

'Investigating Genetic Discrimination in Australia: Perceptions and Experiences of Clinical Genetics Service Clients Regarding Coercion to Test, Insurance and Employment'

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Abstract

Survey and interview-based findings from the Consumer Study of the Australian Genetic Discrimination Project (GDP) are reported. These involve perceptions and experiences of clinical genetics clients regarding coercion to undertake genetic testing and insurance and employment-related issues. Genetic discrimination is defined as the differential treatment of asymptomatic individuals because of actual or presumed genetic differences. Eligible adults (n=2667) who had requested predictive testing for designated mature-onset conditions, 1998 to 2003, were surveyed; 951/1185 respondents met asymptomatic inclusion criteria. Neurological disorders and familial cancers were relevant to the majority. Sources of coercion, where reported, included family members, doctors, geneticists/counsellors and life insurers. Insurance and employment related issues were raised; some respondents reported avoiding or being advised not to apply for life insurance. Interview data further elucidate context and impact of coercion and/or negative treatment. The experiences of respondents where neurological conditions were relevant differed from others. Implications of the study are discussed.