

## UK spurns proposed genetics regulatory commission

The UK government has rejected a proposal for a human genetics commission to regulate genetic testing and to ensure the protection of information on an individual's genetic makeup, opting instead for a less far-reaching "advisory committee."

The initially proposed commission, which would have required legislation to bring it into being, was recommended by a 1995 parliamentary select committee report, *Human Genetics: the Science and its Consequences*. The select committee spent almost a year on its research, holding twelve public hearings and taking evidence from almost 200 witnesses. Committee members wanted the genetics commission to be a national body dealing with all aspects of genetics, including policing the use of genetics information by employers and the insurance industry. The report also recommended that the misuse of genetic information should be a criminal offense.

However, despite the select committee's recommendations, the government announced on January 10, 1996, that it was to set up an advisory committee on genetic testing "to ensure that genetic tests are supplied safely and used ethically." All other aspects of genetic research and medicine will continue to be monitored by the existing patchwork of advisory committees, such as the Gene Therapy Advisory Committee and the Nuffield Council on Bioethics (see table).

In its response to the select committee report, the government rejected the need for any new law to protect genetic information, saying that the privacy of medical information is covered by existing data protection law. The government also failed to back the committee's recommendation that a deadline should be imposed on the insurance industry for the development of a code of practice on the use of genetic information for insurance purposes, or to agree that there was any need to anticipate and control use of genetic information by employers.

The select committee report had expressed particular concern about private genetic screening, warning that "unscrupulous companies may prey on the

fear of disease and genetic disorders and offer inappropriate tests without adequate counseling, and even without the laboratory facilities necessary to ensure the tests are conducted accurately." To prevent this, the committee recommended that the proposed commission should set up a process of protocol review and licensing. (At present the UK has no regulations governing the provision of genetic tests either in the public or private sector.) Although the government acknowledged the need to oversee genetic testing, particularly services available direct to the public, it rejected any system of licensing in favor of voluntary standards.

These standards will be set by the new advisory committee for genetic testing, which will be chaired by John Polkinghorne, the president of Queen's College, Cambridge. Among its terms of reference the advisory committee will "establish requirements, especially in respect to efficacy and product information, to be met by manufacturers and suppliers of genetic tests." But unlike the proposed commission, the committee will have no power to enforce its recommendations.

The Genetic Interest Group, a na-

tional alliance of support groups for individuals and families affected by genetic disorders, says the government has let employers and the insurance industry "off the hook." Employers are under no obligation to avoid discrimination against people who will or may develop a genetic condition in future. Furthermore, by refusing to use the threat of legislation, the government has removed any pressure on the insurance industry to come up with adequate protocols. Thus, the Genetic Interest group claims that the proposed regulatory regime will be inadequate both in its powers and its scope. "Unlike gene therapy, genetic testing can be undertaken by a wide range of organizations," said a group spokesperson. "It therefore seems strange that a body with the same limited powers as that overseeing gene therapy should have been established in the field of genetic testing."

Others are less pessimistic, although still lukewarm in their response to the government's action. David Shapiro, Executive director of the Nuffield Council for Bioethics, said he would give "One-and-a-half cheers" for the advisory committee, objecting that its terms of reference are narrow and fail to include insurance and employment issues.

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The patchwork of UK committees with advisory roles in human genetics

Committee	Status	Role
Gene Therapy Advisory Committee	Nonstatutory	Considers all proposals for gene therapy research on humans.
Local research ethics committees	Nonstatutory	Examines the ethical aspects of all health-related research carried out on patients in the NHS.
Nuffield Council on Bioethics	Independent advisory body	Provides advice on ethical issues arising from current biomedical and biological scientific developments.
Advisory Committee on Genetic Testing (to be established)	Nonstatutory	Will advise on the ethical, social and scientific aspects of genetic tests and will set standards for manufacturers and suppliers.