



NEW SOUTH WALES NURSES AND MIDWIVES' ASSOCIATION
AUSTRALIAN NURSING AND MIDWIFERY FEDERATION NEW SOUTH WALES BRANCH



POSITION STATEMENT ON HUMAN GENETIC TESTING

Re-Endorsed by Annual Conference 2020

NSW Nurses and Midwives' Association
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Position Statement on Human Genetic Testing

THE NSW NURSES AND MIDWIVES' ASSOCIATION RECOGNISES THAT:

- Genetics research produces information that may lead to the detection of genetic susceptibilities to certain diseases, illnesses and disability. This information may be used for the prevention and/or amelioration of suffering due to disease, illness or disability.
- The identification of genetic predisposition to disease, may lead to better identification of non-genetic, environmental risk factors which contribute to the development of disease. This may enable a more directed approach to preventive health care.
- There is the potential for genetic information to be used in a discriminatory manner.

THE NSW NURSES AND MIDWIVES' ASSOCIATION ADOPTS THE POLICY THAT:

1. Participation in predictive genetic testing such as screening for occupationally related diseases, prenatal diagnosis and pre-symptomatic screening must be voluntary and should not be used as a prerequisite for employment.
2. Individuals have a right to privacy and the protection of their health information and civil rights from all external parties, e.g. employers, insurance companies, health funds, partners, family members. Individuals who refuse genetic services, must not be subject to discrimination or penalty.
3. Current and comprehensive information, including all relevant clinical information, must be available in order that an informed, voluntary decision can be made to consent or not consent to testing.
4. Testing should be provided within a specialist multidisciplinary health care environment, which includes knowledge of the particular disorder being tested for, requirements for and processes of testing, and reliability of results.
5. Genetic information can be complex and this needs to be acknowledged in approaches to assisting individuals (and families) in decision-making about genetic testing. The role of the health professional is to assist individuals, couples or families to make decisions that are genuinely their own and appropriate to their personal situation¹.



6. Individuals have the right to determine what action, if any, they wish to pursue in relation to their test results.
7. Individuals have the right to know how the testing result records will be stored and used into the future.
8. Genetic services should be equally available and accessible to all people based on need and not on ability to pay.

REFERENCE

1. National Health and Medical Research Council, 2010 Medical Genetic Testing: Information for health professionals, <https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e99.pdf>.