GeneWatch UK
http://www.genewatch.org/

Department of Health
Genetics - information about genetics, embryology and assisted conception in the NHS
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Genetics/fs/en

British Medical Association
http://www.bma.org.uk

General Medical Council (GMC)
http://www.gmc-uk.org/standards/default.htm

Department of Health publications

Genetics White Paper
"Our inheritance, our future - realising the potential of genetics in the NHS"

Other genetics publications -
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Genetics/GeneticsAssociatedPublications/

Nuffield Council on Bioethics

Genetics and Human Behaviour: the Ethical Context (report published October 2002)

http://www.nuffieldbioethics.org/go/ourwork/behaviouralgenetics/introduction

Genetic Screening: Ethical Issues (report published 1993)
http://www.nuffieldbioethics.org/go/ourwork/geneticscreening/introduction

Useful Websites and contact groups

The Genetics Society
http://www.genetics.org.uk/

The Human Genetics Commission
The Government's advisory body on how new developments in human genetic will impact on health care
http://www.hgc.gov.uk/

Clinical Genetics Society
The Clinical Genetics Society (CGS) was set up in 1970 to bring together doctors and other professionals involved in the care of individuals and families with genetic disorders
http://www.clingensoc.org/

UK Genethics Group
Members of clinical genetics units meet several times a year, with the support of a medical ethicist and lawyer, to discuss dilemmas arising in the practice of clinical genetics
http://www.clingensoc.org/Ethics/genethics_club.htm

Public Health Genetics Unit
Provides news and information about advances in genetics and their impact on public health and the prevention of disease
http://www.phgu.org.uk/index.php

The Genetic Interest Group (GIG)
A national alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders
http://www.gig.org.uk/

Suggested Further Reading

Key texts

Chadwick R, Levitt M, Shickle D *The right to know and the right not to know*,. Aldershot: Avebury, 1997

Thompson AK and Chadwick RF (eds) *Genetic Information: Acquisition, Access, and Control*:, New York, Kluwer Academic/Plenum Publishers, 1999

Human Genetics Commission. Inside information: balancing interests in the use of personal genetic data. London: HGC, 2002

Harper PS, Clarke AJ *Genetics, Society and Clinical Practice* Bios Scientific Publishers Ltd, Oxford 1997

Nuffield Council of Bioethics. *Genetic screening: ethical issues*. London: Nuffield Council on Bioethics, 1993.

British Medical Association. Human genetics: choice and responsibility. Oxford: Oxford University Press, 1998

Buchanan A, Brock DW, Daniels N, From Chance to Choice: Genetics and Justice,

Cambridge University Press, 2000

Further reading

Prenatal testing

Savulescu J, Deaf Lesbians, "designer disability", and the future of medicine, *BMJ* Vol. 325 5th October 2002 page 771

Testing of children

Clarkeburn H Parental duties and untreatable genetic conditions*, J Med Ethics* 2000; *26*:400-403

Clarke A (ed) The Genetic Testing of Children, Bios Scientific Publishers Limited 1998

Skene L *Patients' rights or family responsibilities?*, *Med Law Rev* 1998;*6*:1

Genetic Discrimination

Wong JG and Lieh-Mak F, Genetic discrimination and mental illness: a case report, *J Med Ethics* 2001;*27*:393-397

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 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

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.

Case Discussion - Issues to consider

- The value of the duty of confidentiality owed to Ben by those involved in his clinical care (the GP, cardiologist etc)
- Respect for patient choice
- Is the risk to others (including Ben's brother, Paul) so great that it justifies breaching confidentiality?
- What will be the benefit of disclosing the information – can serious harm be prevented? To whom should the information be disclosed?
- What are the consequences for Ben if information is disclosed in the face of his refusal? Consequences for others.
- Respecting the autonomy of others – Paul and other relatives, Paul's employer, future airplane passengers
- The right to know/ the right not to know

Duty of confidence

Ben is owed a duty of confidentiality by those treating him. In the interests of Ben's care information about his condition will have been shared with professional colleagues. However, Ben's health information cannot be disclosed to others without his consent unless this can be justified by balancing the harms of disclosure against the benefits. Given the importance of the need to maintain confidentiality in health care, in order that patient's feel they can speak freely when seeking treatment, the standard of harm necessary to justify a breach of confidentiality is high. An assessment should be made of the likelihood of risk of sudden cardiac death and whether there are effective treatments or therapies.

Respect for Ben's choice that his brother is not informed

Genetic information is particularly sensitive given its impact on employment and reproductive choices and (potentially) insurance issues. However, respect for Ben's decision that Paul and other family members are not informed may be at odds with respect for the autonomous choices of others. The benefits/harms of disclosure to Ben's family should be discussed with him. It could be argued that Ben is in a better position to know what his brother would want (what would be in his best interests) than the cardiologist who has never met Ben's brother.

Respect for the autonomy of others

Ben has assumed that Paul would not want to know of the family risk of sudden cardiac death, particularly because of the implications for his employment as a pilot. But Paul will be denied the opportunity to make certain decisions about his future, both personally and professionally, unless he has relevant information about the possibility of his genetic condition. Paul could undergo tests to establish whether he is at risk. This will enable him to make important life choices, including whether to have children and, if he does have children, the implications of assessing their risk. If Paul is at risk of sudden cardiac death this carries potential serious risks for passengers on any plane that he flies. Does Paul carry the same risk as Ben (4%)? If so, then although this risk is not statistically high, the potential serious harms to passengers may justify disclosure.

If disclosure in breach of confidentiality is considered justified – to whom should the information be disclosed? Paul/ Paul's GP/ other relatives at immediate risk/Paul's employer?

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Case study

Informing family members at risk

Ben is a 32 year-old man who has been referred to a consultant cardiologist because he has recently come to know about a history in his family of young people dying suddenly. This family history became apparent at a recent Christmas dinner where several generations of the family were gathered together.

Ben went to his GP and explained that several young people in his family had died suddenly of what was thought to be a 'heart attack'. He said that he knew that two siblings of his paternal grandfather, a boy and a girl had died in their teens and that the patient's uncle (his father's brother) had also died suddenly at the age of 20. His father also died of a heart attack but in his early fifties. Ben's aunt on his father's side seems well.

Because of the family history, clinical tests were carried out on Ben including exercise tests, an echocardiogram and the wearing of a heart monitor for 24 hours. As a result of these tests a diagnosis of Hypertrophic Cardiomyopathy (HCM) has been made. Ben was investigated 5 years previously for some dizzy spells for which no cause was found. Taking into account this information and results of the earlier investigations the cardiologist estimates that he has a 4% risk per year of sudden cardiac death.

During counselling following these tests Ben is asked about other family members. HCM is an autosomal dominantly inherited condition. He mentions that he only has one brother, Paul. Paul is 25 and is an airline pilot. Ben asks the cardiologist not to contact his brother. He says that firstly Paul would not want to know, and secondly, if anyone found out Paul would lose his job.

Should the cardiologist inform Ben's brother?

A structured approach to case consultation

1. What are the relevant clinical and other facts (e.g. family dynamics, GP support availability)?

2. What would constitute an appropriate decision-making process?
   - Who is to be held responsible?
   - When does the decision have to be made?
   - Who should be involved?
   - What are the procedural rules e.g. confidentiality?

3. List the available options

4. What are the morally significant features of each option e.g.
   - What does the patient want to happen?
   - Is the patient competent?
   - If the patient is not competent, what is in his or her 'best interests'?
   - What are the foreseeable consequences of each option?

5. What does the law / guidance say about each of these options?

6. For each realistic option, identify the moral arguments in favour and against.

7. Choose an option based on your judgment of the relative merits of these arguments using the following tools.
   - Are there any key terms the meaning of which need to be agreed e.g. 'best interest', 'person'?
   - Are the arguments valid?
   - Consider the foreseeable consequences (local and more broad)
   - Do the options 'respect persons'?
   - What would be the implications of this decision applied as a general rule?
   - How does this case compare with other cases?

8. Identify the strongest counter-argument to the option you have chosen.

9. Can you rebut this argument? What are your reasons?

10. Make a decision

11. Review this decision in the light of what actually happens, and learn from it.

Taken from: A practical guide for clinical ethics support

Section C: Ethical Frameworks, a practical clinical ethics framework that may be useful for a clinical ethics committee to work through in discussion of a case.

should have discretion to disclose information based on the principle of maximising benefit and minimising harm.

(Genetics Interest Group, Confidentiality Guidelines, 1998
http://www.gig.org.uk/docs/gig_confidentiality.pdf. Section 5. The right not to know).

Consequentialism

From a consequentialist position the question of whether it is wrong to breach confidentiality is determined by the consequences of the breach. One of the consequences of a breach of confidentiality could be that the patient will lose trust in his/her doctor, and perhaps doctors generally, resulting in him/her not accessing healthcare in the future with a detrimental effect on his/her (and others?) health. On the other hand there may be situations where there are bad consequences of **not** breaching confidentiality, for example third parties may be denied information which would have serious implications for their health and treatment.

This is taken from a more detailed discussion of ethical issues of confidentiality to be found on the UK Clinical Ethics Network website:
http://www.ethics-network.org.uk
Ethical issues - Confidentiality

The following is taken from:
Medical Ethics Today - the BMA's handbook of ethics and law
(BMJ Publishing Group 2004, page 308)

"Does genetics raise different ethical issues?

Emphasis on the need for doctors to understand the dilemmas raised by genetics has led to a general tendency to assume that genetics is somehow "different" from other areas of medicine and so inevitably requires special rules and added protection. Arguments to justify these differences, however, are frequently not articulated and, in fact, many of the ethical dilemmas that arise in genetics are the same as those that arise in other areas of medicine. They centre on the traditional duties of health professionals to act in the patient's interests and to avoid harm. Facets of those duties are embodied in the accepted obligations to respect patient confidentiality, to provide information in order to obtain valid consent, to evaluate risks and benefits of treatment, and to aim for justice and equity in decision making. In some ways, however, genetics is different, primarily because of its familial nature, which requires that these general principles are supplemented by other considerations such as the inevitable interdependence of interests and duties owed to other family members".

Given the genetic basis of much disease, there may be great benefit to family members in sharing of relevant genetic information (although not all genetic information is familial e.g. spontaneous mutations). A person diagnosed with a serious genetic condition could, by informing relatives of the need for testing, alleviate worry and perhaps unnecessary diagnostic procedures. This could be considered a moral duty.

Paragraph 2.11
"Although considerations of genetic solidarity and altruism will generally take second place to the principle of respect for persons there may be exceptional circumstances in which the contrary is true. In such cases the social interest – or the common good – may be weightier than the individual interest, and certain rights of the individual may take second place".

Respect for Patient Choice

"It is widely accepted that competent patients should have a control over decisions concerning their own medical care. Respect for patient choice means that they should also have a control over what happens to the information shared by them with their health professional. Patients in general accept that health professionals sometimes need to discuss this information with colleagues in the interests of their care, and perhaps too in the interests of training. But this is very different to the sharing of patient information with those not involved in their clinical care Patients reasonably expect that, unless they have given specific permission, health professionals will not disclose the information revealed during the professional relationship to others. To take patient choice and patient autonomy seriously is to place great value on confidentiality in the doctor-patient relationship"
Confidentiality and serious harm in genetics – preserving the confidentiality of one patient and preventing harm to relatives. Anneke Lucassen and Michael Parker European Journal of Human Genetics (2004) 12, 93 – 97 (at page 94).

The right to know and the right not to know

A competent patient must give valid consent to be tested for genetic conditions. However, information about the genetic risk to family members may arise from testing of one person in the family (the index patient). Do family members have a right to know of a potential risk, or perhaps there is a 'right not to know'? Some may prefer to live without the anxiety of knowing that they are at risk of a genetic disease, particularly if it is a disease of late onset and where the likelihood of manifestation of the disease (penetrance) is uncertain.

The BMA has stated that:

"Individuals should be encouraged to share genetic information with others for whom it has significant implications if they are likely to want to know it. Only in very extreme and exceptional circumstances, however, should information be disclosed contrary to the individual's wishes".
Human Genetics, Choice and Responsibility, BMA, Oxford University Press1998

The Genetics Interests Group distinguishes between a situation where an individual knows he is at increased risk but does not want further information and the situation whee the individual has no knowledge of a prior risk. GIG suggests professionals

Specific ethical considerations relevant to genetic issues in healthcare

Respect for persons

The Human Genetics Commission in its report 'Inside Information' suggests that the principle of respect for persons should be a core principle in considering the ethical use of genetic information (*Inside Information* Chapter Two: General Principles, paragraph 2.12).

Paragraph 2.13.
"The principle of respect for persons requires that we acknowledge the dignity of others and that we treat them as ends in themselves and not merely instrumentally as means to ends or objectives chosen by others. This means that we must respect the autonomy of others".

Paragraph 2.18
"In the context of genetic information, respect for persons requires us to be sensitive to the special role that genetic identity has come to play in peoples' lives. Along with their social and psychological identity, genetic identity has particular implications for the individual's sense of self…. If we are to respect persons, then in most circumstances we must respect that which is important to them. It is clear that amongst these important things is genetic identity".

Therefore the notion of respect for others entails respecting the autonomy of others. Respect for autonomy is reflected in the principle of consent. This raises particular difficulty with regard to genetic testing of children – can they give informed consent, should the possibility of their future choice be preserved?

Reproductive choice, the exercise of parental autonomy, and prenatal testing, for example, selecting for an embryo that will be a suitable match for a bone marrow transplant for a sibling with a genetic disorder, may conflict with the 'rights' of a foetus or future child.

A person may decide that he/she does not want his/her family members to be informed of the results of a diagnostic genetic test. The HGC states that:

"Private genetic information about a person should generally not be obtained, held or communicated without that person's free and informed consent". (*Inside Information* paragraph 2.26).

However the principle of respect for autonomy / respect for persons may, in some situations, be outweighed by consideration of welfare of others.

Welfare of others

One aspect of respect for persons/respect for autonomy is the notion that information about a person's genetic inheritance is that person's alone. The notion of genetic privacy is fundamental in engendering confidence in diagnostic genetic testing / screening. However, in some limited situations, the risk to others of not knowing about genetic information that is relevant to their health may be so great that it justifies disclosure without consent.
The HGC refers to **genetic solidarity** – "genetic knowledge may bring people into a special moral relationship with one another" (*Inside Information* paragraph 2.10).

Casuistry

Casuistry, or case based reasoning, does not focus on rules and theories but rather on practical decision-making in particular cases based on precedent. So first the particular features of a case would be identified, and then a comparison would be made with other similar cases and prior experiences, attempting to determine not only the similarities but also the differences.

So if a clinical ethics committee were asked to consider whether it was ethical for a clinician to breach his / her duty of confidence, the committee would identify key factors, like the health risks to others if information was not disclosed. It would then make a comparison with other similar cases, identifying the relative risks of non-disclosure. Casuistry should not be divorced from consequentialism, deontology, or virtue ethics but complement them.

A clinical ethics committee can build up useful experience by identifying key factors that informed a decision in one case and comparing and contrasting the application of these factors in a similar case. This may be particularly useful in a discussion of best interests of a patient. If it was in patient A's best interests to receive treatment, why and how does this differ from an assessment of patient B's best interests in the same circumstances?

The Four Principles

Beauchamp and Childress' Four Principles approach is one of the most widely used frameworks and offers a broad consideration of medical ethics issues generally, not just for use in a clinical setting.

The Four Principles provide a general guide and leave considerable room for judgement in specific cases.

Respect for autonomy: respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices.

Beneficence: balancing benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.

Non maleficence: avoiding causing harm; the healthcare professional should not harm the patient. Most treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of the treatment.

Justice: respect for justice takes several forms:

- Distribution of a fair share of benefits
- Legal justice - doing what the law says
- Rights based justice, which deals in the language, and perhaps the rhetoric, of claimed human rights, and hence goes beyond, though it includes, legal rights.

These principles are prima facie – that is, each to be followed unless it conflicts with one or more of the others - and non-hierarchical i.e. one is not ranked higher than another. In recent years however, respect for patient autonomy has assumed great significance in the context of patient choice, underpinned by the requirement to provide the patient with sufficient information to put him / her in a position to choose.

The 'Four Principles' are intended as an aid to balance judgement, not a substitute for it.

Taken from: Slowther A, Johnston C, Goodall J, Hope T (2004) A practical guide for clinical ethics support. The Ethox Centre. Section C: Ethical Frameworks.

Ethics committees using consequentialist criteria necessarily operate in an area of uncertainty.

- Act and rule utilitarianism

Bentham tended to deal with the consequences of **acts**. However, '**rule** utilitariansim' justifies certain rules on utilitarian grounds. For example, one might justify the general rule 'do not lie' on the utilitarian ground that lying produces more bad consequences than good consequences overall.

In considering what is the right course of action/treatment in any healthcare situation we tend initially to think about the consequences arising from the different options. For example, in deciding whether in particular circumstances a breach of the duty of confidence is justified, we think of the consequences- the harms of breaching the duty and the harms of not warning others of a risk to their health. However, it is often difficult to predict consequences with any certainty.

Deontological Theory

A criticism of consequentialist theory is that it is so concerned with **ends** that it may overlook the moral importance of **means** - the ways in which the ends or goals are achieved. Deontological theory uses rules rather than consequences to justify an action or policy. The best-known deontological theory is that of Immanuel Kant in the 18th century. 'Kantianism' is a modern term, referring to a Kant-like emphasis on duties and rules. Kant defended rules such as 'do not lie', 'keep promises', 'do not kill' on what he claimed were rational grounds. Rules should comply with the *categorical imperative.* The categorical imperative holds that:

- Moral rules should be universalisable i.e. applied to all rational, moral members of the community rather than to just some
- All persons should be treated never simply as means but also always as ends in themselves
- Members of the moral community should take a hand in making the laws as well as living by them

Many modern *Kantians,* as opposed to Kant himself, are not absolutist in their application of moral rules or laws, whilst nevertheless stressing the importance of generally living by moral rules or laws.

The theory is manifested in the idea of a duties owed to a patient – the duty of care and the duty not to harm.

Virtue ethics

Virtue ethics is the name given to a modern revival and revision of Aristotle's ethical thinking. Aristotle's ethics, while not generally thought of as consequentialist, is certainly teleological. For him, the telos, or purpose, of a human life is to live according to reason. This leads to 'happiness' in the sense of human flourishing. This flourishing is achieved by the habitual practice of moral and intellectual excellences, or 'virtues'. For Aristotle, the excellences are of two types. A moral virtue is an excellence of character, a 'mean' between two vices. One of Aristotle's virtues is courage, a mean between recklessness and cowardice, which are vices. Modern virtue ethics sets itself the task of discerning the virtues for our time. In a healthcare setting what virtues would we like doctors, nurses, etc. to possess - self-control, truthfulness, generosity, compassion, discernment, integrity?

Aristotle also identified a second type of excellences, intellectual virtues, which constitute a preference for truth over falsehood and for clarity over muddle, both in pure reason and in practical affairs. Both the moral and intellectual virtues are, for Aristotle, the expression of reason.

Virtue ethics can be seen in the way we feel is the 'right' way to behave towards patients and to colleagues. For example, a virtuous doctor / nurse would take time to explain treatment options to a patient and find out what he/she wants.

Introduction to Moral Theories and Principles that inform ethical decision making in healthcare

Introduction

If a clinical ethics committee (CEC) is to provide support on ethical issues relating to clinical practice, and to facilitate discussion of the ethical dimension of clinical problems, members of a CEC will require an understanding of the moral theories and ethical frameworks that have informed the development of medical ethics.

In this section we provide a brief introduction to some of the key moral theories and ethical frameworks that have had an important influence on health care practice, particularly in Western medicine.

Ethical Theory

We may feel instinctively that a certain conclusion to a problem is 'fair' or 'unfair', but what criteria do we use to make such judgments? There are different ethical theories that can be applied to a problem to elucidate our thinking, but even so the results may not fit with our moral intuition.

There are several types of normative ethical theory including consequentialism, deontology - such as Kantianism - and virtue ethics. They can be applied in several **procedures** of ethical analysis, such as in analysis of cases (casuistry) and in different **settings** such as in a range of 'communitarian ethics': for example, a feminist approach or a social class based approach.

Moral or ethical theory may consider the application of rules or the consequences of actions.

Deontological theory - what one MUST do, based on duties and obligations
Teleological theory - the purpose or consequences of the moral acts

Consequentialist Theory

This is one sub class of teleological moral theory. According to consequentialist accounts of morality the moral value of an act, rule or policy is to be found in its consequences, not in intentions or motives. Utilitarianism is the most influential consequentialist theory. Jeremy Bentham in the late 18th century and John Stuart Mill in the 19th century formulated this way of thinking. Such 'hedonistic' utilitarians argue that the principle to judge our moral thinking is utility, that is, the maximisation of happiness, in the sense of pleasure and the minimisation of suffering, in the sense of pain. In any situation the morally right thing to do is the action that promotes the greatest happiness for the greatest number of people.

However pain and pleasure are not the only criteria that later utilitarians have used to evaluate the consequences of actions, rules or policies. Welfare-utilitarians consider the contribution to, or lessening of, human welfare. Preference-utilitarians seek to establish and satisfy human preferences.

Some key issues:

- Calculate net benefit

The net benefit or dis-benefit is found by balancing the happiness and unhappiness resulting from an act or policy. If one then seeks the greatest happiness of the greatest number that may be taken to justify overriding individual unhappiness in the interests of the happiness of the greatest number.

- Difficulty in calculating consequences

This theory requires that the consequences of acts or policies must be calculated. However in many situations one cannot predict consequences with any certainty and therefore consequentialism is probabilistic, one forecasts the consequences to the best of one's ability.

References for Suggested Pre-Meeting Reading

Parker M, Lucassen A, Concern for families and individuals in clinical genetics. *J Med Ethics* 2003;*29*:70-73
http://jme.bmjjournals.com/cgi/reprint/29/2/70?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=genetics&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT

Kent A. Consent and confidentiality in genetics: whose information is it anyway? *J Med Ethics* 2003;**29**:16-18.
http://jme.bmjjournals.com/cgi/reprint/29/1/16?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=genetics&andorexactfulltext=and&searchid=1&FIRSTINDEX=10&sortspec=relevance&resourcetype=HWCIT

K G Fulda[1] and K Lykens[2] Ethical issues in predictive genetic testing: a public health perspective *Journal of Medical Ethics* 2006;32:143-147;

The process of decision making

As important as the consideration of ethical issues and the development of ethical argument is the **process** of discussion. In discussing ethical issues the CEC should adopt a process that is transparent and can be subject to critical appraisal. In this context it may wish to consider the following:

- The role of Chair in ensuring contribution of all views
- If the CEC can justify and test its views by use of counter-argument
- How the discussion is documented for future review.
- How information is conveyed to those involved in the case.

Further information

In addition, this resource pack includes:

- Suggested further reading
- Useful websites addresses
- A brief summary of professional guidance in this area
- A brief summary of the legal issues

We hope you find this resource pack helpful as a tool in providing the ethics education to members of the CEC. Two other packs are available on Ethics & Resource Allocation and Ethics & the Vulnerable Patient. For copies of these packs and further information please contact:

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Department of Public Health and Primary Care
Gibson Building/Block 21
Radcliffe Infirmary
Woodstock Road
Oxford OX2 6HE
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Introduction to the ethics and genetics education resource pack

This resource pack is designed to be used by a clinical ethics committee or group as part of a process of self education of committee members. It provides an introduction to the ethical issues arising in genetics, and uses a specific case to facilitate a discussion of how these issues impact on day to day clinical practice, and how an ethics committee may approach such a case. It is therefore most useful for ethics committees /groups that are starting to work together to discuss these issues.

The pack can also be used by new members of a clinical ethics committee as an introduction to clinical ethics and the role of an ethics committee.

How to use the resource pack

The idea is that the resource pack will provide tools to facilitate discussion of the ethical issues arising in the case study.

Before the meeting

The suggested pre meeting reading provides background information on this topic. In addition it will be useful for members to read the documents

- Introduction to Moral Theories and principles that inform ethical decision-making in healthcare.
- Specific ethical issues relevant to genetics in healthcare
- A structured approach to case consultation

At the meeting

The case study should form the focus of the discussion. In discussing the case, CEC members should consider:

- Whether any more information is needed?
- How to identify ethical issues?
- Process of ethical discussion - use of ethical frameworks / counter arguments / case comparison
- What is the best course of action in this case, and what are the ethical justifications for this course?

The document **issues to consider** in this case may act as a useful prompt during or after the discussion. It is not an exhaustive list of the issues. The committee may identify other issues, or wish to reconsider an issue already covered in the discussion.

These documents do not attempt to provide a definitive answer, nor do they provide a comprehensive list of every ethical issue arising. Rather this ethics education resource pack aims to develop and facilitate the skills of the CEC (and a CEC with experience in this area may simply wish to use the case study as a basis for discussion).