Important points

- Ethical issues need to be considered if the benefits are maximised and the harms minimised from the increasing ability to use genetic testing to analyse an individual's genetic information. Ethical issues that arise are generated from:
- ***The shared nature and ownership of genetic information***. The doctor's ethical responsibilities include balancing the privacy and confidentiality of the individual and prevention of harm to others (the duty of care). The individual tested also has family responsibilities and obligations including dissemination of genetic test results within the family to enable informed decision-making by their at-risk relatives
- ***Limitations of genetic testing***. While in some cases, genetic tests provide reliable and accurate information on which people can make decisions, in other cases it may not be possible to obtain a definitive result. An individual is much more than the sum of their genes: the individual's environment can modify the expression of genetic messages to the body and many factors are not genetic that make an individual who they are
  - The discovery of a variation in a particular gene may provide some information about the nature of the condition that the person has, will develop or for which they may be at increased risk, but can rarely predict the severity of the condition or the age at which symptoms will first onset and in prenatal testing, the potential for quality of life for the child or the severity of a particular condition
- ***Inappropriate applications of genetic testing*** such as for the sole purpose of family balancing (sexing of a fetus for this reason) or its use in paternity testing without the informed consent of all parties involved
- **The potential for discrimination** especially with the use of information generated by the use of predictive/presymptomatic testing results - generally for adult-onset conditions - in life insurance applications and employment (see Genetics Fact Sheet 23A for more information and about genetic testing and life insurance products in Australia)
- **Setting boundaries in applications of the genetics technology**. This is one of the greatest challenges to find the way to implement regulations internationally such as in the areas of reproductive cloning and genetic testing for enhancement. It is also important to recognise and respect the moral, religious and cultural beliefs that underpin the decision-making by individuals, couples, families or communities
- **Forensic DNA databanks**. Ensuring that they are used for the purpose for which they were collected and protected from misuse. Also, where the public has also assisted the police by volunteering genetic samples to assist in the investigations of unsolved crimes, ensure that special protections are put in place for the DNA samples and the information generated
- **Patenting of genes**. Ensuring that commercial interests do not limit equity and access

The information generated from a genetic test is different from any other health information. Therefore the rapid development in genetic testing and diagnosis over the last decade, in part driven by the Human Genome Project (HGP) and the continuing work in this area (see Genetics Fact Sheet 24) has implications for individuals, families and society at a social, moral and ethical level.

This Fact Sheet discusses some of the ethical issues arising from the ability to detect these faulty genes that run in families.

Principles that govern an ethical genetic service

Genetics services work within a framework incorporating the following principles:

- Justice
- Autonomy
- Beneficence
- Non-maleficence

Justice

Within the context of health care, justice addresses two main themes:

1. The right to a minimum standard of health care, which encompasses values concerning public good and social justice. The interests of one individual or group of individuals should not disadvantage others. Implicit in this notion is respect for the disabled and individual's decisions in regard to their health care
2. Equity of access to services and information regardless of place of residence, ethnicity, gender, religion, age or disability

Autonomy

Autonomy is the principle of self-determination. As an individual right it may have to be balanced against the rights of others and is therefore not absolute.

Essential to achieving and maintaining autonomy is access to information and counselling so that utilisation is on the basis of informed consent. Confidentiality is paramount to ensuring the privacy of that decision-making.

Beneficence and Non-Maleficence

- Beneficence: the obligation to ensure that policies and practices are for the good of the community
- Non-maleficence (*Primum non nocere*): above all, do no harm

Given the shared nature of genetic information and conditions, what is to the good of one individual may result in harm or disadvantage to another. Inevitably there must be a balance of responsibility to the individual, the family and the public good.

Genetic testing

The increased ability to identify and test for information in our genes raises many issues.

Family matters - the shared implications of genetic information

Genetic conditions are family health problems. A diagnosis or a finding of inherited predisposition in a family member has implications for other family members.

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- A genetic consultation or test may elicit information, not only about the individual but also about other blood relatives
- Recording an individual's information in a pedigree or medical record may also create a record of the health status of relatives
- Just as there are ethical responsibilities for the doctor concerning privacy and confidentiality of the individual, so there are obligations to prevent harm or avoid seriously jeopardising the health of others (the duty of care)
- The individual tested also has responsibilities and obligations. People need to appreciate the shared nature of genetic information within families. They may need to consider not only what it means for their own health, but also what that information may mean for their relatives, and their responsibilities towards those relatives

Geographic distance or discord in families can sometimes lead to difficulties in revealing genetic test results that may be important for other family members. Counselling before testing is essential to help avoid such situations.

Predictive/presymptomatic testing – generally for adult-onset conditions

Issues that need to be considered include:

- **Limitations** of the test need to be discussed prior to testing. The tests cannot always identify the mutation, even if it is present
- It may also be necessary to have a **family member who has already been diagnosed with the condition, participate in the testing**. Their help may be needed to identify the faulty gene so that it may be tested for in other family members at risk but who are as yet unaffected, if they wish to do so. For example, a member of the family who already has breast cancer may need to be persuaded to assist
- Detection of the change in the gene is **not necessarily predictive of future symptoms,** such as the severity of the condition or age of onset, or even the likelihood of suffering from the condition at all. For example, if a woman knows that she has inherited the faulty gene that means she has a predisposition to develop breast cancer, it does not tell her if she will ever develop the condition and if she does, when it will occur and how severe it will be (see Genetics Fact Sheet 48)
- Health ethics requires that the patient should give **informed consent** whenever possible
  - This means that the person undergoing the test should only do so on a voluntary basis and with a full understanding of all the implications. There can be a danger of coercion. For example, an enthusiastic researcher or a member of a family may try to persuade others in the family to undergo testing about which they feel uncomfortable
  - Part of the counselling, before informed consent can be given, will include an explanation of the confidentiality attached to the test results. It should be explained to the patient that some third parties might also have an interest in the information revealed by the test, eg for insurance or employment purposes
- **The implications of the test result** for insurance and employment also needs to be discussed (see Genetics Fact Sheet 23A)
- The **emotional impact on family members** of finding out test results also needs to be explored prior to testing. This can be substantial whether the results are bad or good, eg the feelings of guilt often felt by 'survivors'. Coupled with this are the questions of obligation to other family members

Reproductive choices/Prenatal testing

Whether or not to have children is a major decision for any individual. It is even more difficult where one or both of the prospective parents knows, or just suspects, that they may carry a faulty gene associated with a health problem which could affect their children.

The decision to have a baby may lead to a number of further decisions to be made in regards to the possible genetic testing of the embryo/fetus during the pregnancy. Considerations include

- The limitations of testing discussed above. Detection of a faulty gene or a chromosomal abnormality may not provide all the information about the potential or quality of life for the child or the severity of a particular condition
- When a fetal abnormality is detected, support is essential for whatever difficult decision is made. Some expectant parents will decide to continue the pregnancy and try to put in place the professional, medical and social support that will be required. Others may choose to terminate the pregnancy. This decision may conflict with moral, religious and cultural beliefs
- Individual and community beliefs, values and morals (culture) as well as religion may influence the perception of disability and raise a number of issues, including
  - What should be tested for?
  - Should genetic testing be restricted only to conditions that have a significant health impact? For example, different cultures place different values on the sex of a child. The genetic test results will certainly reveal the sex of the child. If no genetic abnormalities are found, what should be the view if the parents want to terminate the pregnancy simply as a way of choosing the sex of the children in their family?
  - Who should place limits?
  - Who should be involved in the decisions when the test results become known?

Ethical issues experienced in the application of human genetics technologies

(a) The shared nature and ownership of genetic information

An individual inherits from their parents half of their father's genes and half of their mother's (see Genetics Fact Sheet 1). Similarly, an individual has in common with other relatives a proportion of their genes: family members are genetically related. The closer the family relationship (brothers, sisters) the more likely it is that they have genes in common.

Therefore the diagnosis of a genetic condition in a family member may mean that relatives, especially close relatives, have a chance of developing that condition or passing on the faulty gene involved in the condition to their children. The results of genetic testing may thus have vital implications for some or all other family members.

The confidentiality and privacy of the individual being tested needs to be protected.

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- The results of a prenatal diagnostic genetic test belong to the parent
- In the case of testing an adult for a condition that will or may develop later in their life, only that individual has the right to disclose the genetic information about themself. The results should not be released to a third party without written consent. Third parties who may have interest include insurance companies and employers

The individual undertaking testing also needs to be aware of his/her responsibilities and obligations: due to the shared nature of genetic information, other family members may have an interest in the results.

- Any person undertaking genetic testing will need to appreciate that while the result may provide information about their own health and well-being, the result may also have profound implications for other relatives

Responsibility and obligation however need to be balanced with the right of an individual to choose to know their personal genetic information or, equally, not to know. The emphasis needs to be on the right of the person to choose. Genetic counselling (see Genetics Fact Sheet 3) is essential both before and after genetic testing so that all the implications of undertaking testing including having information which might be of interest to others can be understood.

Case study:

Susan, a 40 year old woman, embarked on a family research project. During the course of the research, she discovered other family members, hitherto unknown to her who live abroad. While she knew that her mother had been diagnosed with breast cancer at age 43, she was unaware that her mother's five sisters and Susan's three cousins had also been diagnosed with breast cancer, some at relatively early ages.

Given this history, she consulted her GP who advised her about the availability of genetic counselling and possible presymptomatic genetic testing. She informed the genetic counsellor that she did not want her mother or other family members to know she was having genetic testing.

The result indicated that Susan had inherited a predisposition to develop breast cancer that meant that she had a 40%-80% chance of developing breast cancer during her lifetime. Being a private person and because there was some discord within the family, Susan did not wish to discuss this result with other family members. She did, however, tell her 18 year old daughter who now has a 50% chance of having inherited the same faulty gene. She also asked that the genetic counsellor inform her GP of the test result. When it was suggested that her three sisters and three brothers may also want to have information about their chance of having the mutated gene for predisposition to breast cancer, Susan indicated that she would not be communicating with them. Two years later, Susan's older sister, Barbara, who lived interstate, was diagnosed with advanced breast cancer. She was unaware of her risk for developing breast cancer.

Dilemmas

- *Does the genetic counselling team, or a GP, have an obligation to inform Susan's relatives with whom they have had no previous contact that they may also be at increased risk, regardless of Susan's wishes?*
- *What is the situation if Susan's sisters and brothers were also the GP's patients?*
- *Should stronger efforts have been made to encourage Susan to share the information with her family to minimise the harm that followed?*

Just after Susan had received her genetic test result, her younger sister, Mary, applied for life insurance. Susan and Mary are both patients of the local GP. The GP was asked to provide relevant medical information for the insurance policy. When asked about family history of cancer, Mary answered honestly that her mother had breast cancer but that there was no other family history. She was not aware of the research undertaken by Susan. She is also of course unaware of the result of Susan's genetic test.

Dilemmas

- *Regardless of legal issues, is the GP morally obliged to be honest to the insurance company about his knowledge of the family history?*
- *If the GP does reveal the information about Susan to the insurance company, should the company use this information in the assessment of risk for Mary in underwriting any policies issued to her?*

It should be noted that the Insurance and Financial Services Association (IFSA) in Australia have produced a policy statement, mandatory for their members, that states that

- Genetic testing will not be a requirement for assessment of risk for a policy but if a genetic test has been undertaken the insurance company will ask that the results be disclosed
- The insurance industry will not use information from one family member for risk assessment of another family member

See Genetics Fact Sheet 23A for information on the use and disclosure of genetic information in applications for life insurance products in Australia.

(b) Limitations of genetic testing

Genetic technology is a new and rapidly changing area of science and medicine. While in some cases genetic tests provide reliable and accurate information on which people can make decisions, in other cases it may not be possible to obtain a definitive result.

This may be due to insufficient information about the exact nature of the variation in the information in the gene being passed down in the family .

In other cases, the nature of the variation in the gene, or the chromosomal abnormality, may provide only an increased risk of the individual being affected. The above scenario on breast cancer genetic testing illustrates the inherent limitation in some cases of genetic testing (Susan's risk of developing breast cancer due to the presence of an inherited mutated gene is only 40%-80% during her lifetime -not a certainty -and it tells her nothing about the age at which the condition will develop, if at all).

Furthermore, an individual is much more than the sum of their genes: the individual's environment can modify the expression of genetic messages to the body and many factors are not genetic that make an individual who they are.

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The discovery of a change in a particular gene may provide some information about the nature of the condition that the individual has, or will develop, but can rarely predict the severity of the condition or the age at which symptoms will first onset.

This lack of precision in relating the expression of the condition (called the *phenotype*) to an individual's genetic make-up (called the *genotype*) can make the decision-making process in regard to acting on the information very distressing. This is particularly so when the genetic testing is done for prenatal testing of a condition. Genetic counselling is essential to assist families in that decision making process and ensure that the decision is as informed as possible.

(c) Inappropriate applications of genetic testing

Genetic testing for a medical or health reason has many benefits, although accompanied by some disadvantages as described briefly above. Analysis of an individual's genetic make-up however, even with our current incomplete knowledge, has other applications.

It can for example be used to determine the sex of a baby by checking the chromosomes. There are sometimes requests for the use of the technology to ensure that a couple have a baby of a certain sex, for reasons not necessarily related to the health or well-being of the child.

Genetic testing should only ever be carried out for medical or health benefit.

(d) Discrimination potential

Analysis of an individual's genetic make-up could also be used in the future by employers or insurers wishing to know the likelihood of a potential employee or insurance applicant developing a condition for which they carry a predisposition; for example, alcoholism, heart disease or cancer. Such knowledge could lead to

The potential for discrimination has been recognised for some time and recent research has highlighted limited evidence instances of genetic discrimination in the areas of insurance and in the workplace. A comprehensive research study has explored the nature and extent of any genetic discrimination in Australia, particularly through the perspective of three key stakeholder groups:

- Consumers (especially people who are assumed or known to have a genetic predisposition to specific conditions, whether on the basis of family medical history or a genetic test result)
- Third parties (especially insurers and employers)
- Legal authorities (such as anti-discrimination boards and other bodies dealing with complaints of genetic discrimination)

Case study

Huntington disease (HD) is a neurological degenerative disease that has an onset in most people between the ages of 30 and 50. There is no cure for this condition and it is progressive. Features include deterioration in movement, cognition and generalised functioning. Death usually results from respiratory illness.

HD is an inherited condition. A child of an affected person has a 50% chance of inheriting the faulty gene that causes the condition. Genetic predictive testing is now available for persons over the age of 18 who have an affected parent or relative which will tell them in almost all cases whether they will develop the disease at some stage in their life.

Worldwide, of those eligible for the test, only around 15% of people have taken up the option of testing.

Mr H. is a 25 year old man whose grandfather died some 10 years ago from Huntington disease. Mr H's mother has therefore a 50% chance of developing HD. She decided to have the genetic test and has been shown to have the faulty gene. She will definitely develop HD at some time and Mr H is now at 50% risk of developing HD.

Mr H. is an air traffic controller. He loves his job and he feels he could perform his duties most adequately for many years, irrespective of whether he carries the faulty gene for HD or not. He does not wish to have the genetic test. His employer is unaware of his family history.

Dilemmas

- *Do employers in industries involving public safety have the right to demand family health history information? In cases where genetic predictive testing is available for conditions that may impact on public safety, do employers have a right to predictive testing information about an individual whose current health status is excellent?*
- *Who actually 'owns' this information and who should decide who can access it?*

(e) Setting boundaries in applications of the genetics technology

Philosophers on science have put the view that science is morally neutral. It is the uses to which the science is put that might be good, or bad. With the new advances in genetics, as in any powerful new scientific tool, there is a potential for abuse. The boundaries need to be considered.

Much research has been carried out on human populations that have been isolated geographically or culturally. These include the Inuit of North America, the population of Iceland, Ashkenazi Jews, Romany gypsies and isolated tribes in South America. Articulate members of some of these groups worry that the results of the genetic research may stigmatise them. They may be discriminated against in employment opportunities, for instance, because they are thought to be more susceptible to a particular disease isolated by studying them. In cases such as research on isolated tribes not used to western ways, there is a danger that the studies may be exploitative.

The ability to make identical copies of a gene (cloning genes) in the laboratory is an essential step in the ultimate treatment of genetic conditions -correction of a faulty gene known as gene therapy (see Genetics Fact Sheet 27). Recently, applications of the genetic cloning technology have been extended to the cloning of whole animals: a sheep called 'Dolly' and mice (see Genetics Fact Sheet 26).

While it is not yet possible to clone a human, it is now considered technically possible to do so in the future. The reasons that some may support cloning another human may include the satisfaction of egocentric wishes for immortality or providing organ or bone marrow donor for another family member suffering from an incurable disease. The moral, social and ethical difficulties engendered by the application of genetic technology in this way are profound.

The use of genetic technologies for enhancement rather than health benefit is currently not done but may in the future. Society and its governments will need to consider the boundaries that have to be put in place to monitor developments and ensure ethical applications of this new and advancing technology.

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Case study

A General Practitioner (GP) has three male patients. Peter and Karl are aged eight years. Both are short for their age. Peter's short stature is due to a congenital deficiency in human growth hormone. His parents are both over 170 cm tall. Karl, however, is simply short because his parents are both under 165 cm in height. He has normal growth hormone levels.

A pharmaceutical company has used genetic technology to produce human growth hormone. It is an expensive treatment but is being used by many doctors to treat growth problems. Both Peter and Karl's parents want the GP to prescribe it for their sons.

A child's genetic height potential is determined by the genes inherited from both parents as well as by environmental factors such as diet. Therefore the treatment should enable Peter to reach a height similar to that of his parents and attain a normal stature. Karl's potential height is likely to be similar to his parents, that is, on the short side of normal. He will grow taller with the treatment, but will always be on the short end of the normal range for height.

The GP's third patient is Tom, an athlete aged 22. Tom aspires to the 2004 Olympic Games rowing team. Tom has also asked to be treated with human growth hormone. He believes that with the extra muscle bulk and strength that the treatment will give him, he may be able to achieve his Olympic ambitions.

Dilemmas

- *Which of these three people should be entitled to use the genetically engineered product?*
- *Will the use of genetically engineered products such as human growth hormone alter social perceptions and acceptability of characteristics like height?*
- *Could people of 150 cm be seen as having a disability?*

(f) Forensic testing

The use of fingerprints (more accurately known as dermatoglyphic fingerprints) for forensic identification purposes has been in place since the 1890s. One hundred years later 'DNA fingerprinting' is being used to complement the traditional system, or is being used in isolation for identification when real fingerprints are not available (see Genetics Fact Sheet 20).

A DNA fingerprint or profile of an individual relies on the analysis of 10-13 different non-coding repeated sequences of DNA (*loci*) which are known to exist in many patterns (*polymorphic*) in the population. The genes (coding DNA) are not analysed. The procedure concentrates on the non-coding DNA that separates the genes. DNA analysis creates a near-unique capacity for identification. The forensic DNA testing of convicted felons has resulted in many previously unsolved crimes being solved, either with the identification and conviction of the criminal, or the exoneration of a wrongly convicted individual. DNA analysis has also been used in solving cases of missing persons, eg in identifying a body found many years later.

Legislation in NSW, Australia has proposed widening the use of 'DNA Fingerprinting' technology under the NSW Crimes (Forensic Procedures) Act 2000. This legislation came into operation on 1st January 2001. It is intended to become model legislation for other States of Australia, and will result in the creation of a national genetics database ('CrimTrac') containing genetic 'fingerprints' (as well as traditional fingerprints) to assist police investigate crime. This legislation has enabled the establishment of a DNA databank from convicted criminals and suspects.

The public has also assisted the Police by volunteering genetic samples to assist in the investigations of unsolved crimes. In early 2000 all men aged over 18 living in Wee Waa, a small town in Northern NSW, were asked to donate blood for DNA in the search for a rapist of a 90 year old woman. One of the men who participated in the screening, perhaps because of community pressure to do so, admitted to the crime before the DNA was analysed. The DNA *loci* used for identification have no known medical function, so that medical issues have been avoided. There are, however, a number of issues concerned with the collection and testing of these volunteered DNA samples and the analysis and storage of the resultant information. The Wee Waa community screening generated much interest from groups such as the Council for Civil Liberties and the NSW Law Reform Commission. Among their concerns were whether a community screening program placed undue coercion on residents to participate, so overturning usual principles of justice, such as 'innocence until proven guilty' and the 'right against self-incrimination'.

Questions and issues that arise from forensic DNA community screenings:

How may a balance be struck between each citizen's right to individual privacy and the need to protect the safety of the community by identification of dangerous criminals?

- One approach suggested is to use an independent 'GeneTrustee' who would be able to hold the samples subject to strict privacy rules (Burnett L, Barlow-Stewart K, Proos A and Aizenberg H. *The 'GeneTrustee': A universal identification system that ensures privacy and confidentiality for human genetic databases. J Law & Medicine*, 2003, 10(4) 506-513). This third-party, arms-length system was developed for the community genetics carrier screening program for Tay-Sachs disease in NSW (see Genetics Fact Sheet 35). For example, sample results might be provided to police forensic laboratories anonymously. Identification would be provided only for the one sample that matched.

Should the basis of informed consent be different for community screenings than for individual DNA tests involving genes?

- Australians have shown resistance to the idea of a national identity system, eg their rejection of proposals for an Australia Card in the early 1980s, although other countries have accepted such systems. It would now be possible to establish a national DNA database. A national database would provide the potential for public good, but could also be misused.

Patenting of genes

Many of the same issues discussed above clearly arise with any large volumes of data collected for research purposes. Issues are in areas such as the ownership and guardianship of the DNA collected, and the consents that may, or may not, be required if a researcher wants to use the data subsequently for a purpose other than that for which it was originally collected.

The issue of patenting genes as recognition of the intellectual achievement required to isolate a single gene from the 20,000 genes in the cell is contentious. The patent grants an exclusive right to that person or corporation to the intellectual property for a period of time. The person whose body originally produced the gene has no commercial right to it.

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The Australian Law Reform Commission produced a report for the Australian Government on the issue of gene patenting and human health (www.alrc.gov.au) in Australia. The response by the Federal Government is due to be released in mid 2007.

Case Study

Ms AP, now 30 years old, has a rare genetic condition, affecting only about 25 people in Australia. In the course of the diagnosis of the condition, when she was a child, samples of skin and bone were taken for testing and subsequently stored in the pathology laboratory, as is common practice for such tissues. Consent for the tests were obtained from Ms AP's parents. At that time it was not envisaged that these stored samples could be a source of DNA.

Research on the condition has been undertaken over the last five years and DNA has been extracted from the stored samples of skin and bone. Consent was not sought from Ms AP, or her parents, to conduct research on the samples and on the extracted DNA. The research results in the discovery of an important gene and the gene is patented, providing the researcher and the Institution where the research was undertaken, with considerable funding for on-going work.

Dilemmas

- *Who has ownership of the stored sample, and the DNA extracted from it?*
- *Given the rarity of the condition, does Ms AP have the right to refuse consent for the research on her DNA? That is, how should the balance be struck between individual rights and public health in this case?*
- *In the case of a child, a person not legally competent to act, or a deceased person, whose consent (if any) should be required for research, eg a guardian or next of kin?*
- *Are current laws on patenting of genes reasonable?*
- *Should the contribution of individuals or families, who have enabled research by contributing DNA samples, be acknowledged or reimbursed perhaps by some form of royalty?*
- *What avenues of redress should be available to Ms AP (if any)?*

Other Genetics Fact Sheets referred to in this Fact Sheet: 1, 3, 20, 23A, 24, 26, 27, 33, 35, 48

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