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 questionties 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.

policies, please check the box below:

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 fallowing definitions:

By carrier <u>testing</u> 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 ceil 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.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 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 \sim 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

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

Po you offer coverage for either individuals or med Yes(1) No(2)	lically underwritten g	roups?
IF YOU ARE NOT OFFERING EITHER OF THESE TO YOUR SURVEY. THANK YOU VERY MUCH. PLEAS POST-PAID ENVELOPE.		
SECTION 1: INDIVIDUAL AND GROUP STATISTICS		
	Individual Policies	Medically Underwritten Groups
1. What is the a proximate number of persons that you currently insure through:		
What is the approximate number of applications received b 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. Coverd 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	1 00%	100%

	Individual Policies	Medically Underwritten Groups
a A personal health history	%	%
b. A family health history	%	%
IF A FAMILY HISTORY IS REQUIRED, ON CHECK ALL THAT APPLY. spouse (1)	N WHOM WOULD INFOR	RMATION BE REQUEST
Children (5) Other (SPECify)	(6)	
c. An attending physician statement (APS)	%	%
Any Significant diagnosis or symptom Selected diagnoses or symptoms reported in significant conditions reported in family him I I M.I.B. report (5)	orted on application (2) family history (3)	n (1)
d. Physical exam:	%	%
		WOULD TRIGGER THE
IF AN EXAM IS EVER REQUIRED, WHICH REQUIREMENT. CHECK AU THAT APPLY	•	
	orted on application (2) family history (3)	on (1)

ı = Very important; 2 = Impo	rtant; 3= Unimportant; 4	= Never Used
	Individual Policies	Medically Underwritten Groups
a. Age		<u> </u>
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		
	lividual policy applicant	or medically underwritten s) or application:
significant conditions j. Carrier risk for genetic diseases How would you normally treat either an incomposition are groups that disclosed the following conditions: 1 = Accepted with standard rates; 2 = Accepted with excl.	itions in an examination(accepted with exclusion usion waiver at rated p	s) or application: waiver at standard rates; remium;
significant conditions j. Carrier risk for genetic diseases How would you normally treat either an incomposition groups that disclosed the following conditions 1 = Accepted with standard rates; 2 = A	itions in an examination(accepted with exclusion usion waiver at rated p	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low would you normally treat either an inc groups that disclosed the following condi 1 = Accepted with standard rates; 2 = A 3 = Accepted with excl.	itions in an examination(accepted with exclusion fusion waiver at rated p waiver but at rated prer individual	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically
significant conditions j. Carrier risk for genetic diseases low would you normally treat either an indigroups that disclosed the following conditions: 1 = Accepted with standard rates; 2 = A 3 = Accepted with exclusion of the exclusion of th	itions in an examination(accepted with exclusion fusion waiver at rated p waiver but at rated prer individual	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low would you normally treat either an indigroups that disclosed the following conditions of the following c	itions in an examination(accepted with exclusion fusion waiver at rated p waiver but at rated prer individual	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low would you normally treat either an indigroups that disclosed the following conditions 1 = Accepted with standard rates; 2 = Accepted with exclusion of the exclu	itions in an examination(accepted with exclusion fusion waiver at rated p waiver but at rated prer individual	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low would you normally treat either an indigroups that disclosed the following conditions 1 = Accepted with standard rates; 2 = A 3 = Accepted with exclusion of the	itions in an examination(accepted with exclusion fusion waiver at rated p waiver but at rated prer individual	s) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten

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)					
For individual policy applicants only how would the applicant was asymptomatic but had a family hist	e appication norm ory αf:	ally be treated if a policy			
1 = Accepted with standard rates; 2 = Accepted 3 = Accepted with exclusion w 4 = Accepted without exclusion waiver b	aiver at rated pre	mium;			
	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					
-					

4 = Accepted without exclusion was		remium; nium; 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		
Do your standard individual policies and med 1 = At patient request; 2 = On/y	if medically indicated;	-
		3 = Not covered Medically Underwritten
	if medically indicated;	3 = Not covered Medically
1 = At patient request; 2 = On/y	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis	if medically indicated;	3 = Not covered Medically Underwritten
 1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs 	if medically indicated;	3 = Not covered Medically Underwritten
 1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle ceil trait 	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle ceil trait Prenatal tests for:	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle ceil trait Prenatal tests for: d. Cystic fibrosis	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle ceil trait Prenatal tests for: d. Cystic fibrosis e. Tay-Sachs	if medically indicated;	3 = Not covered Medically Underwritten
1 = At patient request; 2 = On/y Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle ceil trait Prenatal tests for: d. Cystic fibrosis e. Tay-Sachs f. Sickle cell anemia	if medically indicated;	3 = Not covered Medically Underwritten

	iver at rated p but rated pre	n waiver at standard rates, premium; mium; 5 = Declined	;
	Individual Policies	Medically Underwritten Groups	
 a. Presmptornatic 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			
ECTION IV: GENERAL ATTITUDES			
12. To your knowledge, has your company ever reimbur Yes(1) No(2)	rsed for carrie	r testing for cystic fibrosis	?
13. Has your company ever conducted an economic ar	•		
	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 d. Genetic testing as part of applicant screening	1	2 2	
14. Under what conditions would a negative financial in (CHECK AU THAT APPLY)	mpact be likely	to occur for your compan	y:
a Widespread availability of genetic tests to the m b. Widespread availability of genetic tests with cor c. Adverse claims or underwriting results from ant	nstraints on ins	surers' access to the results	s

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

	very Likely	Somewhat Likely	Somewhat Unlikely	Very Unlikely
ne next 5 years:				
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 undewriting	1	2	3	4
f. Alter claims payment practices as new genetic tests come on line	1	2	3	4
he 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
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
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 in creased risk of disease. 	1	2	3	4	
 An insurer should have the option of determining how to use genetic infor- mation in determining isk s. 	1	2	3	4	
 Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. 	1	2	3	4	
 d. Carrier status for genetic condtions, 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 coudecide to continue the pregnancy. The health insurance carrier, which paid for the tesks, informs the couple they will have no financial responsibility for the cystic fibr~"s-reiat costs for the ch	r		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 cyst fibrosis. The insurance company declines to pay for the testing, since there is no history of cystic fibrosis in	ic		2		
her family.	1	2	3	4	

ECTION V: DEMOGR	APHICS			
17. What is your job	title?			
18. Which of the fallow	ing lines of insurance	does your company	underwrite?	
Health	1			
Disability	2			
Life	3			
19. What percent of per classified as:	rsons under health insu	rance policies issue	ed by your comp	oany are in policies
Self-insured	Administration	%		
Individual		%		
Medically U	nderwritten Groups	%		
Large Group	os	%		
	TOTAL	100%		

Thank you very much for yo	ur cooperation in answering our questions. \	We would also like to give you an
insurance that you feel our	ny other opinions, concern% or suggestion questions did not address These comments report to Congress. Please write these com	s will be strictly anonymous but
,		
identification number on the making the questionnaire en naires will be retained. The from those that we will have However, if this temporary io	oled and the questionnaires returned. We we questionnaire when you return it. Our staff was itirely anonymous. Absolutely no complabel from the completed questionnaire is desto recontact. Identification makes you uncomfortable, then eciate your help and we want you to feel completed.	will remove the label upon receipt, anies and question- signed to eliminate your company peel off the label before returning
		_
	PEEL OFF LABEL WITH SAMPLE	
	IDENTIFICATION HERE	
	STIONNAIRE IN THE POSTAGE PAID RETUININGERED HAS BEEN LOST, THE RETURN	
	Margaret Anderson Biological Applications Program Office of Technology Assessment U.S. Congress Washington, DC 20510-8025	

CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

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

ATTN: MEDICAL DIRECTOR

Please Respond by July 19.1991

The Congressional Office of Technology Assessment (OTA) is contacting health insurers and HMOS 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 fallowing definitions:

By <u>carrier testing</u> 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).

we mean testing applicants or Policyhdders 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 and HMOS. 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 HMO populations-(1) non-conversion selfpayers who seek HMO membership independency and. without any association with an employer or membership group of any kind; and (2) i.e., those groups whose members must be medically underwritten.

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

[] YES, Medicare policies and statistics are included in our responses to this survey.

SECTION 1: BACKGROUND
 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 STATISTIC	s	
	Individual Policies	Medically Underwritten Groups
5. What is the approximate number of persons that you currently insure through:		
 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%	1 00%

	Individual Policies	Medically Underwritten Groups
a A personal health history	%	%
b. A family health history	%	%
IF A FAMILY HISTORY IS REQUIRED, O CHECK ALL THAT APPLY. spouse (1) Parents ? Grandparents (3) Siblings (4) Children (5)		MATION BE REQUESTE
c. An attending physician statement (APS)		%
IF AN APS IS REQUIRED FOR ANY INDITRIGGER THE REQUIREMENT. CHECK A Any significant diagnosis or symptom Selected diagnoses or symptoms rep An significant conditions reported in Selected diagnoses or symptoms rep An significant conditions reported in ity h I I M.I.B. report (5)	ALL THAT APPLY. ms reported on application ported on application (2) a family history (3)	
d. Physical exam:	%	%
IF AN EXAM IS EVER REQUIRED, WHICH REQUIREMENT. CHECK AULL THAT APP Any significant diagnosis or symptoms re Any significant conditions reported in Selected conditions reported in fami M.i.B. report (5) Any significant diagnosis or symptoms	PLY. ms reported on application ported on application (2) n family history (3) ly history (4)	
e. Blood or urine screens:	%	%

1 = Very impotiant; 2 = Impo	•	
	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		
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ir groups that disclosed the fallowing condi	tions in an examination(s) or application:
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ir groups that disclosed the fallowing condition of the standard rates; 2 = Accepted with standard rates; 2	tions in an examination(s Accepted with exclusion clusion waiver at rated p) or application: waiver at standard rates; remium;
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ingroups that disclosed the fallowing conditions 1 = Accepted with standard rates; 2 = Accepted with excepted	tions in an examination(s Accepted with exclusion clusion waiver at rated p) or application: waiver at standard rates; remium;
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ingroups that disclosed the fallowing conditions 1 = Accepted with standard rates; 2 = Accepted with excepted	tions in an examination(s Accepted with exclusion clusion waiver at rated p waiver but at rated prer Individual) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ir groups that disclosed the fallowing condition of the	tions in an examination(s Accepted with exclusion clusion waiver at rated p waiver but at rated prer Individual) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low woould you normally treat either an ir groups that disclosed the fallowing condition of th	tions in an examination(s Accepted with exclusion clusion waiver at rated p waiver but at rated prer Individual) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases low woould you normally treat either an ir groups that disclosed the fallowing condition of th	tions in an examination(s Accepted with exclusion clusion waiver at rated p waiver but at rated prer Individual) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten
significant conditions j. Carrier risk for genetic diseases How woould you normally treat either an ingroups that disclosed the fallowing condition of the	tions in an examination(s Accepted with exclusion clusion waiver at rated p waiver but at rated prer Individual) or application: waiver at standard rates; remium; nium; 5 = Declined Medically Underwritten

Does your comany specifically inquire, for ea tions in the HMO application in the personal his	ch category of cove story,family history	erage, about the fallowing , or neither:
1 = Personal history only; 2	= Family history; 3	B = Neither
	individual Policies	Medically Underwritten Groups
a Hemophilia		
b. Tay-Sachs		
c. Huntington's disease		
d. Sickle ceil anemia		
e. Cystic fibrosis		
f. Any other genetic disease (SPECIFY)		
For individual policy applicants only how woul applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce	istory of:	
applicant was asymptomatic but had a family h	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce 3 = Accepted with exclusion	istory of: pted with exclusion waiver at rated point or but at rated pref	n waiver at standard rate remium;
applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce 3 = Accepted with exclusion	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce 3 = Accepted with exclusion 4 = Accepted without exclusion waive	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce 3 = Accepted with exclusion 4 = Accepted without exclusion waive	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Acce 3 = Accepted with exclusion 4 = Accepted without exclusion waive a Hemophilia b. Tay-Sachs c. Huntington's disease	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;
applicant was asymptomatic but had a family	pted with exclusion waiver at rated por r but at rated pref Individual	n waiver at standard rate remium;

1 = Accepted with standard rates; 2 = Acc 3 = Accepted with exclusion 4 = Accepted without exclusion wain	n waiver at rated at p	remium;
	Individual Policies	
a Hemophilia		
b. Tay-Sachs		
c. Huntington's disease		
d. Sickle cell anemia		
e. Cystic fibrosis		
f. Duchenne muscular dystrophy		
9. ADA deficiency ("Bubble Boy disease")		
h. Down Syndrome		
Do your standard individual policies and medica $1 = At \ patient \ request; \ 2 = Only \ i$	f medically indicated,	; 3 = Not covered
Do your standard individual policies and medica		3 = Not covered Medically Underwritten
Do your standard individual policies and medica	f medically indicated,	3 = Not covered Medically
Do your standard individual policies and medica 1 = At patient request; 2 = Only i	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica $1 = At \ patient \ request; \ 2 = Only \ i$ Carrier tests for	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if Carrier tests for a Cystic fibrosis	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if Carrier tests for a Cystic fibrosis b. Tay-Sachs	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait Prenatal tests for:	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if 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	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if 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	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if 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	f medically indicated,	3 = Not covered Medically Underwritten
Do your standard individual policies and medica 1 = At patient request; 2 = Only if 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	f medically indicated,	3 = Not covered Medically Underwritten

1 = Accepted with standard rates; 2 = Accepted 3 = Accepted with exclusion waiver 4 = Accepted without exclusion waiver	vaiver at rated p	remium;
	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 Dranatal diagnasia reveala		
d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease		
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimbly Yes(1) No(2)		
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimk Yes(1)	analysis of the c	osts and benefits of:
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimby Yes(1) No(2) 7. Has your company ever conducted an economic and the serious, and the serious serious, and the serious serio	analysis of the c	osts and benefits of: No
fetus affected with a serious, chronic condition or disease TION V: GENERAL ATTITUDES 5. To your knowledge, has your company ever reimby Yes(1) No(2) 6. Has your company ever conducted an economic at a Carrier testing as part of applicant screening	analysis of the c Yes	osts and benefits of: No 2
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimby Yes(1) No(2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covered	analysis of the o Yes 1 d 1	osts and benefits of: No 2 2
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimble Yes (1) No (2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covere c. Carrier testing as part of prenatal coverage	analysis of the o Yes d 1	osts and benefits of: No 2 2 2 2
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimby Yes(1) No(2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covered	analysis of the o Yes 1 d 1	osts and benefits of: No 2 2
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimble Yes(1) No(2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covere c. Carrier testing as part of prenatal coverage	analysis of the o Yes 1 d 1 1	osts and benefits of: No 2 2 2 2 2
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimby Yes(1) No(2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covered. Carrier testing as part of prenatal coveraged. Genetic testing as part of applicant screening. 8. Under what conditions would a negative financial (CHECK ALL THAT APPLY) a Widespread availability of genetic tests to the	analysis of the or Yes d 1 1 1 I impact be likel	osts and benefits of: No 2 2 2 2 y to occur for yourcompar community(1)
fetus affected with a serious, chronic condition or disease CTION V: GENERAL ATTITUDES 6. To your knowledge, has your company ever reimby Yes(1) No(2) 7. Has your company ever conducted an economic at a Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covered. Carrier testing as part of prenatal coveraged. Genetic testing as part of applicant screening. 8. Under what conditions would a negative financial (CHECK ALL THAT APPLY)	analysis of the or Yes d 1 1 1 I impact be likel medical/provider	osts and benefits of: No 2 2 2 2 y to occur for yourcompar community(1) OS' access to the results

19.	How	likely	do	vou	think	it	is	that	vour	HMO	will:
	11044	IIICIY	uu	you	um		13	uiai	you	111110	****

	Very Likely	Somewhat Likely	Somewhat Unlikely	Very Unlikely
In the next 5 years:				
Require genetic testing for appli- cants 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
 Require genetic testing for appli- cants 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 appli- cants 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	<i>3</i>	4
k. Use information derived from genetic tests for underwriting	1	2	3	4
Alter claims payment practices as new genetic tests come on line	1	2	3	4

20	Diago	indicato	whether	VOII:
ZU.	riease	maicate	wnether	vou:

	Agree Strongly	Agree somewhat	Disagree Somewhat	Disagree Strongly
 a. It's fair for HMOS to use genetic tests to identify individuals s with in creased risk of disease. 	1	2	3	4
 An HMO should have the option of determining how to use genetic infor- mation in determining risks. 	1	2	3	4
 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 cou 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.	•	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 cysti fibrosis The HMO declines to pay or the testing, since there is no history of cystic fibrosis in her family.	ic	2	3	4

SECT	ON VI: DEMOGRAPHICS	
21.	What is your job title?	
22.	Which of the fallowing lines of insura	nce does your company urderwrite?
	Health 1	
	Disability 2	
	Life 3	
23.	What percent of persons under HMC as:	O policies issued by your company are in policies classified
	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, m a k i n g t h e q u e s t i o n n a i r e e n t i r e l y a n o n y m o u s . naireswi I I 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 quaify 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) <u>Medically underwritten groups</u>, i.e., those groups whose members must be medically underwritten; and (3) <u>Nongroup open enrollment</u>, individuals/nongroup who seek open enrollment coverage, i.e., without medical underwriting.

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? If yes, is it continuous.

YES (1) NO (2) NO (2) NO (2)

	Individual/Non- group Policies	Medically Underwritten Groups	Nongroup Open Enrollment
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 ex- clusion 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	%	%	9
f. Covered with a waiting period and a rated/risk-adjusted premium	%	%	
g. Declined by your company	%	%	%
h. Other (SPECIFY)	%	%	9
	%	%	9
	%	%	0/
TOTAL	100?40	100'%0	10070

SECTION II: UNDERWRITING PRACTICES			
4. For each category of coverage, please estimate the from whom you require:	proportion of all h	ealth insurance a	applicants
	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 WHO CHECK ALL THAT APPLY.	OM WOULD INFOR	RMATION BE REC	QUESTED.
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 INDIVIDUA TRIGGER THE REQUIREMENT. CHECK ALL TH		ie following \	WOULD
 Any significant diagnosis or symptoms repo Selected diagnoses or symptoms reported of Any significant conditions reported in family Selected conditions reported in family histo M.I.B. report (5) 	n application (2) history (3)	ı (1)	
d. Physical exam:	%	%	0/0
IF AN EXAM IS EVER REQUIRED, WHICH OF T REQUIREMENT. CHECK ALL THAT APPLY.	HE FOLLOWING V	VOULD TRIGGER	THE
Any significant diagnosis or symptoms reported Selected diagnoses or symptoms reported Any significant conditions reported in family Selected conditions reported in family history M.I.B. report (5)] Any significant diagnosis or symptoms identificant diagnosis or symptoms identificant diagnosis or symptoms identificant diagnosis or symptoms.	on application (2) history (3) ory (4)	n (1)	
e. Blood or urine screens:	%	%	0/0
PLEASE ANSWER THE FOLLOWING QUESTIONS (#5-1 1 PURCHASED PRODUCT. IS THIS PRODUCT (CHECK ON		TO YOUR MOST	COMMONLY
Traditional (1 (2) HMO (3)			

1 = Very important; 2 = Imp			
	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 histoty of significant conditions			_
 Family medical history of significant conditions 			_
i. Genetic predisposition to			
significant conditions			_
significant conditions j. Carrier risk for genetic diseases	d you normally treat these or application:	policies if they	 _ disclosed the
significant conditions j. Carrier risk for genetic diseases . For each category of coverage, how would following conditions in an examination(s) of the conditions of the condition of the conditions of the	or application: ccepted with exclusion waiting period at standard waiver at rated/risk-adjust	aiver at standard rates; ted premium; ted/risk-adjusted	d rates;
significant conditions j. Carrier risk for genetic diseases . For each category of coverage, how would following conditions in an examination(s) of the conditions of the	or application: ccepted with exclusion waiting period at standard waiver at rated/risk-adjust	aiver at standard rates; ted premium; ted/risk-adjusted mium; 7 = Decl Medically Underwritten	d rates; I premium; ined Nongroup Open
significant conditions j. Carrier risk for genetic diseases For each category of coverage, how would following conditions in an examination(s) of the conditions of the condition of the conditions of the c	or application: ccepted with exclusion waiting period at standard avaiver at rated/risk-adjusted pread rated/risk-adjusted pread individual/Non-	aiver at standard rates; ted premium; ted/risk-adjusted mium; 7 = Decli Medically	d rates; I premium; ined Nongroup Open Enrollmer
significant conditions j. Carrier risk for genetic diseases For each category of coverage, how would following conditions in an examination(s) of the conditions of the	or application: ccepted with exclusion waiting period at standard avaiver at rated/risk-adjusted pread rated/risk-adjusted pread individual/Non-	aiver at standard rates; ted premium; ted/risk-adjusted mium; 7 = Decli Medically Underwritten Groups	d rates; I premium; ined Nongroup Open Enrollmer
significant conditions j. Carrier risk for genetic diseases For each category of coverage, how would following conditions in an examination(s) of the second seco	or application: ccepted with exclusion waiting period at standard avaiver at rated/risk-adjusted pread rated/risk-adjusted pread individual/Non-	aiver at standard rates; ted premium; ted/risk-adjusted mium; 7 = Decli Medically Underwritten Groups	d rates; I premium; ined Nongroup Open Enrollmer
significant conditions j. Carrier risk for genetic diseases For each category of coverage, how would following conditions in an examination(s) of the second secon	or application: ccepted with exclusion waiting period at standard avaiver at rated/risk-adjusted pread rated/risk-adjusted pread individual/Non-	aiver at standard rates; ted premium; ted/risk-adjusted mium; 7 = Decli Medically Underwritten Groups	d rates; I premium; ined Nongroup Open Enrollmen

SECTION III: GENETIC CONDITIONS			
7. Does your company specifically inquire, for eactions in the application for health insurance in the	h category of cover ne personal history,	age, about the foll family history, or n	owing condi- either:
1 = Personal history only; 2	? = Family history; 3	= Neither	
	Individual/Non- group Policies	Medically Undenrwritten 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 applicant was asymptomatic but had a family h 1 = Accepted with standard rates; 2 = Accepted a Accepted with waiting 4 = Accepted with exclusion waiver or wait 5 = Accepted without exclusion waiver or wait 6 = Accepted with waiting period at rate	istory of: oted with exclusion period at standard er at rated/risk-adjusing ing period but at ra	waiver at standar rates; sted premium; ted/risk-adjusted p	d rates;
	Individual/Non- group Policies		
a. Hemophilia			
b. Tay-Sachs			
c. Huntington's disease			
d. Sickle ceil anemia			
e. Cystic fibrosis			
f. Duchenne muscular dystrophy			
g. ADA deficiency ("Bubble Boy disease")			
h. Down Syndrome			

or adopted child) be affected if the poli asymptomatic but had a family history	01.		
	waiting period at standard on waiver at rated/risk-adjus r or waiting period but at ra	rates; sted premium; ted/risk-adjusted	premium;
	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 diseas	"\		
9.7.27. 40.10.01.0) (2422.0 20) 4.004.0	<u></u>		
h. Down Syndrome For each category of coverage, do you	ur standard policies provide c	-	
h. Down Syndrome	ur standard policies provide of comments of the comments of th	3 = Not covered Medically	
h. Down Syndrome For each category of coverage, do you	ur standard policies provide of the control of the	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you	ur standard policies provide of comments of the comments of th	3 = Not covered Medically	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 =	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait Prenatal tests for:	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait Prenatal tests for: d. Cystic fibrosis	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = Carrier tests for a Cystic fibrosis b. Tay-Sachs c. Sickle cell trait Prenatal tests for: d. Cystic fibrosis e. Tay-Sachs	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Open
h. Down Syndrome For each category of coverage, do you 1 = At patient request; 2 = 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	ur standard policies provide of comments of the comments of th	3 = Not covered Medically Underwritten	Nongrou Open Enrollme

11. For each category of coverage, how would these findings:	policies normally	be affected by the	efollowing
 1 = Accepted with standard rates; 2 = Accepted 3 = Accepted with waiting period 4 = Accepted with exclusion waiver 5 = Accepted without exclusion waiver or waiting 6 = Accepted with waiting period at rated 	eriod at standard at rated/risk-adju g period but at ra	rates; sted premium; ated/risk-adjusted	premium;
	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 reimbu Yes(1) No(2)			
13. Has your company ever conducted an economic	analysis of the co	osts and benefits o	t:
 a. Carrier testing as part of applicant screening b. Genetic counseling of carriers who are covere c. Carrier testing as part of prenatal coverage d. Genetic testing as part of applicant screening 	1	2 2 2 2 2	
14. Under what conditions would a negative financial (CHECK ALL THAT APPLY)	impact be likely to	o occur for your o	company:
a. Widespread availability of genetic tests to the b. Widespread availability of genetic tests with co. Adverse claims or underwriting results from a d. Other (SPECIFY)	onstraints on insur	ers' access to the	

	Very Likely	Somewhat Likely	Somewhat Unlikely	Very Unlikely
the next 5 years:				
Require genetic testing for applicants with family histories of serious conditions	1		3	4
 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
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
Require genetic testing for applicants with no known risk to genetic disease	1	2	3	4
 Offer optional genetic testing and carrier testing 	1	2	3	4
k. Use information derived from genetic tests for underwriting	1	2	3	4
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 in- creased risk of disease. 	1	2	3	4
b. An insurer should have the option of determining how to use genetic infor- mation in determinining rieks.	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 coup 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 chi		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.		2		
ner ranny.	ı	4		

SECTION V: DEMOGRAPHICS	
17. What is your job title?	
	_
18. Which of the fallowing lines of insurance doe	es your company underwrite?
Health 1	
Disability 2	
Life 3	
19. What percent of persons under health inst classified as:	urance policies issued by your company are in policies
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