

Privacy Implications of Genetic Testing

March 1999

Categories of genetic testing

There are three categories of genetic testing:

- **carrier testing**, where the implications are usually for reproduction
- **diagnostic testing**, for the benefit of the person who is already symptomatic or for whom treatment is required and
- **predictive testing**, where the test predicts the onset of a disease at some future time.

Where the genetic testing is diagnostic, the situation is comparable to any diagnostic test, and the information about the patient will usually be shared readily between health professionals involved in their care. However, the results of predictive or carrier testing relate to healthy people and there is often no identified group of comparable care givers. Divulging predictive or carrier test results to health professionals will require the patient's permission in most instances.

The HGSA recognises that genetic testing, but more particularly predictive testing, raises complex issues for the individual tested. Many of these issues are currently being explored by a number of bodies including the Australian Health Ethics Committee, the Australian Medical Association (July 1998 position statement) and the Privacy Commissioner.

At this time in Australia there is no Commonwealth or State legislation specifically on the topic of genetic testing. Members of the HGSA hold a special position as providers of clinical genetic counselling and testing services, and wish to make the following points in relation to genetic testing.

Genetic testing should be:

- offered in the context of genetic counselling
- based on informed choice, without coercion/compulsion
- performed for the benefit of the person tested and
- only undertaken if the person tested has autonomy, ie control over who has access to their results. Where the person is not competent consultation through their legal guardian is essential.

Access to test results

The HGSA believes that the level of control on access to genetic test results should depend on the relationship between the person tested and the person seeking this information. Therefore:

- predictive test results should not be divulged to any third party (eg employers, insurers) without the written permission of the person tested
- less access restriction is needed for the current spouse/partner
- for blood relatives who may share the same gene mutation, each situation will need to be assessed.

It will be necessary to consider in each case the need to maintain patient confidentiality and autonomy not to disclose, versus the duty to inform other family members, who may suffer potential harm if their risk status is not disclosed. The doctor patient relationship is bound by the ethics of confidentiality and a duty of care, however when there is an inherited disorder in the family which may result in serious illness or shortened survival, duty of care may need to extend to the family group.

Ownership of test results

Genetic testing may determine the nature of the gene mutation in the family and which family members have the mutation. The HGSA proposes that information about the gene mutation belongs to all blood relatives, whilst results of tests specific to an individual are confidential. Once the distinction has been discussed, most people would not chose to withhold genetic information from family members. It is the challenge of the clinician and the genetic counsellor to find a way of making blood relatives aware of their risk without breaking the patient's confidence.