

Responses to questions: Professor Alexander McCall Smith.

1) Background to the establishment of ethics commissions

In the United Kingdom there is no national ethics commission concerned with the full range of bioethical issues. The preferred approach has been to create a number of specialised committees or commissions to deal with particular issues. These co-exist with one major independent commission (The Nuffield Council on Bioethics, funded by the Wellcome Trust and the Nuffield Trust), and with various ad-hoc committees of Parliament which may look from time to time at issues of a bioethical nature. An example of the latter is the House of Lords Committee on Medical Ethics which considered the question of euthanasia. There is currently a House of Lords Committee which is looking at embryonic stem cell research.

The overall situation is as follows:

Committees of Parliament (Parliament initiates these)

Committees or Commissions set up by the Government to advise on a particular issue (for example, on new reproductive technology and embryo research)

Inquiries set up by Government following upon public controversies (for example, inquiries into the retention of human organs following post-mortem examination)

Permanent Commissions (which may be advisory or regulatory), established by Government. The two main examples of these are the Human Fertilisation and Embryology Authority (which has licensing powers) and the Human Genetics Committee (which is an advisory committee). The answers below are mainly concerned with the Human Genetics Commission.

2) Links with existing institutions

The Human Genetics Commission is appointed by the Ministers of Science and Health. It is an advisory committee located within the Department of Health. It reports to government ministers but may communicate directly with the public and the press through its press offices. Its publications do not have to be approved by Ministers, although they are usually circulated within the relevant government department prior to publication. The Government may, if it wishes, reject the advice offered.

3) Composition.

Vacancies for members are advertised in the public press. Anybody may apply. The members are chosen by a committee set up within the Department of Health. This committee operates within the guidelines approved for public appointments. This includes the presence on the appointing board of an outside member.

Most of the members are experts in genetics, health, public policy, law or bioethics. There are, however, other members who bring a different expertise (commerce or industry, for example). There are no politician members.

The Commission sets out to be representative of the broader society. We have no specific quotas in relation to gender, religion etc. We try, however, to achieve a balance in these matters.

4) Tasks

The Human Genetics Commission gives advice to Government on all legal, ethical and social aspects of genetics, as well on scientific matters in this area. We regard it as open of our main responsibilities to communicate with the public about genetic issues. We therefore make direct comment to the public and the scientific community about matters of genetic interest.

We are not required by legislation to consider certain matters. We have some questions referred to us by ministers; others are identified by ourselves. We discuss our work plan with ministers.

5) Working methods.

We aim in our discussion to identify a consensus which is acceptable to the Commission as a whole. We work through working groups, which deal with very specific issues and then report back to the whole commission for further discussion.

We are keen to establish relationships with other commissions in other countries. We have had discussions with counterparts in Washington and the Netherlands. We are in touch with others, and we very much look forward to establishing close contacts with German colleagues.

We take particular note of the contents of international instruments (eg the UNESCO Universal Declaration on the Human Genome and Human Rights, the European Convention on Human Rights and Biomedicine, and the ECHR).

We liaise with national bodies and consult professional and other associations frequently. This is usually done by putting out a consultation paper and inviting responses. These responses are analysed and taken into account in our recommendations.

6) Influence on legislative procedures and other political decision-making.

The Commission makes recommendations to Government Ministers. These recommendations are advisory in status.

7) Participation.

The Human Genetics Commission consults the public in the way described above. The Commission admits the public to its full meetings and publishes on the Web the minutes of all meetings, including those of working groups.

At our main commission meetings it is not unusual for the Chair to invite particular members of the public present (usually those representing particular groups) to make a comment.

8) We are funded by Government. The Secretariat discusses our financial needs with the Government departments involved and a budget is agreed with Ministers.