

# ETHICAL PRINCIPALS FOR DECISION MAKING

- ◆ Autonomy
- ◆ Beneficence
- ◆ Non-Maleficence
- ◆ Justice

## AUTONOMY

- ◆ 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 the maintenance and achievement of autonomy for individuals using genetics services are:

- ◆ information and counselling
- ◆ consent

## BENEFICENCE AND NON-MALEFICENCE

*primum non nocere – above all, do no harm*

Beneficence and non-maleficence are subjective terms. Given the shared implication of genetic inheritance and disorders, 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.

Practically all interventions by health care professionals have a capacity to cause harm. Health care professionals have to exercise judgement as to whether any particular intervention is justified by the balance of potential benefit and potential harm. They must maintain and employ high levels of professional skills, knowledge and attitudes.

Some harmful outcomes arise from obvious cases such as failure to perform a surgical procedure with due skill and care, prescribing the wrong medication for an illness or conveying the incorrect information. Some causes of harmful outcomes may be less obvious.

## JUSTICE

- ◆ Fair, equitable and appropriate treatment
- ◆ Respect for people with disabilities
- ◆ Recognise the intrinsic value of individuals regardless of their disorder.
- ◆ Acknowledges that provision of testing to enable the avoidance of a particular disorder does not devalue persons with that disorder.
- ◆ Acknowledges the need for support for people with disorders and for those making difficult decisions concerning the avoidance of a particular disorder.
- ◆ Respect for patient's or families decisions
- ◆ Recognises that informed understanding and autonomy should underpin a patient's decisions.
- ◆ Accepts that individuals are free to decide whether or not to make use of facilities
- ◆ Accepts that opinions should be put in a non-judgmental way and choices supported.
- ◆ The allocation and distribution of limited resources to enable equity of access to services and information regardless of:
  - place of residence
  - ethnicity
  - gender
  - religion
  - age
  - disability

## **Family Matters eg. Implications of a high risk result for breast cancer**

*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 aged 43, she was unaware that her mother's 5 sisters and 3 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 predictive genetic testing through a mail order system in the USA. She could utilise this without her mother or other relatives having to know.*

*The result indicated that Susan had inherited a predisposition to develop breast cancer which meant that she had an 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. However, she did tell her 18 year old daughter who now has a 50% chance of having inherited the same faulty gene. She also requested that her GP not communicate this information to her 3 sisters or 3 brothers, although her GP did suggest she inform other family members. Two years later, her older sister, Barbara, who lived interstate, was diagnosed with advanced breast cancer. She was unaware of her risk for developing breast cancer.*

**Issues:           Duty of care, privacy and confidentiality, obligations to other family members**

### **Dilemmas:**

- ? What obligation does the GP have toward his/her patient versus obligations to other family members, if they are not also patients of the GP?
- ? What is the situation if Susan's sisters and brother were also the GP's patients?
- ? Should the GP have made stronger efforts to encourage Susan to share the information with her family to minimise the harm which followed?

## **PREDICTIVE TESTING FOR GENETIC DISORDERS EG HUNTINGTON DISEASE**

*Huntington disease (HD) is a neurological degenerative disease which has its onset in most people between the ages of 35 and 60 (approx.) There is no cure for this disorder which is slowly progressive over around 10 years and involves a deterioration in movement, cognition and generalised functioning. Death usually results from respiratory illness.*

*HD is an autosomally dominant inherited disorder. A child of an affected person has a 50% chance of inheriting the faulty gene which causes the disorder. 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.*

*Harry is a 25 year old man whose maternal grandfather died some 10 years ago from Huntington disease. Harry's mother (Anne) has therefore a 50% chance of developing HD. She decided to have the predictive genetic test and has been shown to have the faulty gene. She will definitely develop HD at some time and Harry and his two sisters are now at 50% risk of developing HD.*

*Harry is an air traffic controller. He loves his job and 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.*

**Issues:            Privacy, employment issues, ownership of information, access to information by third parties, rights of the individual versus public good.**

### **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 disorders which may impact on public safety, do employers have a right to predictive testing information about an individual whose current health status is excellent?

## **Newborn Screening Program and Retention of Samples**

*Agnes and Robert have a daughter Sarah aged 12 years. Their older daughter Margaret had cystic fibrosis and died in 1985.*

*Agnes and Robert wish to start another pregnancy and ask about the possibility of prenatal diagnosis. They undergo DNA testing and the CF mutation is found in Robert but not in Agnes. (She must have a mutation but it is not one that the laboratory can detect). They are advised that prenatal testing might be possible if there was DNA or tissue stored from Margaret, for example from an autopsy. They don't know of any such stored DNA or tissue.*

*Agnes and Robert are surprised to learn that there is probably a blood spot from Margaret, retained after routine newborn screening tests, which could be used. Agnes vaguely recalls that Margaret had a newborn blood test but she does not recall whether anyone told her what it was for or asked for her consent to proceed with it.*

*The blood spot is obtained and prenatal diagnostic testing is successful.*

### **Issues: Consent for testing, storage of DNA, testing of minors Dilemmas**

- ? Did the circumstances by which the laboratory obtained Margaret's blood sample meet good ethical standards? If not, how could the process be improved?
- ? Was the laboratory ethically justified in retaining the sample without the knowledge of Margaret's family?
- ? If not, does the successful outcome justify the process which took place?
- ? Agnes and Robert want Sarah's carrier status determined, which is possible now that the blood spot has been obtained. From an ethical viewpoint, should that proceed?