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OFFICE OF TECHNOLOGY ASSESSMENT
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OTA RELEASES SURVEY RESULTS ON GENETIC TESTS AND HEALTH INSURANCE

The ongoing project to map human genes will almost certainly expand the number of DNA-based tests for genetic disorders by an order of magnitude over the next decade. How health insurers view such tests will affect their use, says the congressional Office of Technology Assessment (OTA).

An OTA background paper issued today describes the results from a 1991 OTA survey of U.S. health insurers' attitudes toward genetic tests and genetic information -- both their attitudes toward genetic information in making determinations of insurability and how they might reimburse consumers for genetic tests. The survey supports OTA's August 1992 assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, requested by the House Committees on Science, Space, and Technology, and on Energy and Commerce, and Rep. David R. Obey.

Results from OTA's survey of health insurers apply to a small slice of the insured population -- the 12.7 million people who have individual or medically underwritten group coverage through survey respondents. Respondents were asked how they would treat certain conditions or scenarios, not whether they had already encountered them. OTA surveyed commercial health insurers, Blue Cross and Blue Shield plans (BC/BS), and health maintenance organizations (HMOs).

All respondents -- commercial insurers, HMOs, and BC/BS plans -- reported that personal and family medical histories were the most important factors in determining insurability. The most important determinants in deciding about insurability and rates are smoking habits, age, occupation, and sex.

For individual policies, the majority of commercial insurers did not ask applicants about any of several genetic conditions listed by OTA (including cystic fibrosis and hemophilia) in either the personal or family history. More than half the HMOs and BC/BS underwriters also did not inquire about the listed conditions. OTA found that a family history of a genetic condition did not always mean the applicant would be declined; in fact, a majority would be accepted at standard rates.

When presymptomatic testing reveals the likelihood of a serious, chronic future disease (i.e. Huntington disease), more than half the commercial insurers would decline an individual applicant, while about a quarter would accept the applicant at standard rates. Slightly less than half of BC/BS plans that provide individual coverage said they would decline such an applicant, and about a quarter would accept the applicant at standard rates.

When tests show that an applicant is a carrier of a serious genetic condition that could be passed on to his or her children, slightly more than half of commercial insurers and slightly less than half of BC/BS plans that write individual policies would accept the applicant. Carrier test results would not cause any of the HMOs to decline coverage.

From OTA's survey results, it is evident that carrier and prenatal tests often are not reimbursed under individual and medically underwritten group policies unless a family history exists.

OTA found that none of the insurers responding had conducted an economic analysis of the costs and benefits of carrier or other genetic tests as part of applicant screening. In addition, none had conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered. Almost none had conducted an economic analysis of carrier testing as part of prenatal coverage.

The majority of commercial insurers and chief underwriters at BC/BS said a negative financial impact for their companies would not occur if genetic tests were widely available to the medical community. HMO respondents, however, were equally divided. But all insurers agreed that a negative financial impact for their companies would likely occur if genetic tests were widely available, but with constraints on insurers' access to the results. Similarly a majority of respondents thought a negative financial impact would result if the availability of genetic tests resulted in adverse claims or underwriting results due to adverse selection.

(more)

Copies of the 75-page background paper *Genetic Tests and Health Insurance: Results of a Survey* for congressional use may be obtained by calling 4-9241. Copies for noncongressional use are available at the Superintendent of Documents, Government Printing Office (GPO), Washington, D. C. 20402-9325; phone (202) 783-3238. The stock number is 052-003-01310-0; the price is \$5.00.

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