

‘Verification of Consumers’ Experiences and Perceptions of Genetic Discrimination and its Impact on Utilization of Genetic Testing’

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**Abstract**

**Purpose:** To undertake a systematic process of verification of consumer accounts of alleged genetic discrimination.

**Methods:** Verification of incidents reported in life insurance and other contexts that met the criteria of genetic discrimination, and the impact of fear of such treatment, was determined, with consent, through interview, document analysis and where appropriate, direct contact with the third party involved.

The process comprised obtaining evidence that the alleged incident was accurately reported and determining whether the decision or action seemed to be justifiable and/or ethical.

**Results:** Reported incidents of genetic discrimination were verified in life insurance access, underwriting and coercion (9), applications for worker’s compensation (1) and early release from prison (1) and in two cases of fear of discrimination impacting on access to genetic testing. Relevant conditions were inherited cancer susceptibility (8), Huntington disease (3), hereditary hemochromatosis (1), and polycystic kidney disease (1). In two cases, the reversal of an adverse underwriting decision to standard rate after intervention with insurers by genetics health professionals was verified. The mismatch between consumer and third party accounts in three life insurance incidents involved miscommunication or lack of information provision by financial advisers. **Conclusion:** These first cases of verified genetic discrimination make it essential for policies and guidelines to be developed and implemented to ensure appropriate use of genetic test results in insurance underwriting, to promote education and training in the financial industry, and to provide support for consumers and health professionals undertaking challenges of adverse decisions.