

The HRC Development Conference: "Whose Genes are they anyway?", Wellington, July 1995

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The richness and diversity of this consensus development conference, bringing together people from a wide variety of backgrounds, is impossible to discuss adequately in a short review, hence I shall confine myself to some particular themes and shall not attempt to identify individual speakers.

First, the need for greater dissemination of information about advances in genetics was apparent. The Human Genome Project has so many far-reaching implications for society that it is important that there is open discussion and debate about how to deal with them. One of the striking things was the fundamental difference in opinion about the status of science itself, some seeing it as a global enterprise not specific to one culture, others seeing it as an aspect of cultural dominance. When worldviews are so far apart in their interpretation of the whole scientific enterprise, it is not surprising that they differ over specific applications, and this only reinforces the importance of free discussion of the issues.

The disagreements over the Human Genome Diversity Project provided a good example of the extent of difference in opinion. Whereas the Human Genome Project aims to provide a complete map and sequence of the human genome, the Human Genome Diversity Project has as its goal the investigation of the variation in the human genome between different population groups.

On the one hand it was argued that it has the potential to undermine racism, by showing for example that what we call 'race' is not underpinned by significant genetic differences. Those who support the HGDP argue that it can benefit humanity as a whole by facilitating the application of effective therapies to all the world's populations rather than a proportion,



the assumption being that the latter would reflect the populations of already privileged societies.

Against this view, however, it was clear that there was considerable distrust of the HGDP from Maori and representatives of other indigenous peoples, who regarded it as exploitative of those peoples. In fact there was a specific Maori recommendation at the conference calling for the absolute and immediate halt of the project.

Informed consent is a particularly difficult issue in thinking about the HGDP, in the light of different cultural attitudes towards the acceptability of consent by *representatives*. This was an issue that also came to the fore in discussing the introduction of screening programmes, in the context of exploration of the clinical applications of genetic knowledge. In Europe there has been considerable interest of late in the criteria for the introduction of such programmes. In the past, genetic screening or testing tended to follow the identification of a particular case, so that then the genetic relatives of a person could be offered testing. Human genome analysis,

however, paves the way for population wide screening for conditions where there is no reason to believe that any particular person has the condition in question. So when would it be acceptable to do this? Criteria under discussion at the conference included the importance of the health problem, the possibility of acting on the information acquired, assurance of confidentiality, availability of counselling and recognition of cultural needs. In the workshop discussion of this topic however, it became clear that for some population groups a screening programme could not justifiably be offered to a population without the whole population having agreed *to the offer being made*. In other words it is not sufficient to have individual consent to an offer. In such circumstances, population screening would not be practically feasible.

A further issue is access to and control of the information acquired in the course of genetics screening and testing. This arises not only in the context of clinical practice but also in the commercial world: employers and insurers, for example, have interests in genetic information.

In clinical practice there is a presumption in favour of confidentiality. Despite arguments to the effect that because family members share some genes they should perhaps have access to genetic information about relatives that is relevant to reproductive decision making, there are also strong arguments in support of maintaining confidentiality. For some this is connected with ideas of ownership of genetic material; for other with considerations of encouraging trust in the service.

In the employment and insurance world, however, there are other factors. The discussion of insurance at the conference took into account the fact that genetic information has the potential to undermine the whole conceptual basis of insurance, which is concerned with sharing risks in society. Genetic information, as it becomes more precise, may differentiate the population to such an extent that the idea of risk distribution becomes redundant. Of course allowance has to be made for uncertainties in predictive power of genetic tests, but in the light of this possibility it is unclear whether genetic testing is to the advantage of insurance companies or not. Representatives of the industry were concerned to find a way forward that would enable insurance to survive, but also argued that out of the concern not to discriminate *against* persons with particular genetic predispositions, there might be a resulting systematic disadvantage for groups who are suffering from conditions that are not clearly identifiable as genetically based.

Although there was as much disagreement as agreement this consensus conference brought home the point that disagreement can in some ways be more productive than agreement, in pointing to areas where more work has to be done eg, in raising public awareness about issues concerning the acquisition, control and implications of genetic information.

Grant Gillett gave his Inaugural Professorial Lecture on August 11 titled "Is There Anything Wrong with Hitler These Days?" The venue was filled to capacity; an achievement as it was held in one of the larger lecture theatres on campus. Grant argued that post modern criticisms of truth present a challenge for ethics. His solution was that truths about moralities involve many different perspectives in order to get a full grasp of the complexity of a moral situation. Thus a claim about a moral truth from a perspective that tried to claim supremacy would miss out important moral features of a situation. Grant concluded by arguing that post modern criticisms do not stop us from continuing to condemn the atrocities of Nazi Germany.

Until now Otago University has not had a tradition of inaugural lectures for newly appointed professors. The invitation to Grant to deliver the first one in this new series is a tribute to his scholarship and a recognition of the high standing of the Bioethics Research Centre in the University.

Planning is well underway for the Bioethics Summer Seminar to be held in Dunedin in February 1996 (see notice on p?). The Health Research Council is joining with the Bioethics Research Centre in supporting the weekend sector of the Seminar focussing on Research Ethics. Following the weekend two parallel streams "Moral Management of Health" and "Teaching and Learning in Bioethics" will be held.

The organisation of such an event is a major task. The Centre is pleased to welcome Aidan Stenton, who has been employed to help administer the help.

During the last few months a several academics have visited from abroad. Mal Parker, senior lecturer in Medical Ethics at the

University of Queensland Medical School visited at the beginning of July and informed us of the developments of the medical ethics program where he works. Professor Ruth Chadwick visited from 27-31 August, during which time she presented a public lecture "Mapping our Destiny: Ethical issues in genetic research" and led a workshop "What counts as success in genetic counselling?". Ruth's visit was sponsored by the Otago Postgraduate Medical Society. Loane Skene crossed the Tasman to attend the ANZCCART conference in Wellington. We were lucky that she could come down to Dunedin and deliver two presentations "Legalising Euthanasia: the Australian Experience" and "ANZCCART and Animals in Teaching and Research"

Professor Kathryn Hunter from the Medical Ethics and Humanities Program of the NorthWestern University Medical School, Chicago visited the Centre at the beginning of July. While here she presented as part of the Medicine and The Humanities Open Lectures "Sherlock Holmes, Clinical Reasoning and Moral Knowledge"

We are continuing to develop our international networks. During the last year we have exchanged articles and publications with the editorial staff of "Medical Ethics: Journal for Forum of Medical Ethics". The journal is published in India and features important ethical concerns and developments from that country. The most recent issue of the journal included articles and letters on kidney transplants (and some on the black market surrounding organ transplants). Those interested in developments on the subcontinent would find this resource very valuable. The address for "The Forum" is

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