetic tests to "identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An insurer should have the option of determining how to use genetic information in determining risk s. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | 3 | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The insurance company declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | 3 | 4 |

SECTION V: DEMOGRAPHICS

17. What is your job title?

18. Which of the following lines of insurance does your company underwrite?

Health 1

Disability 2

Life 3

19. What percent of persons under health insurance policies issued by your company are in policies classified as:

Self-insured Administration _____%

Individual _____%

Medically Underwritten Groups _____%

Large Groups _____%

TOTAL 100%

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us as any other opinions, concern% or suggestions related to genetic testing and insurance that you feel our questions did not address These comments will be strictly anonymous but may be incorporated in our report to Congress. Please write these comments below.

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. Absolutely no companies and questionnaires will be retained. The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

PEEL OFF LABEL WITH SAMPLE
IDENTIFICATION HERE

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025

SECTION 1: BACKGROUND

1. Do you offer coverage for either self-paying individuals (other than on a conversion basis) or medically underwritten groups?

Yes _____ (1)
No _____ (2)

IF YOU ARE NOT OFFERING EITHER OF THESE TYPES OF COVERAGE, THIS COMPLETES YOUR SURVEY. THANK YOU VERY MUCH. PLEASE RETURN IT IN THE PRE-ADDRESSED POSTAGE-PAID ENVELOPE.

2. Is your plan federally qualified? Yes (1) No (2)

If no, is Federal qualification pending? Yes (1) No (2)

If yes, do you have a non-federally qualified subsidiary Yes (1) No (2)

3. Does your plan have an open enrollment period (i.e., no medical screening) for self-payers?

Yes (1) No (2)

If yes, is it continuous? Yes(1) No (2)

4. Which model type is your plan? Check all that apply, but if more than one type is offered, indicate which is primary, secondary, etc. by the number of patients covered.

Staff Model Plan _____

Group Model Plan _____

Network Model Plan _____

IPA Model Plan _____

SECTION 11: INDIVIDUAL AND GROUP STATISTICS

| | Individual Policies | Medically Underwritten Groups |
|--|------------------------|-------------------------------------|
| 5. What is the approximate number of persons that you currently insure through: | _____ | _____ |
| 6. What is the approximate number of applications received by your company per year for coverage under | _____ | _____ |
| 7. What portion of those applications are: | | |
| a. Accepted at standard rates | _____ % | _____ % |
| b. Covered with an exclusion waiver, but standard premium | _____ % | _____ % |
| c. Covered with a rated premium, but not exclusion waiver | _____ % | _____ % |
| d. Covered with an exclusion waiver and a rated premium | _____ % | _____ % |
| e. Declined by your company | _____ % | _____ % |
| f. Other (SPECIFY) | _____ % | _____ % |
| _____ | _____ % | _____ % |
| _____ | _____ % | _____ % |
| TOTAL | 100% | 100% |

SECTION III: UNDERWRITING PRACTICES

8. For each category of coverage, please estimate the proportion of all HMO applicants from whom you require:

| | Individual Policies | Medically Underwritten Groups |
|------------------------------|------------------------|-------------------------------------|
| a. A personal health history | _____ % | _____ % |
| b. A family health history | _____ % | _____ % |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

- spouse (1)
- Parents (2)
- Grandparents (3)
- Siblings (4)
- Children (5)
- Other (SPECIFY) _____ (6)

c. An attending physician statement (APS) _____ % _____ %

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

- Any significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- Any significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)

d. Physical exam: _____ % _____ %

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

- Any significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- Any significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)
- Any significant diagnosis or symptoms identified in APS (6)

e. Blood or urine screens: _____ % _____ %

9. For each category of coverage, please indicate the importance of much of the following factors in determining insurability (not in rating):

1 = Very impotiant; 2 = Important; 3= Unimportant; 4 = Never used

| | Individual Policies | Medically Underwritten Groups |
|---|---------------------|-------------------------------|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of significant conditions | _____ | _____ |
| h. Family medical history of significant conditions | _____ | _____ |
| i. Genetic predispositbn to significant conditions | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

10. How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the fallowing conditions in an examination(s) or application:

1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
 3 = Accepted with exclusion waiver at rated premium;
 4 = Accepted without exclusion waiver but at rated premium; 5 = Declined

| | Individual Policies | Medically Underwritten Groups |
|----------------------------|---------------------|-------------------------------|
| a. Hypertension | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ |
| d. Hemophilia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Sickle ceil anemia | _____ | _____ |

SECTION IV: GENETIC CONDITIONS

11. Does your company specifically inquire, for each category of coverage, about the following conditions in the HMO application in the personal history, family history, or neither:

1 = Personal history only; 2 = Family history; 3 = Neither

| | individual Policies | Medically Underwritten Groups |
|--|------------------------|-------------------------------------|
| a. Hemophilia | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Huntington's disease | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ |

12. For individual policy applicants only how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;

3 = Accepted with exclusion waiver at rated premium;

4 = Accepted without exclusion waiver but at rated premium; 5 = Declined

| | Individual Policies |
|--|------------------------|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

13. For individual policy applicants only how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

- 1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
- 3 = Accepted with exclusion waiver at rated at premium;
- 4 = Accepted without exclusion waiver but at rated premium; 5 = Declined

| | Individual Policies |
|--|------------------------|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

14. Do your standard individual policies and medically underwritten policies provide coverage for:

- 1 = At patient request; 2 = Only if medically indicated; 3 = Not covered

| | Individual Policies | Medically Underwritten Groups |
|----------------------------|------------------------|-------------------------------------|
| Carrier tests for | | |
| a. Cystic fibrosis | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Sickle cell trait | _____ | _____ |
| Prenatal tests for: | | |
| d. Cystic fibrosis | _____ | _____ |
| e. Tay-Sachs | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |
| g. Down Syndrome | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ |
| Genetic counseling | _____ | _____ |

15. How would individual policies and medically underwritten policies normally be affected by the following findings:

1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
 3 = Accepted with exclusion waiver at rated premium;
 4 = Accepted without exclusion waiver but at rated premium; 5 = Declined

| | Individual Policies | Medically Underwritten Groups |
|--|---------------------|-------------------------------|
| a Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious chronic future disease (e.g., predisposition to heart disease) | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ |

SECTION V: GENERAL ATTITUDES

16. To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?

Yes _____ (1)
 No _____ (2)

17. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|-----|----|
| a Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

18. Under what conditions would a negative financial impact be likely to occur for your company: (CHECK ALL THAT APPLY)

- a Widespread availability of genetic tests to the medical/provider community _____ (1)
- b. Widespread availability of genetic tests with constraints on HMOS' access to the results _____ (2)
- c. Adverse claims or underwriting results from antiselection _____ (3)
- d. Other (SPECIFY) _____ (4)

19. How likely do you think it is that your HMO will:

| | Very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|---|-------------|-----------------|-------------------|---------------|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |
| in the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require Carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and Carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

20. Please indicate whether you:

| | Agree Strongly | Agree somewhat | Disagree Somewhat | Disagree Strongly |
|--|-------------------|-------------------|----------------------|----------------------|
| a. It's fair for HMOS to use genetic tests to identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An HMO should have the option of determining how to use genetic information in determining risks. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The HMO, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The HMO declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | 3 | 4 |

SECTION VI: DEMOGRAPHICS

21. What is your job title?

22. Which of the following lines of insurance does your company underwrite?

Health 1

Disability 2

Life 3

23. What percent of persons under HMO policies issued by your company are in policies classified as:

Self-insured Administration _____ %

Individual _____ %

Community-rated Groups _____ %

Experience-rated Groups _____ %

TOTAL 100%

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us as any other opinions, concerns or suggestions related to genetic testing and insurance that you feel our questions did not address. These comments will be strictly anonymous but may be incorporated in our report to Congress. Please write these comments below.

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. naireswi | | The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

PEEL OFF LABEL WITH SAMPLE

IDENTIFICATION HERE

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025

CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

**SURVEY OF HEALTH INSURERS' ATTITUDES AND PRACTICES
REGARDING GENETIC TESTING FOR CYSTIC FIBROSIS**

ATTN: CHIEF UNDERWRITER

Please Respond by July 19, 1991

The Congressional Office of Technology Assessment (OTA) is contacting health insurers who offer individual coverage in a national survey of attitudes and practices regarding cystic fibrosis screening. This questionnaire has been directed to you as the person in your organization whose responsibilities include underwriting. We request your assistance in answering some questions about genetic testing and underwriting in your company. If you are not the Chief Underwriter, we would appreciate it if you would please forward the questionnaire to the appropriate person.

For the purposes of this survey, OTA has adopted the following definitions:

By *carrier testing*, we mean testing an unaffected individual to reveal the possibility that off-spring may have a serious chronic condition or disease (e.g., cystic fibrosis or sickle cell disease).

By *genetic testing*, we mean testing applicants or policyholders for certain inherited characteristics either presymptomatically to reveal future serious chronic disease (e.g., for Huntington's disease or for risk oriented purposes (e.g., predisposition to heart disease).

This is an important study that has been requested by the U.S. Congress, and is designed to represent the attitudes and practices of health insurers. We need to know how insurers view the technologies of genetic testing in terms of their current and future applications in health insurance.

Please read each question and mark the space that most nearly corresponds to your answer. Please feel free to qualify your answers. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions. The survey responses will be kept strictly anonymous as well as confidential.

PLEASE NOTE: This survey focuses on three health insurance populations---(1) *Medically underwritten individuals/nongroup* who seek insurance independently and without any association with an employer or membership group of any kind; (2) *Medically underwritten groups*, i.e., those groups whose members must be medically underwritten; and (3) *Nongroup open enrollment*, individuals/nongroup who seek open enrollment coverage, i.e., without medical underwriting.

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Conversions should be excluded from your responses. In addition, we prefer that you exclude Medigap insurance from your responses. If because of reporting or other reasons, you must include Medigap policies, please check the box below:

YES, Medigap policies and statistics are included in our responses to this survey.

Does your plan have an on enrollment period? YES (1) NO (2)
If yes, is it continuous. \ \ YES (1) \ \ NO (2)

SECTION 1: INDIVIDUAL AND GROUP STATISTICS

| | Individual/Non- group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|-----------------------------------|-------------------------------------|--------------------------------|
| 1. What is the approximate number of persons that you currently insure through: | _____ | _____ | _____ |
| 2. What is the approximate number of applications received by your company per year for coverage under: | _____ | _____ | _____ |
| 3. What portion of those applications are: | | | |
| a. Accepted at standard rates without exclusion waiver or waiting period | _____ % | _____ 0/0 | _____ 0/0 |
| b. Covered with an exclusion waiver, but standard premium | _____ % | _____ % | _____ % |
| c. Covered with a waiting period, but standard premium | _____ % | _____ % | _____ % |
| d. Covered with a rated/risk-adjusted premium, but not exclusion waiver or waiting period | _____ % | _____ %0 | _____ 0/0 |
| e. Covered with an exclusion waiver and a rated/risk-adjusted premium | _____ % | _____ % | _____ % |
| f. Covered with a waiting period and a rated/risk-adjusted premium | _____ % | _____ % | _____ % |
| g. Declined by your company | _____ % | _____ % | _____ % |
| h. Other (SPECIFY) | _____ % | _____ % | _____ % |
| _____ | _____ % | _____ % | _____ % |
| _____ | _____ % | _____ % | _____ 0/0 |
| TOTAL | 100?40 | 100%0 | 10070 |

SECTION II: UNDERWRITING PRACTICES

4. For each category of coverage, please estimate the proportion of all health insurance applicants from whom you require:

| | Individual/Non- group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|------------------------------|-----------------------------------|-------------------------------------|--------------------------------|
| a. A personal health history | _____ % | _____ % | _____ % |
| b. A family health history | _____ % | _____ % | _____ % |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

- Spouse (1)
- Parents (2)
- Grandparents (3)
- Siblings (4)
- Children (5)
- Other (SPECIFY) _____ (6)

c. An attending physician statement (APS) _____ % _____ % _____ %

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

- Any significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- Any significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)

d. Physical exam: _____ % _____ % _____ %

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

- Any significant diagnosis or symptoms reported on application (1)
- Selected diagnoses or symptoms reported on application (2)
- Any significant conditions reported in family history (3)
- Selected conditions reported in family history (4)
- M.I.B. report (5)
- Any significant diagnosis or symptoms identified in APS (6)

e. Blood or urine screens: _____ % _____ % _____ %

PLEASE ANSWER THE FOLLOWING QUESTIONS (#5-1 1) AS THEY APPLY TO YOUR MOST COMMONLY PURCHASED PRODUCT. IS THIS PRODUCT (CHECK ONE):

- Traditional _____ (1)
- PPO _____ (2)
- HMO _____ (3)

5. For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

1 = Very *important*; 2 = *Important*; 3 = *Unimportant*; 4 = *Never used*

| | Individual/Non-group Policies | Medically Underwritten Groups |
|---|-------------------------------|-------------------------------|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. Lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of significant conditions | _____ | _____ |
| h. Family medical history of significant conditions | _____ | _____ |
| i. Genetic predisposition to significant conditions | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

6. For each category of coverage, how would you normally treat these policies if they disclosed the following conditions in an examination(s) or application:

1 = *Accepted with standard rates*; 2 = *Accepted with exclusion waiver at standard rates*;

3 = *Accepted with waiting period at standard rates*;

4 = **Accepted with exclusion waiver at rated/risk-adjusted premium**;

5 = *Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium*;

6 = *Accepted with waiting period at rated/risk-adjusted premium*; 7 = *Declined*

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|----------------------------|-------------------------------|-------------------------------|--------------------------|
| a. Hypertension | _____ | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ | _____ |
| d. Hemophilia | _____ | _____ | _____ |
| e. Sickle cell anemia | _____ | _____ | _____ |

SECTION III: GENETIC CONDITIONS

7. Does your company specifically inquire, for each category of coverage, about the following conditions in the application for health insurance in the personal history, family history, or neither:

1 = Personal history only; 2 = Family history; 3 = Neither

| | Individual/Non- group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|--|-----------------------------------|-------------------------------------|--------------------------------|
| a. Hemophilia | _____ | _____ | _____ |
| b. Tay-Sachs | _____ | _____ | _____ |
| c. Huntington's disease | _____ | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ | _____ |

8. For individual policy applicants **only** how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;

3 = Accepted with waiting period at standard rates;

4 = Accepted with exclusion waiver at rated/risk-adjusted premium;

5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;

6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined

| | Individual/Non- group Policies |
|--|-----------------------------------|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

9. For individual policy applicants only how would the coverage of a family member (e. g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

- 1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
- 3 = Accepted with waiting period at standard rates;
- 4 = Accepted with exclusion waiver at rated/risk-adjusted premium;
- 5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;
- 6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined

| | Individual/Non- group Policies |
|--|-----------------------------------|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

10. For each category of coverage, do your standard policies provide coverage for:

- 1 = At patient request; 2 = Only if medically indicated; 3 = Not covered

| | Individual/Non- group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|-----------------------|-----------------------------------|-------------------------------------|--------------------------------|
| Carrier tests for | | | |
| a. Cystic fibrosis | _____ | _____ | _____ |
| b. Tay-Sachs | _____ | _____ | _____ |
| c. Sickle cell trait | _____ | _____ | _____ |
| Prenatal tests for: | | | |
| d. Cystic fibrosis | _____ | _____ | _____ |
| e. Tay-Sachs | _____ | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ | _____ |
| g. Down Syndrome | _____ | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ | _____ |
| Genetic counseling | _____ | _____ | _____ |

11. For each category of coverage, how **would** these policies normally be affected by the following findings:

- 1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;
 3 = Accepted with waiting period at standard rates;
 4 = Accepted with exclusion waiver at rated/risk-adjusted premium;
 5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;
 6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined

| | Individual/Non- group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|-----------------------------------|-------------------------------------|---------------------------------------|
| a. Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) | _____ | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ | _____ |

SECTION IV: GENERAL ATTITUDES

12. To your knowledge, has **your** company ever reimbursed for carrier testing for cystic fibrosis?

- Yes _____ (1)
 No _____ (2)

13. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|-----|----|
| a. Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

14. Under what conditions would a negative financial impact be likely to occur for your company:
 (CHECK ALL THAT APPLY)

- a. Widespread availability of genetic tests to the medical/provider community _____ (1)
 b. Widespread availability of genetic tests with constraints on insurers' access to the results _____ (2)
 c. Adverse claims or underwriting results from antiselection _____ (3)
 d. Other (SPECIFY) _____ (4)

15. How likely do you think it is that your company will:

| | Very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|--|----------------|--------------------|----------------------|------------------|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | | 3 | 4 |
| In the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

16. Please indicate whether you:

| | Agree Strongly | Agree Somewhat | Disagree Somewhat | Disagree Strongly |
|---|-------------------|-------------------|----------------------|----------------------|
| a. It's fair for insurers to use genetic tests to identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An insurer should have the option of determining how to use genetic information in determining risks. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | 3 | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The insurance company declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | | |

SECTION V: DEMOGRAPHICS

17. What is your job title?

18. Which of the following lines of insurance does your company underwrite?

Health 1

Disability 2

Life 3

19. What percent of persons under health insurance policies issued by your company are in policies classified as:

Self-insured Administration _____ %

Individual _____ %

Small Groups _____ %

Large Groups _____ %

TOTAL 100%

Thank you very much **for your cooperation in answering** our questions. We would also like to give you an opportunity to give us as any other opinions, concerns, or suggestions related to genetic testing and insurance that you feel our questions **did not address**. These comments will be strictly anonymous but may be incorporated **in our report to Congress. Please write these comments below.**

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. Absolutely no linkage between companies and questionnaires will be retained. The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

PEEL OFF LABEL WITH SAMPLE
IDENTIFICATION HERE

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025