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Genetic(al) correctness

A week after the opening of *GATTACA*, the Hollywood movie about genetic discrimination in a future society (see last month's review), the 47th annual conference of the American Society of Human Genetics took place in Baltimore, Maryland. Apart from exchanging genetic information, most of the 5,000 participants also learned about genetic discrimination and privacy. One of the meeting's educational sessions was entirely devoted to the topic. In addition, the plenary session on 'This Year's Genetic Highlights' was concluded by Francis Collins, director of the National Human Genome Research Institute, who discussed genetic privacy and discrimination in the context of existing and future practices of genetic testing.

Genetic tests will become a part of daily life over the next few years. A National Institutes of Health Consensus Development Panel, for instance, recently recommended that genetic testing for cystic fibrosis mutations be offered to all couples in the United States planning a pregnancy or seeking prenatal testing. Public interest and concern are increasing, and the first data on 'consumer reception' are available. Overall, it seems that the interest in being tested is less than some scientists would have hoped. Some of the individuals at risk—who would benefit most from the tests—are reluctant to be tested because they are afraid of discrimination, not only against themselves but also against other family members.

In a recent poll, 85% of Americans surveyed said that they are afraid of genetic discrimination (the unfair treatment of individuals or groups of people based on genetic information). Lawyers and lawmakers define genetic discrimination as 'discrimination against an otherwise healthy individual based on genetic information', with 'genetic information' defined as 'information about genes, gene products, or inherited characteristics that may derive from the individual or a family member'. What is special about genetic information? It is deeply personal—in that it reveals the 'innermost characteristics and secrets' about an individual that are not obvious from any other test—and it can be predictive of future characteristics. As the definition above indicates, knowledge about one person's genes tells you something about his or her relatives as well, and it can be misused to stigmatize and discriminate. In the United States and other countries without a national health service, the immediate concern is discrimination by health insurance providers. Increasingly (and predating *GATTACA*), there is also concern about education and employment discrimination.

A significant part (5%, or \$6.9 million this year) of US federal funding for the Human Genome Project is set aside for a special programme designed to anticipate, analyse and address the ethical, legal and social implications (ELSI) of the accumulating knowledge about human genetics. One of the goals of the ELSI program is to develop pol-

ELSI/NAPBC recommendations

- Insurance providers should be prohibited from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment, or contribution requirements.
- Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.
- Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.
- Insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure would be made.

icy options that ensure that genetic information is used for the benefit of individuals and society. In pursuing this goal, ELSI—in collaboration with the National Action Plan on Breast Cancer, a 'genetics activist' group—has developed recommendations for American policy-makers regarding issues of genetic discrimination and privacy (see box).

Partly as a consequence to these recommendations, many US states have enacted laws to restrict the use of genetic information in health insurance and employment decisions. In addition, a federal law that includes protection against genetic discrimination in health care came into effect earlier this year. This law, the Health Insurance Portability and Accountability Act (or HIPAA), provides for portability of workplace coverage and limits insurers' ability to deny coverage for pre-existing conditions. It states that "a group plan insurance provider may impose a pre-existing condition

exclusion only if (1) such exclusion relates to a condition (physical or mental), regardless of the cause of the condition, for which medical advice, diagnosis, care or treatment was recommended or received within six months prior to enrolling in the new plan; and (2) such exclusion extends for a period of not more than 12 months after the enrollment date". Genetic information is specifically included among the factors that may not be used to deny or limit health-insurance coverage and explicitly excluded from being considered a pre-existing condition in the absence of a diagnosis of the condition related to such information.

Although HIPAA is a significant step in the right direction (and not just from a genetic discrimination point of view), it also contains large holes: US health insurance is divided into a group and an individual market, and only the group market is covered by HIPAA. A second concern is the question of insurance premiums—although HIPAA prohibits insurers from treating individuals within a group differently from one another, it does not protect the group as a whole from a rate increase based on genetic information from one or several members of the group. The third problem concerns genetic privacy: HIPAA does nothing to limit access to or to prevent release of genetic information.

Francis Collins is confident that the open issues will be resolved by legislation in the near future. His optimism is based on the evidence for strong political support. In addition to President Bill Clinton's explicit commitment to protect genetic privacy and "ban all health plans, group and individual, from denying coverage and from raising premiums on the basis of genetic tests", there is strong bipartisan support in the US Congress for closing the loopholes left open by HIPAA. There is still work to be done, but it is encouraging to see political awareness and commitment to ensure that social policy keeps pace with genetic research, so that individuals will be able to benefit from its advances without the risk of privacy violation and insurance discrimination.

What do scientists have to do with all of this? During the discussion in Baltimore, geneticists were accused of having a clear conflict of interest when it comes to genetic privacy and discrimination, of having a vested interest in playing down the risks so as not to lose consent of their research subjects. Is there a split between the interests of genetic researchers and those of consumers? If there is, then clearly sight of the common goal—to use genetic knowledge to improve human health—has been lost. Like most basic research, genetics is largely funded by the public. Moreover, it is becoming increasingly dependent on the participation of large numbers of volunteers. If genetic discrimination is legal, public support will diminish and genetic endeavour will suffer accordingly. In acknowledging that genetic discrimination and privacy are important issues, scientists should be aware of the current legislation and take an active role in educating the public as well as improving the protection of research participants and consumers of genetic tests.

