sharing of information with those affected. In the BMA's experience, often patients will be willing to share relevant information. However, unless there are overwhelming reasons to override a decision not to inform family members, refusals to do so must be respected.

If patients cannot be persuaded to share relevant information with their relatives for whom it has implications, doctors should consider the following points:

- the severity of the disorder
- the level of predictability of the information provided by testing
- what, if any, action the relatives could take to protect themselves or to make informed reproductive decisions, if they were told of the risk
- the level of harm or benefit of giving and withholding the information
- and the reason given for refusing to share the information.
- If having considered these factors the doctor feels that the balance lies in favour of making a disclosure against a patient's wishes, he or she must discuss this with the patient before disclosing the information, and must explain the reasons why this is considered to be justified. Wherever possible in such cases it is advisable for information to be passed to family members in a way that does not identify the patient, for example by saying that information has been gained from "a relative" without naming him or her.

  Whether information is to be shared with relatives with or without consent, the process of sharing must be approached with sensitivity to protect family members' rights not to know. Information should not be forced upon an unwilling recipient."

- (Taken from the BMA's publication Human genetics: Choice and responsibility, OUP, 1998: 72.)

See also:

Human genetics: choice and responsibility (1998)
Consideration of the ethical issues raised by human genetics
http://www.bma.org.uk/ap.nsf/Content/Human+genetics%3A+choice+and+responsibility

Consent, rights & choices in health care for children & young people
December 2000

'Inside Information, balancing interests in the use of personal genetic data'
A report by the Human Genetics Commission (May 2002)
Chapter 4: Consent and confidentiality: special cases in genetics
http://www.hgc.gov.uk/insideinformation/iichapter4.pdf
Genetics Interest Group
Genetic Interest Group. *Confidentiality guidelines.* London: Genetic Interest Group, 1998.

In deciding whether disclosure can be justified it will be necessary to assess:

- the seriousness of the harm
- the likelihood of the harm occurring
- the availability of effective intervention /options

The Genetics Interest Group considers that disclosure should be limited to situations where there is effective intervention.
Genetics Interest Group. Confidentiality Guidelines, 1998; www.gig.org.uk

General Medical Council: Confidentiality: protecting providing information. April 2004

Disclosures to protect the patient or others

"27. Disclosure of personal information without consent may be justified in the public interest where failure to do so may expose the patient or others to risk of death or serious harm. Where the patient or others are exposed to a risk so serious that it outweighs the patient's privacy interest, you should seek consent to disclosure where practicable. If it is not practicable to seek consent, you should disclose information promptly to an appropriate person or authority. You should generally inform the patient before disclosing the information. If you seek consent and the patient withholds it you should consider the reasons for this, if any are provided by the patient. If you remain of the view that disclosure is necessary to protect a third party from death or serious harm, you should disclose information promptly to an appropriate person or authority. Such situations arise, for example, where a disclosure may assist in the prevention, detection or prosecution of a serious crime, especially crimes against the person, such as abuse of children".

http://www.gmc-uk.org/standards/default.htm

British Medical Association: Confidentiality and disclosure of health information
14 October 1999

"Genetic information

The principles of confidentiality apply equally to genetic information as to other health information. With information which has a genetic component however, the results of specific tests or more generalised family histories for example, there is an added dimension of the information's direct relevance to family members. This can present health professionals with a conflict between the preservation of one person's confidentiality and a duty to protect others from avoidable harm and suffering.

It is the BMA's advice that in all areas of health care, the doctor's duty of confidentiality to their patients is of fundamental importance and should only be breached for the reasons identified in this guidance. The Association also believes that individuals have moral responsibilities to their relatives, which means that they should at least consider the implications of their actions for their family, and take an informed decision about whether to share the results of genetic tests with their relatives. Health professionals have an important role to play in advising people of the implications of test results for other family members, and in encouraging the

Professional Guidance

Consent

In clinical genetics, as with any health care practice it is important that the patient has given valid consent before any treatment or intervention is carried out. In order to be valid, consent must be given by a patient who is competent and informed. It must be given voluntarily. To be able to give informed consent to a genetic test the patient must be given sufficient information about:

- the various courses of action available
- information about the condition
- chance of positive or negative test results
- likelihood of manifestation of the condition (if a positive test result)
- the symptoms
- implications for family members
- available treatments and surveillance

Particular issues are raised where it is proposed that children are tested, where they cannot give valid consent themselves. Those with parental responsibility may give consent on behalf of children and young people, but the views of young people must be taken into account, where they are capable of understanding the issues, in deciding whether genetic testing would be in their best interests.

Paternity testing using testing kits available directly to the public raises the possibility of samples being tested without consent of an individual. Although samples from the putative father and child are always required it is no longer necessary for the mother to provide a sample in order to obtain a meaningful result. This raises the possibility of testing without the knowledge or consent of the mother. · The BMA believes that, ethically, 'motherless' paternity testing should only go ahead where the mother, and if sufficiently mature, the child, consents.

BMA Paternity testing – guidelines for health professionals
Guidance from the BMA Ethics Department, revised February 2004

Confidentiality

The public interest in maintaining confidentiality may be outweighed in particular instances where the public interest may justify disclosure of confidential patient information without consent. The health professional will have to balance these competing public interests in deciding whether or not to disclose. Assistance can be gleaned from legal cases and professional guidance

In assessing when 'harm' become serious enough to justify breach of confidentiality in genetic practice particular issues relevant in genetics should be considered. They include the

- diversity of potential harms
- wide variety of risks of occurrence of harms (near certainty to low probability)
- variability of interventions – effective treatment / surveillance / reproductive choice

The Human Genetics Commission states that disclosure may be justified where a patient refuses to consent to disclosure and the benefit of disclosure substantially outweighs the patient's claim to confidentiality.