



Baroness Helena Kennedy QC AcSS
Human Genetics Commission
Area 652C
Skipton House
80 London Road
London SE 6LH

4 March 2003

Dear Baroness Kennedy

Re: HGC 2003/2005 Work Plan

I am writing to you as the Chair of the Academy's Working Party on the New Genetics in response to your letter of 20 February 2003 to Professor Forbes, Chair of the Council of the Academy of the Social Sciences. This response is informed by the wealth of current research by social scientists both here and abroad on the ethical, legal and social aspects of genomics. In the United Kingdom such research has been supported by a range of different funding organisations including, inter alia, the Economic and Social Research Council, the Wellcome Trust, the Medical Research Council, the European Commission, and a number of charities and lobby groups. The Academy Working Party is currently considering this research, and its membership and terms of reference are attached.

1. Review of Achievements to Date

1.1. The 2003/2005 Work Plan has much to commend it and is therefore most welcome. In particular the list of achievements against previous Plans suggests that members of HGC are addressing the key issues with the appropriate degree of the seriousness, while the published Reports illustrate the thoroughness of the HGC's approach. A particular source of commendation is the close relations developed with related regulatory agencies, stakeholder groups, and research organisations. The joint working party considering the licensing of pre-implantation diagnosis and testing with the Human Fertility and Embryology Authority provides a useful example of 'joined up' policy-making that could fruitfully be emulated elsewhere.

2. Current Work Plan and Priorities

2.1. The current focus on genetics and testing, reproductive choice and the use of personal genetic information reflects the results of most of the current social science research. Society is aware that the new genetic health technologies are rapidly moving

from laboratory research into clinical practice through a variety of pathways including the diagnosis, monitoring, prevention and treatment of a range of single and, increasingly, multi-factorial diseases. Social science research indicates that serious concerns have arisen following suggestions that the next steps may include improving the gene pool, eliminating familial diseases, selecting traits for offspring, and perhaps even creating a superior species. There continue to be a range of concerned but less hostile views expressed on issues such as population-based genetic screening, and individual and family genetic testing and counselling, around informed consent, privacy and confidentiality. There are also reservations expressed about the availability of genetic tests for the assessment of reproductive risk, and prenatal testing particularly for disorders for which there are no therapeutic interventions available, as well as for mental and other multi-factorial disorders. As a result, the focus on such issues by the HGC is welcomed since they clearly indicate a number of substantive ethical, legal and social implications that need to be addressed.

3. Stem Cell Research

3.1. The United Kingdom is generally acknowledged as one of the leaders in stem cell research, and the UK has become the first country to approve research into the use of embryonic stem cells. Concerns have already been raised about the nature and extent of the regulatory arrangements, and the input of HGC in these deliberations is welcomed. However, while recognising that the remit of HGC is limited to an extent by its UK perspective, it is clear that such a move has wider global implications, particularly in the areas of patenting and commercialisation. Genomic science has begun to design drugs with the optimal shape to produce therapeutic results – the right pill for the job – while minimising adverse reactions. Stem cells may be useful in the future for screening new drugs and toxins, as well as understanding birth defects and aiding regenerative medicine.

3.2. The impact of this commercialisation process on healthcare systems has generated some concern, especially as the promise so far exceeds the delivery of more than a handful of viable products. This concern has increased with the rapid development of stem cell research and both therapeutic and reproductive cloning in the UK. This area has potentially far reaching consequences for National Health Service provision, including the differential availability and costs of treatments. Society, in addition, appears to have unrealistically high expectations both of the timeframe for the introduction of new treatments but also their efficacy. It would therefore appear that stem cell research should take on greater prominence in the future work of HGC.

4. Communication and Public Involvement

4.1. The expanding role of HGC in advising on ways to increase public knowledge and understanding of human genetics is welcomed, while recognising that who frames what is acceptable as ‘knowledge’ is not without its problems. Recent research around the world suggests that most members of the general population, and indeed the majority of healthcare professionals, are relatively less well informed about the new genetic technologies, and their associated ethical, legal and social implications, than is appropriate for the generation of healthy and open debate. The new information generated by human genetics research is changing biomedical research, clinical practice, and public perceptions and understanding. Concerns are now being voiced about whether health professionals possess the appropriate knowledge, skills and

resources to integrate this new knowledge and its associated technologies efficiently in the diagnosis, treatment or prevention of disease.

4.2. Concern about inadequate education however is not something limited solely to health care professionals, but extends to the regulators and policy makers, and, of course, to the wider public. The proposal to map the level of 'public' knowledge about these issues will therefore need to recognise that the category of the 'public' includes an untypically broad range of stakeholders including scientists, health professionals and practitioners, policy makers and regulators, and interest groups, as well as the public at large. HGC may also wish to co-operate with the newly formed Genomics Network established by the Economic and Social Research Council, and particularly with the Genomics Survey to be undertaken by the University of Surrey.

5. Horizon Scanning and Future Activities

5.1. The NHS and New Genetic Health Technologies. It is increasingly becoming clear that the NHS will need to develop an implementation strategy for introducing genomic technologies and treatments into clinical practice. No doubt this will be at the centre of the forthcoming Green Paper. The HGC will need to be closely involved while maintaining its independent advisory role. It may find this facilitated by utilising existing, or commissioning further, social science research on the embedding of new technologies in society.

5.2. Biohazards and Bio-terrorism. Threats to international security are high following September 11th, and it is likely that they may increase. Emerging technologies, including biotechnology and genomics, already play a role in developing biological weapons of mass destruction. Such development and use could result in the unintended release of highly contagious, genetically engineered viruses and other organisms. The consequences are well illustrated by the current rapid dispersion of the SARS virus. HGC should begin to focus on this relatively less developed area of concern as it grows in importance following the war in Iraq.

In conclusion, the Academy wishes to assure HGC that through its individual members, and as the representative of forty three of the learned societies in the social sciences in Britain, it is committed to participating closely in the work of all government advisory bodies. The importance of this commitment for ensuring informed governance, is a key finding of the recent report of the Rhind Commission on the Social Sciences, *Great Expectations: the Social Sciences in Britain* launched on 25th March 2003. The Academy is therefore happy to respond to your request for comments on the HGC Work Plan for 2003/2005, and participate in any future consultations.

Yours sincerely,

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Chair, Academy Working Party on the New Genetics