Chapter 1
Introduction

Health insurance in the United States is not monolithic. U.S. health care financing, which totaled more than $800 billion in 1991, is a mixture of public and private finds. For the majority of Americans, however, access to health care-and the health insurance that makes such access possible-is provided through the private sector. Privately financed health insurance for medical expenses covers more than 189 million persons through self-funded companies, commercial insurance companies, Blue Cross and Blue Shield (BC/BS) plans, and managed care programs (e.g., health maintenance organizations (HMOS) and preferred provider organizations) (l). Among these entities, business practices vary widely within and among the categories, and each is subject to different State or Federal regulations (2).

The majority of Americans obtain health insurance through employment-either directly as employees or as family members of the employed. Most people covered in this manner obtain health insurance as members of large groups, with no diagnostic tests or physical examinations required for entry (i.e., no medical underwriting). Some individuals, however, obtain health insurance through small groups, which require some diagnostic tests or physical examinations, on which the insurance contract's coverage and costs are based. Finally, persons without group coverage can seek individual health insurance from commercial insurers, BC/BS plans, or HMOS.

Organizations that medically underwrite individual or group policies classify risks on actuarial data. Currently, about 10 to 15 percent of individuals with health care coverage are medically underwritten. This selection process—i.e., differentiation based on medical characteristics-is an integral part of the insurance mechanism. Risk classification is the foundation, in fact, for the concept of private insurance.

In the coming years, an increasing number of underwriting decisions and reimbursement policies will revolve around the tests, information, and services arising from the Human Genome Project. The number of DNA-based tests for genetic disorders and predispositions will almost certainly expand by an order of magnitude in the next decade. How insurers view such tests will affect their utilization. This background paper describes results from a 1991 OTA survey of U.S. health insurers' attitudes toward genetic tests and genetic information—both how they currently view information from various sources (e.g., genetic tests, other medical tests, or family histories) in underwriting decisions and how they might reimburse consumers for genetic tests. It also reports data on the role health insurers expect genetic tests and genetic information will play in their business practices over the coming decade.

HEALTH INSURANCE AND GENETICS

Perhaps the most widely raised social question stemming from the Human Genome Project is what effect genetic tests have (and will have) on health care access in the United States. Consumers fear exclusion from health care coverage due to genetic, or other, factors. Because health care access involves private health insurance for most citizens, concern focuses on this market.

Some commentators speculate that, overall, genetic analyses will mean fewer people will have access to private health insurance because such tests identify or refine risks. They argue genetic tests, in precluding more and more people from health insurance, will provide the best reason yet for a nationalized health care system. Others contend, however, that genetic assays could rule out an individual's risk for a disorder and hence increase access to health care coverage. That is, making use of genetic information would allow insurers to better assess risks, with the result that individuals at elevated risk will pay more (or be denied access), but people with low risk will pay less. Still others point out that as the number of identified genes increases, so will the number of people who will be identified as at risk, which could spread risk. The ultimate impact of genetic tests, then, will depend, in part, on the practices and attitudes of insurers toward tests for genetic disorders, as well as the morbidity and mortality associated with particular conditions (2).

SCOPE AND ORGANIZATION OF THIS BACKGROUND PAPER

For its assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening (2),* OTA found a paucity of information about health insurers' current attitudes and policies toward genetic tests or any future role such tests might play in their business practices. To gain some understanding about these issues, OTA surveyed commercial insurers, BC/BS plans, and selected HMOS that offered individual or medically underwritten group policies in June 1991. This survey did not extend to large group contracts or to the practices and attitudes of self-funded companies, which cover the largest percentage of individuals who have private health care benefits.

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 provided through survey respondents. Further, most of the information presented in the following chapters should not be construed to represent either the numbers or percentages of commercial entities, BC/BS plans, or HMOS that have dealt with the issues presented. Respondents were asked how they *would* treat certain conditions or scenarios presented (currently or in the future, depending on the questions), not whether they, in fact, *had* made such decisions.1

This background paper reports the complete results from OTA's survey of health insurers, but does not analyze them in a public policy context. That analysis is presented in the aforementioned report for which this survey was undertaken (2). Chapter 2 of the background paper describes general characteristics of the respondents and the populations they serve. Following this, data related to genetic tests, genetic information, and underwriting are discussed in chapter 3. Chapter 4 presents data about health insurers' policies toward reimbursing consumers for various genetic tests and services, and chapter 5 examines insurers' overall attitudes toward current and future use of genetic tests and information. Appendix A details the survey method, including population selection, and appendix B presents verbatim comments made by respondents in space provided for open ended statements. Survey instruments are reproduced in appendix C.

CHAPTER 1 REFERENCES

1. Health Insurance Association of America, *Source Book of Health Insurance Data 1991* (Washington, DC: Health Insurance Association of America, 1991).
2. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening, OTA-BA-532* (Washington, DC: U.S. Government Printing Office, August 1992).

[1] In a few instances, as evident through question wording, OTA did ask about an actual practice—e.g., "To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?" As is clear from the survey questionnaires reproduced in appendix C, however, most questions inquired about how the respondent "would" treat a given situation.