The mapping of the human genome has made it possible to identify virtually all disease-causing genes and to develop tests to detect the mutations stemming from single-gene disorders. Genetic tests are being developed at an impressive rate and many have already reached the market. This represents a major achievement for medicine and biotechnology, but also poses tremendous socio-economic challenges: what genetic tests to adopt and reimburse? Who should be tested? How to counsel patients, to protect their right to privacy and to ensure quality standards which are internationally compatible?

These and related issues are discussed in a new OECD publication Genetic Testing: Policy Issues for the New Millennium. It stresses the need for more international co-operation in this area, in order to ensure that people benefit from these new technological advances.

Genetic markers may be used to identify disease susceptibility genes, for example testing for haemoglobin disorders or breast cancer. The growing number of available tests, which tend to replace traditional diagnostics, is expanding demand for genetic testing. This poses a problem for all OECD countries as the number of professionals trained in medical genetics and counselling have not kept pace with demand. Although there is a need for protecting intellectual property rights to encourage investment in R&D, the rapid proliferation of licensed tests (patents) also raises the question of national and international quality assurance and equitable access.

The increased collection and storage of DNA equally poses important ethical questions concerning privacy protection, informed consent, access and confidentiality of genomic information. The OECD developed benchmark principles on data protection in 1980, all relevant to electronic data, which have been integrated in the legislation of many countries. In 1997, the OECD similarly presented a set of guidelines to be taken into account by governments when developing policies on cryptography. The Organisation has also surveyed the international and national policies on export, import and domestic use of encryption technologies in the Member countries. The future of genetic databanks will to a great extent depend on the user trust generated by the use of such technologies, in particular against the background of increased public/private research alliances and the transborder flow of data.

Journalists may obtain this report from the OECD Media Relations Division (request by fax: 33 45 24 40 80 03 or news.contact@oecd.org).

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