

## REPORT OF A DINNER/DISCUSSION

**Genetic Databases – Threat or Opportunity?**Held at the Royal Society on Wednesday, 30<sup>th</sup> May, 2001

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In the Chair:    **The Rt Hon The Lord Jenkin of Roding**, Chairman, The Foundation for Science and Technology

Speakers:     **The Lord Oxburgh**, House of Lords Select Committee on Science and Technology,  
**The Baroness O'Neill of Bengarve CBE FBA**, Principal, Newnham College, Cambridge,  
**Dr Peter Goodfellow**, Senior Vice-President Discovery Research, GlaxoSmithKline

The discussion followed the publication of the report by the House of Lords Select Committee on Science and Technology "Human Genetic Databases: challenges and opportunities". The invited speakers drew particular attention to the recommendations on informed consent, on the setting up of a Medical Data Panel to approve the secondary use of NHS and medical research data, and on the management of information in the Health Service.

International organisations wanted to collect genetic information, and it was questioned whether a UK approach could be developed in isolation. In response it was argued that the arrangements recommended by the Report could cope with the international dimension. The Medical Data Panel could deal with requests from UK holders of information to take part in international studies. Experience in any case showed that it might be unwise to wait for international agreement to be reached before putting a system in place in the UK.

A step had already been taken in the direction recommended by the Select Committee. Sections 61 and 62 of the Health and Social Care Act 2001 enabled the Secretary of State, in consultation with a Patient Information Advisory Group, to make regulations providing for the processing of prescribed patient information for medical purposes in the interests of improving patient care or in the public interest.

One speaker hoped that the Medical Data Panel would guide local ethics committees, which sometimes made wayward decisions. It would be

impractical for the Panel to look at every study, but the report proposed that it should lay down guidelines for local ethics committees to follow. A further possibility might be for it to hear appeals against decisions by the committees.

The Select Committee had not considered in detail how the Panel should be composed or appointed. One view was that it should have no more than dozen members, at least half being lay people. Its independence might be guaranteed by giving a range of appropriate bodies the power to appoint members.

The report recommended a procedure for seeking consent to the collection of genetic information for research purposes. The Committee attached importance to solidarity between people asked to participate in genetic research now and those who had done so in the past and so contributed to the medical progress from which succeeding generations benefitted. Information for past research had often been collected without consent. Nevertheless, in availing themselves of some types of treatment people gained advantage from data collected in the past, even if it had been gathered in ways which would not be acceptable now.

One speaker argued that benefit and detriment had to be balanced in considering the need for informed consent. Epidemiological studies were particularly at risk from people opting out, and this had been a problem for much of the early work on smoking. Nevertheless consent could hardly be dispensed with, and the Select Committee was

optimistic about the willingness of the public to assist medical research. It would be important, however, not to oversell the benefits. These would accrue over decades, not overnight, and stories of instant cures for obesity did not help. There was also concern that by insisting on disclosure of the results of genetic tests the insurance companies might provoke a public backlash against the gathering of genetic information comparable to that against genetically modified food, though one speaker argued the companies had a better understanding of the difference between single factor and multi-factorial disorders than was commonly supposed.

A speaker wondered whether in some circumstances it might be right to allow the courts or the police to have access to medical databases. One response was that Chinese walls should be maintained, initially at least. For forensic purposes the main use of genetic information was in any case simply to match a DNA sample as an aid to identification, and for this purpose medical information was not needed.

It was argued that people convicted of serious crimes could justifiably lose some control over their genetic data. There was a public interest in retaining samples for a reasonably long time following conviction, given that wrong convictions or wrong acquittals could come to light after many years. The hard question was how long it might be right to retain DNA samples from people convicted of minor offences.

The Medical Research Council, Wellcome Trust and Department of Health planned for the UK Population Biomedical Collection to gather information from 500,000 middle-aged people. The aim was to shed light as soon as possible on the diseases of adult life, in view of the potential impact on the Health Service. Against this it was argued that the most significant environmental exposures, especially infectious exposures, took place in the first 10 years of life. Ideally children as well as adults should be covered.

Collecting genetic information from children raised particular issues. It had to be accepted that parents could give consent on behalf of their children, but there was a risk that when the children came of age they would be unwilling to co-operate further. It was generally agreed, moreover, that children should not be subject to genetic tests the results of which would be disclosed, unless the tests were of immediate therapeutic value. If this difficulty were overcome by permanently “de-linking” the information, so that it could not be connected with the person concerned, that would carry a cost both for the individual and for the study. Indeed, de-linking would rule out a cohort study. The important thing, it was suggested, was to collect medical information on children, so that they could be approached later and asked to supply genetic data and agree to it being linked with the

medical information for research purposes.

The Select Committee warned that the development of genetic databases would generate vast amounts of data, and that storing and processing it would stretch resources to the limit. In discussion it was observed that computing capacity was continuing to grow very fast, and it was suggested that information on phenotypes was relatively manageable. Sequencing everyone’s genome in a commercially realistic way remained out of reach for the time being, but the cost of this too was coming down rapidly and it should be possible in the foreseeable future.

Handling information on the environmental influences on health presented an even greater challenge, given the very large number of relevant factors. For the time being it was difficult to do more than model them. If, for example, a child lived near a road some estimate of its exposure to pollution could be made. In the meanwhile usable medical data would be a step in the right direction.

It had to be borne in mind that there was little need for any genetic input when dealing with some of the major health problems. Smokers had a very high risk of contracting smoking-related cancer. Certainly there was a genetic component in addiction to alcohol and smoking, and in the response of individuals to the addiction, but it made sense to concentrate simply on modifying the behaviour because it was so strongly linked with damage to health. It was argued that successful action against smoking would do more for health than all publicly and privately funded health research for the next 20 years.

Attitudes toward life and death and religious beliefs also played a major part in people’s lives. People who believed that there was more to them than DNA and environmental influences might well enjoy a selective Darwinian advantage.

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