

Human Genetic Issues

1998. Revised 2000. Revised 2002.

Preamble

Medical practitioners have a duty to maintain a level of knowledge in this field appropriate to their area of practice.

The health and privacy of patients should be the paramount consideration in the application of medical genetics.

An individual's genes are only one factor that contributes to their health. Other factors include environment, lifestyle, complex interactions between inherited genes, spontaneous mutations occurring during life, and chance. Genetic information is usually about possibilities rather than certainties. In some cases, only a proportion of individuals with a particular disease-related mutation will develop the disorder.

The AMA, whilst recognising the prospects for improvement in health by the increased knowledge of the human genome, reaffirms the fundamental principle of equal dignity inherent in all people and asserts that the human genome should be regarded as the common heritage of humanity. Discrimination on the grounds of genetic characteristics is unacceptable. It is inconsistent with the *AMA Code of Ethics* and with the ethical principles of the doctor-patient relationship for a patient's genetic characteristics to determine their access to medical care.

The AMA supports research related to the human genome, but also recognises the range of complex ethical issues which arise as a consequence. Concurrently with research, resources should be directed to the consideration of these issues, and to community education regarding the benefits and risks of the application of genetic research.

1. Research into the Human Genome

- 1.1 Has the potential to benefit humanity.
- 1.2 Must be conducted under appropriate ethical guidelines.
- 1.3 Should be conducted in secure environments according to recognised international standards.
- 1.4 Should be applied to the prevention, management and treatment of disease.
- 1.5 Can be non-specific if the information is in a de-identified format.
- 1.6 May be conducted in the absence of consent if testing is part of a research project [approved by a human research ethics committee](#) on stored genetic material in a fully de-identified form.

2. The Holding of Patents

- 2.1 Should not infringe the principle that the human genome is the common heritage of humanity.
- 2.2 Should not present an obstacle to the prevention, management and treatment of disease.

3. Performance of Medical Genetic Testing

- 3.1 Access to genetic testing should be reasonable and equitable.
- 3.2 Genetic testing should not be undertaken in the absence of appropriate counselling. A doctor has an obligation to counsel, or to arrange appropriate genetic counselling for, the patient before every genetic test and after the result is obtained. This is particularly important where the result is likely to cause harm, social stigma, effect employment or have adverse insurance consequences.
- 3.3 Doctors should respect a patient's request that others be present during counselling.
- 3.4 Unless required by law, there should be no compulsion on any person to undertake any genetic test.
- 3.5 Tissue from a deceased person may be used for genotyping if such testing is of significance to the health of another person.

4. Consent by Patients or Responsible Persons for Medical Genetic Testing

- 4.1 The provision of information should be test-specific and unhurried prior to the harvesting of any tissue.
- 4.2 The information provided should include the reasons for, and the possible social, psychological, physical and reproductive consequences of, genetic testing.
- 4.3 Consent should be restricted to the investigation or diagnosis of specific conditions clinically relevant to the person, family or to their offspring.
- 4.4 Consent should be given without coercion and where possible in writing, prior to the harvesting of any tissue including blood.
- 4.5 Unless required by law, consent by living persons should normally be sought for incidental genotyping on their stored identifiable tissue and must be specific, contemporaneous and, where possible, in writing.
- 4.6 A person consenting on behalf of a minor needs to consider the minor's right to know or not to know relevant genetic information if it relates to a disease likely to cause significant suffering.
- 4.7 An individual has the right to withdraw from genetic testing and to require that their sample be destroyed at any time before the genetic test results are relayed to them. An individual also has the right to ask for a second opinion on the genetic test results.

5. Privacy of Genetic Information

- 5.1 Everyone is entitled to privacy and confidentiality of genetic information.
- 5.2 The strictest safeguards must be instituted to preserve the privacy of genetic information. Particular cognisance of privacy issues needs to be taken into account when genetic information is stored in electronic format.
- 5.3 Unless required by law, there should be no compulsion on, or coercion of, the person, the attending doctors or the staff of a genetics laboratory or register to acknowledge or in any other way to reveal that a genetic test has been undertaken, or to divulge the results of any test which may have been undertaken.

- 5.4 Governments, the criminal justice system, employers and insurers should not be authorised to compel patients to provide samples which would disclose genetic traits or disorders, unless in the interest of public health.
- 5.5 Unless specific disease intervention or prophylaxis is available, children should not normally undergo predictive genetic testing until they have reached the age of consent and so are able to request the test on their own behalf.
- 5.6 Incidental genetic information should be divulged to the patient only in circumstances where failure to do so would create a significant risk to their health or to the health of their offspring. This should occur associated with appropriate genetic counselling.
- 5.7 Genetic information acquired in the context of the doctor-patient relationship should not be disclosed to a third party without the patient's specific, and where possible, written consent (Refer to *AMA Code of Ethics, February 1996, 1.3(d)*).

6. Cloning

- 6.1 The cloning of human beings should be prohibited.
- 6.2 With approval by a human research ethics committee, human genetic tissue can be used for processes involving cloning techniques.

7. Eugenics

- 7.1 The practice of eugenics violates human rights.
- 7.2 In the absence of effective therapy, genetic testing of pre-implantation embryos or of a foetus should be restricted to fatal or seriously and permanently disabling diseases.
- 7.3 It is not ethical to practise genetic selection on the basis of gender (except in order to avoid hereditary gender-related disease), or on the basis of characteristics or traits which are unrelated to disease.