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Genetic testing when there is a mix of compulsory and voluntary health insurance

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Abstract

When the insurer has access to information about test status, genetic insurance can handle the negative effects of genetic testing on insurance coverage and income distribution. Hence, efficient testing is promoted. When information about prevention and test status is private, two types of social inefficiencies may occur; genetic testing may not be done when it is socially efficient and genetic testing may be done although it is socially inefficient. The first type of inefficiency is shown to be likely for consumers with compulsory insurance only, while the second type of inefficiency is more likely for those who have supplemented the compulsory insurance with substantial voluntary insurance. This second type of inefficiency is more important the less effective prevention is. It is therefore a puzzle that many countries have imposed strict regulation on the genetic information insurers have access to. A reason may be that genetic insurance is not yet a political issue, and the advantage of shared genetic information is therefore not transparent. © 2002 Elsevier Science B.V. All rights reserved.

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1. Introduction

On 26 June 2000, the leaders of both the publicly and the privately funded human genome projects announced that a draft of the human genome has been made. During the next few years, this knowledge is likely to be applied in the development of predictive tests for many diseases. The tests will be able to distinguish between high- and low-risk individuals at

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a pre-symptomatic stage of disease. Presently, tests for over 800 diseases are offered,¹ including tests for Huntington's disease and cystic fibrosis. Two important breast cancer genes (BRCA1 and BRCA2) have been identified, and the US Food and Drug Administration has approved a gene-based test that may help to predict the recurrence of breast cancer. The number of tests is expected to increase rapidly in a few years, in parallel to the mapping of the human genes. For instance, tests for genes that imply an elevated risk of several types of cancer, cardiovascular diseases, and Alzheimer's disease are already available or are expected to be available in the near future.

The information from gene-based tests may be important for initiating measures for postponement and prevention of disease. Genetic tests are also expected to have an important impact on the organization of health systems and, in particular, health insurance. There is a concern that insurers can make use of information to deny coverage for individuals with an increased risk of disease or require them to pay prohibitively high insurance premiums. Regulation of the access to, and the use of information from, genetic testing is therefore an important health policy issue in many countries, and the regulations imposed vary between countries. In the US, a majority of the states have banned the use of genetic information by insurers. The Congress in 1996 passed legislation that forbids group health organizations from denying coverage on the basis of genetic information. Efforts are also being made to extend the prohibition to all health insurers and to ban insurers from raising premiums based on genetic data (Schwartz, 1998). Recently (February 2001), a bill to prohibit discrimination on the basis of genetic information with respect to health insurance was introduced in the US Senate and referred to the Committee on the Health, Education, Labor, and Pensions.

In Europe, there is mixed attitude. For instance, the Council of Europe, recommends (R(92)3 and R(97)5) that predictive genetic tests should not be used when the terms of insurance is decided. Among European countries,² Belgium, Denmark, France, The Netherlands, Norway and Austria have approved restrictive laws while other countries have less formal regulation and might prepare regulation by law. In Finland, France, Germany, Sweden, Switzerland and The Netherlands insurance companies have chosen to impose a moratorium. In Norway, the majority of a public commission (Ministry of Health and Social Affairs, 2000) has suggested that insurance companies should have the right to require information about health status, including genetic information, for life insurance contracts exceeding a certain amount. The suggestion has led to much public debate and no support among political parties. Recently, also the Norwegian Biotechnology Advisory Board advised the government to turn down the commission's suggestion. In the UK, the Genetics and Insurance Committee (GAIC) has been established by the Department of Health to give advice related to the use of genetic test results in insurance risk assessment. The Association of British Insurers (ABI) has given an assurance that if tests are not approved by the GAIC then their member companies will cease to use the results of the test and will retrospectively recalculate any insurance premiums affected. In September 2000 GAIC approved the use of genetic test results for Huntington's disease in the underwriting

¹ This is according to <http://www.genetests.org> funded by the National Library of Medicine of the NIH.

² This is according to information in Ministry of Health and Social Affairs (2000) and European Society of Human Genetics Public and Professional Policy Committee (2000).

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