

**RECOMMENDATIONS from the
key findings of the Genetic Discrimination Project (GDP)
MARCH 2009**

Genetic discrimination is a complex issue. While genetic discrimination is often perceived only as a legal concept, negative and unfair treatment of people on the basis of their genetic characteristics can be experienced in a range of contexts including family and social relationships as well as the broader institutional contexts like insurance and employment. As a result of the complexity of the concept of genetic discrimination, the following recommendations based on findings from the GDP relate to a range of contexts. However the cases that have been verified within the research as constituting genetic discrimination relate to practices that can be regarded as illegal.

In order for the health benefits of genetic testing developments to be realised, the issue of genetic discrimination requires focused and appropriate policy responses, ongoing monitoring and continued research.

Recommendations specific to consumers

- As genetic discrimination appears most likely to occur through the misunderstanding of genetic information and its implications for individuals and families rather than deliberate bad faith, community education is required to increase genetic literacy in Australia and increase awareness about continuing developments in genetic testing technology and the issue of genetic discrimination
- Although most attention regarding the potential for genetic discrimination in Australia has related to life insurance, awareness and discussion of the issue within community and clinical services contexts should be extended to include employment, health services and family and social domains
- For people who may be concerned about or believe they have experienced genetic discrimination there should be clear pathways and mechanisms for accessing support and information from anti discrimination, clinical genetics and health care services; this has resource and education implications
- Individuals with genetic test or family history information should understand that they have a right to discuss and/or challenge life insurance decisions that appear unreasonable; clinical genetics services may be able to assist with advocacy and/or providing genetic risk information relevant to insurance applications or claims
- It is advisable that individuals seeking life insurance products that involve risks related to genetic tests or family history should communicate directly with insurers as they are more likely than other insurance-related advisors to be aware of the complexities and changing nature of genetic health sciences that underpin genetic risk assessment

Recommendations specific to life insurance

- We endorse implementation of the ALRC/AHEC *Essentially Yours* Report recommendations with regard to life insurance directed to improving the underwriting process (Recommendations 27-1 to 27-11) including:
 - The need for an independent process to determine which particular genetic tests should be used in underwriting mutually rated insurance, having regard to their scientific reliability, actuarial relevance and reasonableness.
 - the need for life insurers to give written reasons for unfavourable underwriting decisions based on genetic information, explaining the actuarial, statistical or other basis of the decision;
 - expand consumers' appeal options in respect of unfavourable underwriting decisions to allow for review of underwriting decisions involving the use of genetic information;
- In addition to these recommendations from the *Essentially Yours* Report, we also recommend that insurers should routinely be seeking genetics specialist advice to inform their decision-making where genetic information is involved, particularly in cases where the genetic test result is positive and may result in life insurance being declined or offered on non-standard terms.

Recommendations specific to employment

- We support the implementation of the *Essentially Yours* Report recommendations in relation to the use of genetic testing in employment (Recommendations 30-1 to 33-1) the effect of which would be to prohibit employers for using genetic test information of employees unless it can be shown to be required on occupational health and safety or other valid grounds.

Recommendations specific to the legal system study

- In view of the significant challenges individuals face in pursuing legal redress for alleged genetic discrimination, aggrieved individuals need to be supported to have access to legal remedies, for example, through an advocacy support service.