



Fact sheet

GENETICS & ETHICS

The applications of human genetic research have great potential to improve medical treatments and prevent disease. On the other hand, it raises many potential issues that will affect individuals, families and society.

To participate in the debate surrounding the use of these technologies, we need to:

1. ask why genetics raises ethical issues;
2. consider and utilise basic principles for examining the different sides of the issue; and
3. develop sound strategies for presenting and debating our opinions, whilst being open to hearing those of others.

BASIC PRINCIPLES OF MEDICAL ETHICS

Four basic principles are commonly applied by the medical profession in ethical dilemmas. These can provide a useful framework for analysing the issues surrounding genetics:

1. Beneficence

A duty to do more good than harm. (Benefits can be physical, psychological, economic or social)

Ask yourself: *Who will benefit from this technology and in what way?*

2. Non-maleficence

The duty not to cause harm (Harms can also be physical, psychological, economic or social)

Ask yourself: *Who might be harmed by this technology and how can this be minimised?*

3. Individual rights

Respect for an individual's autonomy (their right to be their own person and choose their own source of action). This involves privacy, informed consent and confidentiality (genetic information is sensitive and access should be limited to those authorised to receive it).

Ask yourself: *Are the individual rights of all individuals considered and respected?*

4. Justice & equity

Fair, equitable and appropriate treatment for all.

Ask yourself: *Are the interests of all in the community considered and potential discrimination prevented?*

These four principles can provide a guide as to what is ethically important and a conceptual framework for discussing ethical issues. They do NOT provide hard and fast rules to operate by. Keeping these four principles in mind, ask yourself:

- WHO is affected? (from the individual, to family, to wider community)
- HOW are they affected?





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A guide to ethical decision making for human genetics-related issues

1. Identify the decision to be made

- What is the bioethical issue or decision and who must make that decision?

2. Describe the scientific and bioethical issues raised by the technology

- What issues are presented by the technology and what moral dilemmas does it pose?

3. Assess the information available

- What factual information do you need to make an informed decision?
- Where will you find this?
- What opinions do you have about the use of this technology, and why?
- What opinions do others have about the use of this technology, and why?

4. Determine who is or will be affected by this test

- Who are the relevant people involved? (eg. partner, children, parents, siblings, other relatives etc)
- In what way might each party be affected?
- What values and immediate priorities do each party have?

5. Alternatives and dealing with competing reasons

- What are the alternative outcomes on the use of this technology?
- Describe the advantages and disadvantages of each outcome for all affected parties.
- Which outcomes are unacceptable and why?
- Prioritise what may be the best decision at this time, and why.

6. What would your decision be? (Remember, there is no right or wrong answer)

- How would you argue your decision to each of the parties involved?

