

'Investigating Genetic Discrimination in Australia: A Large-Scale Survey of Clinical Genetics Clients'

*Clinical Genetics* Vol 74 (2008) pp 20-30

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**Abstract**

We report first results from the Australian Genetic Discrimination Project of clinical genetics services clients' perceptions and experiences regarding alleged differential treatment associated with having genetic information. Adults (n = 2667) who had presented from 1998 to 2003 regarding predictive or presymptomatic testing for designated mature-onset conditions were surveyed; 951/1185 respondents met inclusion criteria for current asymptomatic status. Neurological conditions and familial cancers were primary relevant conditions for 87% of asymptomatic respondents. Specific incidents of alleged negative treatment, reported by 10% (n = 93) of respondents, occurred in life insurance (42%), employment (5%), family (22%), social (11%) and health (20%) domains. Respondents where neuro-degenerative conditions were relevant were more likely overall to report incidents and significantly more likely to report incidents in the social domain. Most incidents in the post-test period occurred in the first year after testing. Only 15% of respondents knew where to complain officially if treated negatively because of genetics issues. Recommendations include the need for increased community and clinical education regarding genetic discrimination, for extended clinical genetics sector engagement and for co-ordinated monitoring, research and policy development at national levels in order for the full benefits of genetic testing technology to be realised.