nature genetics

Twelve lords a-leaping

The UK House of Lords Science and Technology Committee reports that genomic medicine is already in practice but needs a coordinated set of infrastructural and training systems to allow the healthcare system to cope.

A landed aristocrat immersed to the waist in a salmon river might make an ideal biosensor and a sensitive environmental legislator. Unfortunately, this particular mode of regulation is no longer available in the United Kingdom, which ejected hereditary peers from its second house of Parliament in 1999 in favor of political appointees selected for excellence in a range of fields of expertise. Luckily for the field of genetics, however, the UK now has in place a national Committee with the right mix of experience and ability to marshal expert outside advice in order to form a plan to coordinate the national health service (NHS) in light of the flood of new genomic information that is currently illuminating the practice of medicine. Lord Patel and the other physicians, scientists and philosophers who make up the House of Lords Science and Technology Committee have assembled an impressive set of accessible technical reports in the last few years, but their report on genomic medicine is particularly timely and comprehensive and may be taken as a model for discussion in other countries (http://www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/107i.pdf).

At the heart of the Lords' proposals is the recognition that "two unique sources of information"—clinical health records and genomic sequence information—need to be merged on a secure platform to be planned by experts at a new Institute of Biomedical Informatics; this institute will also serve to train a new expert medical informatics workforce. Handling and sharing of data so as to promote further research requires new guidelines from the Information Commissioner consistent with existing UK data protection legislation. In this respect, the UK should provide leadership in reforming European Union data law.

Medical educators are now tasked with introducing a coordinated plan for undergraduate and graduate training in genomic medicine that should be considered a core competency for junior doctors; in addition, the dwindling speciality of genetic pathology should be resuscitated. General practitioners should be able to provide advice on predictive tests for common diseases. Genetic counsellors should be trained to deal with both common and monogenic diseases, and genetics and genomics should be a standard part of the nursing curriculum.

If doctors are to be required to use genomic test results in making diagnoses, they will need evidence that the tests are accurate; therefore, the Department of Health's National Institute for Health and Clinical Excellence (NICE) is asked to take on the task of evaluating the validity, utility and cost-benefit of pharmacogenetic tests for common diseases, just as the UK Genetic Testing Network does for single gene tests. The Department of Health should also review the administration of all kinds of genetic tests. It is not clear whether the Committee recommended that genomic tests meet the more stringent 'medium risk' classification under the EU *In Vitro* Diagnostic Medical Devices Directive in order to persuade NICE to take on this role, or to provide a model for other EU countries to follow, possibly both. In any case, the Committee's proposal includes plans for public engagement and a consumer website to publicize the approved tests.

From the perspective of someone in the United States, where the Genetic Information Nondiscrimination Act (GINA), covering employment and insurance, was recently adopted, it is rather strange that the UK report urges not legislation but 'watchful waiting'—in other words, restraint and muddling through—on the issue of genetic discrimination. This seems odd, given the 50% of employers interviewed in 2000 by the Institute of Directors who were in favor of testing employees for genetic vulnerability to workplace exposures. And it also seems odd given that the UK Department of Health is apparently disbanding its Genetics and Insurance Committee just as the voluntary agreement negotiated between the government and private insurance providers expires. However, as a result of being covered by the NHS, the UK population apparently takes a lot on trust. According to one interview in the report, even after the Treasury lost a disc containing 22 million confidential child benefit records, nobody withdrew from the UK Biobank.

It is now up to the Office for the Strategic Coordination of Heath Research to produce a parliamentary White Paper with the details needed to convince the NHS Trusts that research translation is indeed part of their duty-of-service provision. The Lords have considered the matter from at least a dozen angles and have taken the first big leap in the right direction. ■