

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

Sandra Taylor¹, Susan Treloar², Kristine Barlow-Stewart³, Margaret Otlowski⁴, Mark Stranger⁴

¹Department of Social Work and Human Services, Central Queensland University, Rockhampton, Australia; ²Centre for Military and Veterans' Health, University of Queensland, Brisbane, Australia; ³Centre for Genetics Education, Royal North Shore Hospital, Sydney, Australia; ⁴School of Law, University of Tasmania, Hobart, Australia.

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.

Keywords: Genetic discrimination; Australia; coercion; insurance; employment; clinical genetics clients.

Introduction

Consumer perceptions and experiences regarding human genetic technologies and associated legal, ethical and social issues are topical issues in Australia as elsewhere (Australian Law Reform Commission & Australian Health Ethics Committee of the National Health & Medical Research Council NHMRC (ALRC/AHEC) 2003; Geller 2002; Petersen & Bunton 2002). A key ethical, legal and social concern associated with the rapid development of genetic testing technology has been the potential for genetic discrimination, defined as the differential treatment of asymptomatic individuals or their relatives on the basis of real or assumed genetic differences or characteristics (Otlowski et al 2002; Geller 2002; Billings et al. 1992). Although such differential treatment can potentially be to the advantage or disadvantage of an individual, most concerns have related to negative treatment.

Information about a person's genetic makeup, characteristics or health can be suggested from their family history or from the results of a genetic test. There are currently over 1300 conditions for which genetic tests are available in clinical settings and a further 300 are being developed in research contexts (<http://www.genetests.org>). Within the Australian context, more than 220 gene tests are now available; in addition, tests can be accessed internationally (ALRC/AHEC 2003). Such tests can be used to diagnose genetic conditions, to screen population groups for genetic risks or predispositions and to identify carriers of faulty genes in the context of reproductive risk. Genetic tests can also be utilised to assess a person's potential for developing conditions in the future through identifying mutations in genes that cause or predispose individuals to illness (Haan 2003); such tests are referred to as *pre-symptomatic* or *predictive* tests depending upon whether the result can indicate definite development of a future condition or an increased risk of developing such a condition in the future, respectively.

Identifying potential characteristics of an individual's future health through predictive genetic testing when the person is otherwise healthy and free of any symptoms of the relevant genetic condition, is potentially beneficial in many ways. It can enable early detection, treatment and preventive strategies regarding particular genetic conditions and assist in people's choices and life planning where there is no treatment or prevention. However, predictive testing can also be associated with the potential for individuals to be treated differently based on what people know or even wrongfully assume about the tested individual's genetic characteristics as a result of them being tested. Such differential treatment can constitute genetic discrimination. There are many genetic conditions that can now be predictively tested for and which are therefore associated with the potential for genetic discrimination; these include neurodegenerative conditions like Huntington disease (HD) or familial Alzheimer disease and familial cancers such as inherited predisposition to breast or bowel cancers¹.

Reports of negative genetic discrimination have been published in Australia (ALRC/AHEC 2003, Barlow-Stewart & Keays 2001), the United States (Billings et al. 1992; Geller et al. 2002, 1996; Hall et al. 2005), Canada (Lemmens et al. 2004), the United Kingdom (Low et al. 1998) and Europe (Hendricks 1997; Sandberg 1995). Such reports have been in regard to alleged negative treatment in organisational or institutional contexts like health, life and disability insurance and employment (Otlowski 2005, 2002, 2001); clinical, health care and blood bank services; fertility and adoption services and intake to armed services (Barlow-Stewart & Keays 2001; Billings et al. 1992; Geller et al. 2002; Lapham et al. 1996). Discussion of insurance within the Australian context relates mainly to life, rather than health, insurance, as the latter is community-rated in Australia, similar to Canada and the United

Kingdom; this is unlike the United States where individually-rated health insurance significantly increases the potential for genetic discrimination (ALRC/AHEC 2003; Barash 2000). Insurers in Australia are also legally entitled to discriminate between applicants because of exemptions under the *Commonwealth Disability Discrimination Act* (1992) (Cth), provided their decisions can be substantiated actuarially (Otlowski 2001).

Negative treatment can also occur in informal or social contexts like families or interpersonal relationships where legal analysis may be less relevant (Geller et al. 2002; Lemke 2005; Treloar et al. 2004). In such instances, for example where the reproductive fitness of a person with a known genetic risk is called into question, negative treatment can be based on prejudicial attitudes and social stigma regarding people perceived to have 'bad blood' (Lemke 2005; Otlowski 2005). Experiencing genetic discrimination, according to Geller et al (2002, p.256), can result in a range of personal and psychological reactions for both the individual and their close others including 'loss of self-esteem, alienation from family members and others, and alterations in family dynamics'. Findings from a recent Canadian study undertaken by Bombard et al. (2007) describe some of the strategies that individuals have adopted in order to cope with and manage the risk that they may encounter genetic discrimination if they are found to have the positive Huntington disease mutation. Such strategies, like 'keeping low', avoiding both genetic testing and insurance applications or engaging in highly selective disclosure of their genetic risk or genetic test information have now been reported in several studies (Bombard et al. 2007; Geller et al. 1996; Peterson et al. 2002; Taylor 2004). This suggests that, in spite of ongoing societal, ethical and legal concerns about the potential for genetic discrimination to occur, it has for many individuals become a real threat and one that is significantly impacting upon their behaviour.

Within the Australian context, anecdotal accounts and case studies of genetic discrimination have been reported for some years (for example, Barlow-Stewart & Keays 2001; Taylor 1998). In the 2001 study by Barlow-Stewart and Keays, 48 cases were identified, mostly in regard to access to life insurance as well as some alleged discrimination in employment. Partially as a result of this research, genetic discrimination became a focus of the national inquiry in Australia into The Protection of Human Genetic Information conducted jointly by the ALRC and the AHEC (ALRC/AHEC 2003). The report from the inquiry entitled *Essentially Yours*, provided a comprehensive overview of the issue of genetic discrimination as well as recommendations which included the establishment of a dedicated body in Australia to investigate and monitor this and other genetics-related issues in Australia in an ongoing way. In 2005, the Commonwealth Government established a Human Genetics Advisory Committee under the auspices of the National Health and Medical Research Council to advise government regarding genetic issues, genetic health services and related issues (Commonwealth Department of Health and Ageing 2005). Whilst these developments have been very significant within the Australian context, the issue of genetic discrimination has not been empirically investigated in Australia until recently (Taylor et al. 2004).

The potential for people to experience genetic discrimination therefore is now widely accepted within Australia and elsewhere (ALRC/AHEC 2003). Information about the risk of such discrimination for people on the basis of their family history information or genetic testing where undertaken is readily available through genetic support and information services in Australia (for example, Centre for Genetics Education (CGE) 2003) while clinical genetics services routinely incorporate discussion and advice about life insurance issues into pre-test counselling protocols (Human Genetics Society of Australasia (HGSA) 1999).

Genetic discrimination is a complex concept to investigate (Treloar et al. 2004). While Barash (2000) noted that genetic discrimination is a 'household word' within the United States due to

its potential for broad occurrence involving health insurance, in Australia and countries that have community-rather than individual-rated health care, it is a less familiar concept within the general community and therefore challenging to investigate empirically. The community-based rating of health insurance which is legislatively endorsed in Australia may also significantly reduce the scope for genetic discrimination to occur in this country when compared with others (Otlowski 2001). People's familiarity with the concept and its relevance to them can influence participation rates in community surveys; at the same time explicit use of the term 'genetic discrimination' within a research context can elicit response bias (Wertz 2002). Establishing the prevalence of genetic discrimination within any community is also potentially difficult as it requires a relevant and defined population from within which a proportion of cases of alleged discrimination can be identified (Treloar et al. 2004).

Finally a key feature of genetic discrimination is that it refers to differential treatment of a person who has no manifest symptoms of a condition or disorder and which has occurred allegedly on the basis of their genetic characteristics or makeup, either real or assumed. Determining that an individual is clinically free of any manifest expression of symptoms of a genetic disorder at the time of their alleged negative treatment is theoretically and practically difficult. Further, determining that an incident of alleged discriminatory treatment has been unequivocally based on a person's inherent *genetic* characteristics rather than any other factors is also difficult. In spite of these difficulties and because most accounts to date regarding genetic discrimination have been anecdotal, anonymous or case study reports, some commentators have questioned whether community concerns about genetic discrimination are based more on fear rather than reality (Nowlan 2003; Wertz 2002). Wertz (2002 p.496), for example, proposed that *fear* of discrimination, rather than being well-founded, may reflect "a 'genetic dread' that pervades society".

This paper presents selected findings from the Genetic Discrimination Project (GDP)², a comprehensive investigation of genetic discrimination in Australia that has been undertaken from 2002 to 2005 (Otlowski, Taylor & Barlow-Stewart 2002). The GDP was of triangulated design and comprised several sub-projects. The Consumer Study sub-project aimed to survey a targeted sample of asymptomatic clients of clinical genetics services regarding their attitudes and experiences of alleged genetic discrimination, to establish the prevalence of such discrimination within the sample, to describe the domains within which such incidents occurred and, where possible, to follow up and verify the extent to which such incidents could be said to constitute genetic discrimination. This paper reports selected survey findings and case studies from the Consumer Study which relate to respondent perceptions and experiences regarding coercion to undertake testing and insurance and employment issues. A forthcoming paper (Taylor et al., 2007, paper in review) describes the consumer survey methodology in detail including response bias information and presents other survey findings regarding participants' perceptions about benefits and disadvantages of having genetic information, the prevalence of specific incidents of alleged discrimination within the sample and the domains in which discrimination had allegedly occurred. Other GDP papers to date have reported on methodological challenges associated with investigating genetic discrimination (Treloar et al. 2004), the use of genetic test results in insurance underwriting in Australia for the period 1999-2003 (Otlowski et al. 2007a), the use of legal remedies for pursuing genetic discrimination in Australia (Otlowski et al. 2007b) and a comparison of attitudes about genetic issues between consumers in this study and the broader Australian community (Barlow-Stewart et al. 2005). Finally, other forthcoming papers will report on attitudes and experiences of Australian employers regarding genetic testing in the workplace and the verification of incidents of alleged genetic discrimination as reported by consumers.

Materials and Methods

A targeted postal survey was undertaken of eligible clients of 14 Australian clinical and research genetic services who agreed to participate in the study ^(Appendix A). Participating services were located in every Australian State and serviced both urban and rural communities. Ethical clearance was obtained from all relevant Human Research Ethics Committees (HRECs) with regard to the research.

The Sample

In keeping with the research focus on differential treatment that was allegedly based on an individual's genetic characteristics, participating services identified from their records *asymptomatic* adults aged 18 years and over who had requested, or inquired about, predictive genetic testing for a range of mature-onset genetic conditions, during the period January 1998 to December 2003. The genetic conditions included hereditary hemochromatosis; inherited predisposition to blood clots (hereditary thrombophilia); hereditary breast and ovarian cancers; hereditary bowel cancer (familial adenomatous polyposis (FAP) and hereditary non-polyposis colon cancer (HNPCC); familial melanoma; rare syndromes e.g. multiple endocrine neoplasia (MEN), Von Hippel-Lindau syndrome; neurodegenerative conditions (spino-cerebellar ataxia; Huntington disease; early onset Alzheimer disease; motor neurone disease; prion disease); familial hyper-cholesterolaemia; familial hypertrophic cardiomyopathy; hereditary hypertension; hereditary emphysema (e.g. α -1 antitrypsin deficiency); adult polycystic kidney disease and 'other'. Clinical services provided the research team with all mailed individuals' gender, relevant genetic condition and year of birth for later comparison between those mailed and those who responded to the survey.

Clinical services mailed all eligible individuals a research package that contained a cover letter about the research, a Participant Information Sheet, a questionnaire and a reply-paid envelope. Individuals received reminder packages approximately two weeks after initial mail out. Consent was implied by completion and return of questionnaires. Respondents could also volunteer their contact details on returned questionnaires for clarification of their survey responses and/or further follow-up.

Questionnaires were developed by preliminary interviews and focus groups with consumers, advice from the GDP's Expert Reference Group, and piloting. Explicit use of the term 'genetic discrimination' was avoided in the questionnaire so as to minimise bias (Geller et al. 2002; Treloar et al. 2004). The questionnaire comprised seven sections: genetic status and family history; genetic testing; perceptions and experiences regarding benefits and/or disadvantages associated with having genetic information; specific incidents of perceived disadvantage or unfair treatment; life insurance and employment information; attitudes towards genetic issues; and socio-demographic information. Respondents were asked to complete their questionnaires with regard to the genetic condition most relevant to them, which they specified from a list provided¹.

Where follow up contact details were provided by respondents, interviews were conducted by SDT as possible. The interviews varied in length from around 10 to 30 minutes and aimed to confirm and/or clarify respondents' written responses regarding their experiences and perceptions.

Data Analysis

Survey data were analysed using the Statistical Package for the Social Sciences (SPSS) Version 12.0 (SPSS Inc. 2004). Basic descriptive statistical analyses were undertaken,

including frequencies, cross-tabulations and categorical association testing which was based on Pearson chi-square testing; where cell counts were less than 5, cross tabulations were based on empirical p-values and exact tests.

Results

From 2667 eligible individuals who were mailed questionnaires, 1185 respondents returned fully or partially completed questionnaires. Respondents from every Australian State and Territory were represented in the survey. The survey response rate was 51% after 319 packages marked as 'return to sender' or reported inappropriate for inclusion in the study were deleted from the total responses.

In keeping with the research focus of the study, stringent criteria were applied to the respondent sample regarding asymptomatic status. Eighty percent, or 951/1185 respondents met these criteria regarding asymptomatic status at the time of questionnaire completion. Of these, 96% (916/951) nominated *one* genetic condition regarding which they had a family history, a known genetic risk or a genetic test result. The most frequently nominated genetic conditions were Huntington disease (33%; n = 301), hereditary breast or ovarian cancer (31%; n = 280), hereditary bowel cancer (21%; n = 185) and hemochromatosis (5%; n = 45). For purposes of analysis, genetic conditions of relevance were organised into four groups: Group 1 neurodegenerative conditions (37%; n = 332), Group 2 familial cancers (53%; n = 481), Group 3 hemochromatosis (5%; n = 45) and Group 4 'other' genetic conditions (5%; n=46). Group 4 comprised a range of conditions that were substantively different in their characteristics, as a result of which results were often difficult to interpret; Group 4 results are therefore reported less frequently than results for other groups.

Characteristics of the Sample

The average age of respondents was 46 years, with 69% (n = 656) being female and 77% (n = 727) being married or partnered. Australia was the place of birth for 87% (n = 828) of respondents and 14 individuals (1.5%) identified as being of Aboriginal or Torres Strait Islander descent. Overall the sample was characterised by relatively high educational levels with almost half having diploma, bachelor or postgraduate qualifications. Almost two thirds of respondents reported that they were working full time at the time of the survey. At the time of the survey, 69% respondents held private health insurance and 41% held life insurance cover, compared with 49% and 33% respectively of the Australian population (Australian Institute of Health and Welfare (AIHW) 2004; Investment and Financial Services Association (IFSA) 2002).

Ninety-five percent of survey respondents who answered the question regarding genetic testing (n = 729) reported having had a predictive genetic test³, with 2001 being the median year of testing. Thirty nine percent of respondents overall (n = 286) reported having received a positive test result, that is, a test result confirming the presence of the genetic mutation associated with the relevant genetic condition or disorder in their family; 55% (n = 399) reported having received a negative test result, that is, a test result confirming that the relevant mutation was not present; and 6% (n = 44) reported not having been tested or not having received their test result at the time of the survey. Figure 1 indicates the percentages of negative and positive test results for respondents according to genetic condition groupings of relevance. The high proportion of test-positive respondents in relation to hemochromatosis was likely to be associated with recruitment from specialist a clinical research collection rather than a general clinical genetics service.

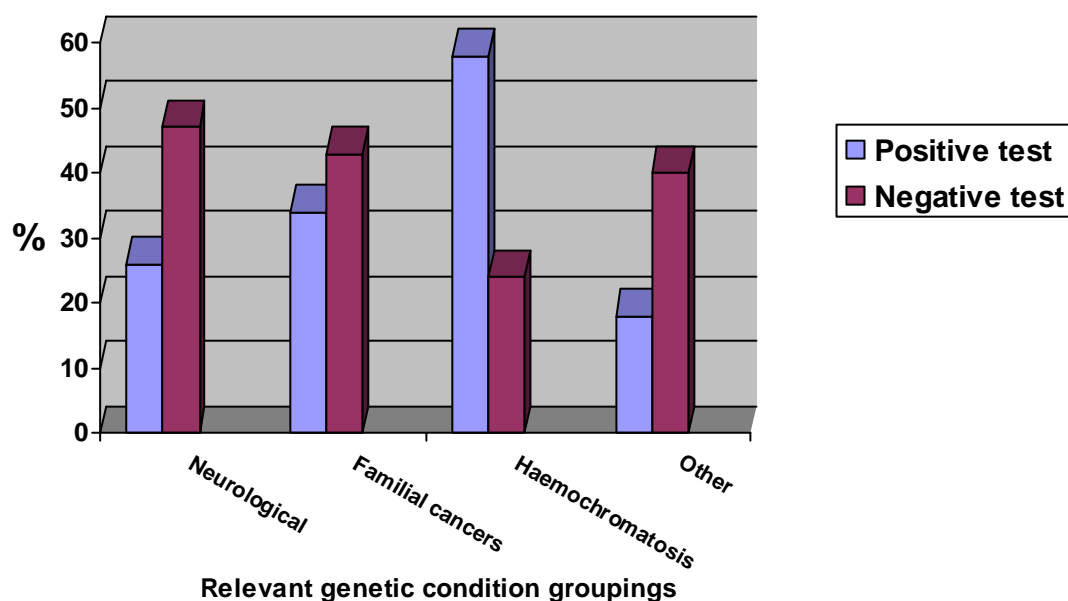


Figure 1. Percentage of positive and negative genetic test results for respondents according to genetic condition groupings of relevance

Perceived or Experienced Coercion to Undertake Genetic Testing

Most respondents reported feeling no coercion or pressure to undertake a genetic test from the range of potential sources provided. Where reported, sources most frequently nominated from a given list were family members, doctors, geneticists/counsellors, life insurance companies and researchers; Table 1 provides further details. Genetic test result was not significantly associated with reporting of coercion.

Table 1. Reported sources and amount of experienced coercion or pressure to undertake genetic testing.

Source of felt coercion	None		Some		A Lot		Total
	N	%	N	%	N	%	
Family member	489	68	174	24	57	8	720
Doctor	615	88	68	10	12	2	695
Geneticist/counselor	622	89	65	10	9	1	696
Insurance company	630	96	16	2	11	2	657
Employer	649	99	7	1	2	0	658
Bank/financial lender	653	99	4	1	2	0	659
Researcher	637	96	23	4	3	0	663
Other	537	96	13	3	7	1	557

The most frequently nominated 'other source' of coercion was 'self' (n=13), with respondents' attached comments describing a sense of responsibility to undertake testing in order to clarify the genetic risks of significant others such as their children. There were no significant differences in experiences of coercion ('none', 'some', 'a lot') across the four groups for any sources apart from insurance companies ($\chi^2_6 = 24.8$, $P < .001$) where higher than expected levels of coercion were reported by respondents for whom neurological conditions (Group 1, ND) were relevant. In this case, 22/27 (82%) of respondents who reported feeling 'some' or 'a lot' of coercion were in Group 1 (ND), four were in Group 2 (familial cancers) and one was in Group 3 (hemochromatosis).

Table 2 presents selected examples of interviewed cases reflecting perceptions and experiences in regard to coercion. Details of three respondents who had undergone presymptomatic testing for Huntington disease and who received a negative test result are provided.

Table 2. Perceived or experienced coercion to undertake genetic testing.

Personal Information	Description of Experience	Reported Impact
Huntington disease		
Case A. Male aged 46 years. No past or present health problems. Negative gene test.	Applications for income protection insurance accepted with restrictions prior to negative test result. Required insurance as a business owner. Able to get insurance at standard rate after negative test result was sent to insurer.	Felt coercion to have testing in order to secure insurance.
Case B. Male aged 32 years. No past or present health problems. Negative gene test.	Respondent had superannuation but required income protection insurance. Application was accepted with significant loading prior to negative test result. Other companies had declined. Required insurance due to type of employment. Able to get insurance at standard rate only after his negative genetic test result was sent to insurer.	Financial planner recommended the man undertake testing due to loading.
Case C. Male aged 54 years. Negative gene test.	Respondent applied for life insurance as he established his own business after arriving in Australia. Insurer rang him to advise that he would have to be tested for HD (and demonstrate a gene negative result) if he wanted the insurance. Respondent thinking already of undertaking testing so as to be able to inform his children of their risk.	Respondent reported coercion by insurer to undertake testing but also acknowledged family reasons for testing.

Insurance

Given its significance within the genetic discrimination context, one section of the questionnaire asked about respondent perceptions and experiences regarding life insurance. At the time of the survey, the types of insurance products held by respondents related to private health cover (69%), death (41%), accidental death (32%), mortgage (29%) and disability/income protection (24%). Significantly more than expected male respondents and fewer than expected females held life insurance ($\chi^2_1 = 4.4$, $P < .05$), disability/income protection insurance ($\chi^2_1 = 15.6$, $P < .001$) and accidental death insurance ($\chi^2_1 = 5.0$, $P < .05$) at the time of the survey.

Respondents were asked about the importance of life insurance given their family history or genetic test information. On a scale from zero (very unimportant) to ten (very important), the median score of (720/951) respondents was seven. Of 668 respondents who perceived a need for life insurance in light of their family history or genetic test information, 79% (n=529) reported needing the same amount of insurance as they otherwise would have, 3% (n=17) needed less and 18% (n=121) needed more. Regarding the purchase of insurance products, 94% (650/695) reported not purchasing more insurance than they would otherwise have, 6% (40/711) reported purchasing more and 1% (7/711) indicated they did not know. Three percent of question respondents (24/709) reported feeling the need to make multiple simultaneous applications in case of refusal. Two percent of question respondents reported that relatives had withheld family history information from them (13/711) and that they had withheld risk information from relatives (11/711), respectively, because of insurance concerns.

Of 182 respondents who reported applying for life insurance products with knowledge of their level of risk, 146 respondents reported they were offered standard cover in all applications and 18 in some applications. Thirty-nine respondents reported being refused cover for one or more life insurance products, involving mostly death cover and income protection insurance (where specified). Types of non-standard cover, most frequently relating to life insurance and income protection, involved higher premiums (n=28), limited cover (n=17) and limited term cover (n=8). Type of cover offered did not differ significantly across the four groups or according to whether respondents were mutation positive or negative at the time of survey; respondents were also describing insurance cover that had been set in place prior to testing and therefore according to family history. Where reported, communication to respondents about non-standard cover was done verbally (31/61), in writing (19/73), directly from the company (23/69) or through an agent or broker (37/55). Twelve respondents reported having been asked to undertake predictive testing by a life insurance company, agent or broker, but there were no apparent differences between groups.

Thirteen percent of question respondents reported 'avoiding' (92/710) or 'giving up' (93/711) applying for insurance because of fears of disclosing family risk information; 9% (62/713) had been advised not to bother applying because of the genetic condition in their family or their risk. When asked who had advised them, life insurance companies, agents or brokers (n=29); family members (n=16); genetic clinical advisors (n=7); friends (n=3); medical practitioners (n=1) and an accountant (n=1) were nominated. Group 1 (ND) respondents were significantly more likely, and Group 2 (FC) or 3 (HH) respondents less likely, to report avoiding applying for insurance ($\chi^2 = 12.1$, $P < .01$), 'giving up' before applying ($\chi^2 = 13.1$, $P < .01$) and being advised 'not to bother' applying for insurance ($\chi^2 = 19.7$, $P < .001$). Seven percent of question respondents (47/703) had postponed testing in order to put desired life insurance into place first; where nominated, sources of advice to postpone were clinical genetics advisors (n=11), themselves i.e. it was a personal decision (n=9), family members (n=5) and medical practitioners (n=2).

Several respondents provided accounts of their experiences regarding life insurance at follow up interview. Table 3 presents details of five cases involving genetic testing for the mutations(s) causing predisposition to bowel and several other cancers (HNPCC), breast and ovarian cancer and Huntington disease. With regard to the health insurance issue reported by Case A, health insurance is community-rated in Australia although waiting periods can be applied by insurers in regard to particular pre-existing illnesses.

Table 3. Insurance issues

Personal Information	Description of Experience	Reported Impact
Hereditary non-polyposis colorectal cancer (HNPCC)		
<p>Case D. Female aged 40 years. No past or present health problems. Positive gene test HNPCC</p>	<p>Respondent held trauma and income protection insurance with insurance company linked to employer's superannuation policy. Respondent took voluntary redundancy (un-related to genetic test result) but felt forced to stay with insurance company linked to previous employer although this was not financially optimal for her. Respondent did not want to reveal her genetic test information to a new insurer. In addition, when respondent applied for private health insurance, she was advised she would have a 12 month wait for coverage because of her 'pre-existing condition'. Respondent sought advice from staff of genetics service who successfully advocated on her behalf; they argued that a positive genetic test result did not equate with having familial cancer.</p>	<p>Respondent having regular bowel screening but anxious about future coverage by health insurer. She perceives she was limited in her choice of insurer which had financial implications.</p>
<p>Case E. Male aged 28 years. No past or present health problems. Positive gene test HNPCC</p>	<p>Respondent applied after testing through a broker for life insurance (death cover) and trauma insurance. Respondent declared family history and test result honestly and also noted he was having regular screening. He was offered death cover but denied trauma insurance.</p>	<p>Self-employed; newly married and birth of first child occurred recently. Respondent was greatly concerned about providing for his family's financial future.</p>
Huntington disease		
<p>Case F. Female aged 36 years. Tested for HD; waiting for result</p>	<p>Respondent contacted broker to inquire about applying for life insurance; disclosed family history of mother's recent HD diagnosis. Mother had long-standing diagnosis of schizophrenia and respondent had believed until recently that she was at risk of mental illness. Aunt had suicided but now believed to have had HD. Broker was unable to secure insurance and advised the respondent and her husband that it would be very difficult to secure insurance or to make any claim even if she was successful in gaining insurance. Respondent did not proceed with any applications.</p>	<p>Respondent reported feeling 'very powerless and disheartened'; still in shock at being at risk for HD. Described the insurance experience as being the first indication that "life had changed, I am in a new space, I am vulnerable and discrimination is possible".</p>
<p>Case G. Female aged 51 years. Intermediate range test result for HD⁵</p>	<p>Respondent undertook presymptomatic testing for HD and received an 'intermediate' test result⁵. She requested of her broker if she could apply for an increase in her life insurance policy. Broker said that he was aware of genetic conditions as he also had a family history of a genetic condition (not for HD) and advised her not to apply. Respondent understood that she was never likely to develop HD herself but did not challenge the broker's advice. Respondent reported that her sister will not be tested because of insurance concerns and in order to protect her (sister's) son, his privacy and his right to access insurance.</p>	<p>Respondent accepted broker's advice although she knew her situation was 'more complicated than normal for Huntington's disease'.</p>
Breast and ovarian cancer (BRCA1)		
<p>Case H. Female aged 47 years. Tested positive for BRCA1 gene</p>	<p>Respondent had had life insurance for >10 years. She had purchased insurance policy in light of family history of breast cancer. She and husband had 4 children. Respondent regarded her insurance policy as 'my gift to them if I died'. Respondent was subsequently tested and found to be positive for BRCA1 mutation. Later respondent lost her job in rural recession and could not afford to make premium payment on time; 10 days overdue. Insurer advised her that policy was cancelled. She and husband challenged the decision but insurer advised that although they would have liked to reinstate her policy they could not in light of new information regarding genetic test result and she must re-apply. Respondent's re-application for insurance was rejected.</p>	<p>Respondent described the impact of this insurance experience as being significant: "I was angry and totally devastated".</p>

Employment

Regarding employment, less than one third (n=135, 31%) of respondents to whom it applied reported that their employers were aware of their family history of the relevant genetic conditions or of their genetic risk in relation to such conditions. Few employers (n=12) or potential employers (n=9) had ever asked for such information. Of those who had asked for such information, three respondents nominated the Australian Defence Forces, one nominated both the Police Force and a medical practice, and three nominated pre-employment medical assessments without specification.

Several respondents described the consequences for them of employers knowing details of their genetic status including situations where sympathetic employers approved respondents' requests to rearrange work schedules in order to undertake testing. Some respondents also described difficulties they had encountered in the employment area. Table 4 presents details of two cases which were related to Huntington disease testing.

Table 4. Employment issues

Personal Information	Description of Experience	Reported Impact
Huntington disease		
Case I. Female aged 44 years. No symptoms. Negative gene test HD.	Family history of HD and new diagnosis in family led to respondent seeking a predictive test. She was employed in service industry with significant responsibilities. When respondent 'innocently' requested time off for an appointment for the genetic test, employer immediately advised her to "step down and take time off" until the result was known. Employer also expressed concern about their own liability regarding employee's continued performance in the public arena even though test result was unknown. Employer also requested the test result which respondent provided when her gene negative result became available.	Respondent believed that as soon as her employer and co-workers knew she was undertaking a genetic test for HD, they assumed she had the condition and responded to her very differently than before they had this information, for example, constant surveillance and increased supervision of her work. Respondent was sole bread-winner for her family at the time. She found the genetic testing stressful and was simultaneously dealing with the implied threat of losing her employment; this had a significant negative impact on her and family. Respondent challenged the negative treatment however and reported that this resulted in greater education of her employer and co-workers re genetic issues.
Case J. Female aged 45 years. Currently well and self-employed. Positive gene test HD.	Termination of employment three months after disclosure of the test result to employer with rationale that the company was being restructured. Termination settlement was made with a non-disclosure clause. The respondent later learnt that the employer had informed colleagues that she had resigned due to a serious illness.	Participant's reaction to the test result led to short term depression. Privacy and loss of employment due to misunderstanding of meaning of test result.

Concerns about Life Insurance and Employment

Respondents were asked if any concerns they had regarding the use of genetic information by third parties related more to employment, life insurance, both equally, neither or they could stipulate other concerns. Five percent nominated employment alone, 20% nominated insurance alone, 49% said they were equally important and 22% nominated neither as being important. Three percent nominated other concerns relating to privacy, confidentiality or personal ownership of genetic information (n=12); the need for family members to be aware (n=3); human rights (n=2); and discrimination (n=2).

Discussion

The Genetic Discrimination Project is the first comprehensive research program of its kind to be conducted in Australia. While concerns about, and accounts of alleged genetic discrimination have been reported in the Australian context, (ALRC/AHEC 2003; Barlow-Stewart and Keays 2001; Otlowski 2002, 2001; Taylor 1998), there has been no comprehensive empirical research to date regarding the issue or its prevalence in Australia. While the Consumer sub-project of the GDP investigated clinical genetics services clients' perceptions and experiences regarding various aspects of genetic discrimination, this paper reports perceptions and experiences regarding coercion to undertake predictive genetic testing and insurance and employment-related issues.

The 51% response rate was comparable to other mail-based surveys in Australia (Brown et al. 2004; Sale et al. 2004; Steginga et al. 2001) and to a large UK study undertaken by Low and colleagues (1998) regarding genetic discrimination in life insurance. Greater participation by women in our survey (69% of the sample) is consistent not only with social science research generally (Broom 2002) but with genetics-related activity where Richards notes (1996 p. 258) '[I]n almost all aspects of genetics activity, it is the female members of a family who most often take the initiating role'. Richards (1996) describes women as most likely to adopt roles of 'genetic housekeepers' and 'kin-keepers' within families. Uptake of genetic testing for some conditions like mature-onset neurological conditions, carrier testing for cystic fibrosis and susceptibility testing for inherited cancer syndromes appears also to be at differentially greater rates by at-risk women compared with their male counterparts (Taylor 2005). The relatively higher educational level of respondents is also consistent with findings of some studies relating to utilisation of genetic testing by people where HD is relevant (Meiser & Dunn 2000).

Within our study, respondents overall reported no or little coercion to undertake predictive testing. Our sample comprised mainly individuals who undertook predictive testing however and their reported experiences of coercion may differ from people who chose not to undertake testing. Where reported, experiences of coercion included those where respondents believed external pressure had been applied to them to undertake predictive testing as well as those that reflected subjective feelings to undertake testing because of its availability or for other reasons (Geller et al. 2002; Petersen & Bunton 2002; Taylor 2004). Within family and healthcare contexts, individuals have reported a sense of coercion to undertake testing associated with their sense of responsibility and altruistic desire to help relatives like offspring determine *their* risks (Chapman 2002; Hallowell 1999; Taylor 2004) and to help others by participating in genetic research (Treloar et al. 2007). In our study, the most common sources of coercion where cited were family, doctors and geneticists/counsellors; this differed from the frequently expressed concern that third parties like life insurers or employers are most likely to be coercive (Otlowski 2005). The potential complexity and challenge for people in terms of family dynamics and relationships where

highly relevant genetic information is shared and where genetic test decisions and results can significantly impact on close others has been widely discussed (Chapman 2002; Chapman & Burn 1999; Cox & McKellin 1999; Geller et al. 2002; Hallowell 1999; Richards 1996; Taylor 2004). How this might translate into experiences of coercion within the family context is largely under researched but respondents in our study certainly reported incidents of differential treatment and coercion within family contexts. How individuals and family members are managing and negotiating these challenges within the context of their shared genetic legacies and the family context merits further investigation.

Clinical geneticists and counsellors were also a source of coercion reported by respondents in our study. Geller et al (2002) described instances where clinical professionals pressured people to undertake prenatal testing or advised them not to have children; similar incidents were reported in our study and were experienced as both highly coercive and distressing (Taylor et al. 2007, manuscript in review). The expression of such imperatives by well-respected authority figures like clinical or medical professionals can represent and reinforce the social stigma that is experienced by many families with genetic conditions like HD (Cox & McKellin 1999; Taylor 2004). The potential for genetics clinicians to be 'directive' in their counselling and information-giving has also been widely discussed in the literature (Marteau & Richards 1996; Petersen & Bunton 2002). Where familial cancers are relevant, clinically-based discussions about causative mutations in families and genetic testing may be more likely to occur in a shared family-based context (Chapman & Burn 1999; Haan 2003) compared with those regarding predictive testing for neurological conditions like HD where the focus may be more individualised and 'private' and primarily involve just the individual seeking testing plus a support person. The potential for differential treatment or discrimination exists for positive-testing individuals in relation to both types of conditions however (Bombard et al. 2007; Lynch et al. 2003; Markman 2004; Peterson et al. 2002). Whether some individuals could experience testing within the familial cancer context as potentially coercive due to authoritative clinical input or simply out of a sense of responsibility to family in that context is unknown. However, the principle of non-coercion remains central to best clinical genetics practice as does the responsibility of the clinician to ensure that the client's decision to undertake predictive genetic testing for any disorder is underpinned by fully autonomous and well-informed consent (Haan 2003).

While survey respondents also reported a relatively small amount of coercion in the insurance context, such experiences varied across groups. The significantly greater degree of insurer-based coercion that was reported by people where neurological conditions, mostly HD, were relevant is likely to reflect the historical position and long-standing experiences of such individuals regarding difficulty accessing life insurance products in Australia. Unlike people for whom conditions like familial cancers or hemochromatosis are relevant, individuals where HD is relevant have historically been denied access to life insurance products altogether in Australia, have had significant loadings imposed or been denied insurance even with exclusions (Otlowski et al. 2007a). Such underwriting decisions by life insurers appear legal at face value within the current context, based on an exemption granted to them under the *Disability Discrimination Act (1992)* (Ch) and provided such decisions can be substantiated actuarially. The actuarial justification in regard to the single-gene, highly penetrant mutation for Huntington disease has generally been regarded as conclusive therefore (Otlowski et al. 2007a; Otlowski 2005) although assumptions about the lack of variability in HD for insurance-related underwriting have been challenged in recent times (Gutiérrez & MacDonald 2004; Otlowski et al. 2007a). The approach taken by the Australian life insurance sector is not the same for example as that in the United Kingdom where a positive test result or family history regarding HD does not necessarily result in the

outright denial of the life insurance application or the imposition of loadings or penalties. However, recommendations from the recent ALRC/AHEC Inquiry into the Protection of Human Genetic Information in Australia (ALRC/AHEC 2003) have included the need for insurers within the Australian context to improve their policies, practices and communications with consumers regarding insurance underwriting that utilises genetic information.

People with family histories or positive genetic test information regarding HD have experienced insurance-related difficulties for over two decades in Australia as predictive genetic testing for HD, with its associated insurance implications, was the earliest predictive test for a mature-onset disorder to be offered in this country⁴ (Taylor 1994; Turner et al. 1988). The challenges associated with accessing life insurance products for these individuals and families have therefore been cumulative over many years and have typically involved multiple family members and relatives. For such individuals, life insurance has realistically only been accessible to those who have agreed to undertake testing and have been subsequently able to demonstrate a negative genetic test result to their insurer; those receiving a positive test result however become virtually uninsurable within the current Australian context. The cumulative experiences of families whose 'uninsurable' status is legally and socially affirmed through sanctioned insurance exemptions within anti-discrimination legislation can reinforce the social stigma associated with such conditions. Under all of these circumstances, it may not be surprising that survey respondents where HD was relevant described feelings of 'coercion' associated with undertaking testing within the insurance context. Such a sense of coercion to test may be particularly pertinent where life insurance products are needed by people for purposes of business, self-employment or financial or mortgage borrowing.

Although the nature of insurance-related experiences as reported by people for whom HD is a relevant genetic condition appeared to differ from other respondents, insurance was rated as an important issue by most respondents in the survey. As noted, unlike the United States, health insurance in Australia with regard to both the universal Medicare system and private health insurance, is community- rather than individually-rated and thus information about family history or genetic test information, as with all medical information, is not assessable for purposes of accessing either public or private health care services. Community-rated health insurance in Australia is also likely to significantly reduce the potential for genetic discrimination to occur in this country as health insurance has been a primary site for such discrimination in the United States (Otlowski et al. 2002).

Given that gender has been shown to influence uptake of life insurance and associated products (Gandolfi & Miners 1996), reported uptake of life insurance, as well as the reporting of insurance-related concerns, may have been greater had there been more male survey respondents. The discrepancy between respondent and population rates in regard to life insurance could reflect either the increased importance of insurance to respondents or 'adverse selection' where individuals with genetic information that is unavailable to insurers seek large amounts of life insurance (Otlowski et al. 2002). The potential for adverse selection to occur has been an issue of concern to life insurers. Respondents reported declaring their genetic risks honestly within the life insurance context however and almost all reported that they had not purchased more insurance products than they would otherwise have, given their family history or genetic test information; Zick et al (2000) found similarly. Several respondents reported that, on the advice of clinicians, they had organised life insurance prior to undertaking predictive testing or had submitted insurance applications simultaneously to maximise chances of success; Bombard et al. (2007) and Geller et al (1996) reported similarly. These options are consistent with current clinical policy and

practice guidelines in Australia and do not contravene applicants' disclosure obligations to insurers provided relevant family history is disclosed (Centre for Genetics Education, 2003; Human Genetics Society of Australasia 1999).

Some respondents, most likely those where neurological conditions like HD were relevant, also reported avoiding, giving up or being advised not to apply for life insurance, based on their or others' beliefs that their applications would be unsuccessful. Similar strategies and self-protective behaviours used by people in order to pre-empt the risk that they will be differentially treated and/or to protect themselves from such risks have been reported in other studies (Bombard et al. 2007; Geller et al., 1996; Hall et al., 2005; Low et al., 1998). These experiences were reported by several respondents at interview as having significant impact or implications for them. Inexperienced individuals, advised by insurers, agents and brokers that their insurance applications will not succeed, and also likely to be aware that other family members have been unable to access insurance as in the case of HD, are unlikely to contest the advice. Low et al. (1998) questioned how well life insurance personnel like sales agents or brokers are informed about human genetics to be in a position to provide such preliminary risk assessments for potential life insurance applicants. Some respondents in our survey reported being advised at first point of inquiry by brokers and agents, as well as by insurers *per se*, that their applications would not succeed, resulting in an elimination of their applications prior to formal risk assessment. Life insurance under-writing decisions in applications involving genetic factors can vary across companies, even where the same genetic condition is relevant (Otlowski et al. 2007a; Gutiérrez & MacDonald 2004). Recently in Australia for example, some life insurers appear willing to be more flexible in their underwriting in regard to conditions like HD than has traditionally been done (Otlowski et al. 2007a). The practices of front-line advisors in the life insurance sector where genetic factors appear relevant to applications seem worthy of attention. The elimination of insurance applications before they have been properly assessed, coupled with consumers who may be self-selecting out of insurance for self-protection and fear of negative treatment, are all likely to be impacting on life insurance sector reports in Australia that small numbers only of insurance applications have been unsuccessful because of genetic risk factors (Otlowski et al. 2007a).

As noted above, the recent ALRC/AHEC Inquiry into the Protection of Human Genetic Information in Australia (ALRC/AHEC 2003) has resulted in recommendations to Australian life insurers to improve their policies, practices and communications with consumers regarding insurance underwriting that utilises genetic information. All consumers are entitled to submit applications for life insurance products, to have them assessed accurately and to be advised of the reasons for special conditions or denial of insurance as well as their right to appeal such decisions. The potential support of clinical genetics specialists in support of life insurance applications where genetic factors are involved is also worthy of widespread promotion to the general community, the clinical genetics community and through networks of genetic support groups (Otlowski et al. 2007a).

Regarding employment, also a central issue when analysing genetic discrimination (ALRC/AHEC 2003; Geller et al. 1996; Knoppers et al. 2004; Low et al. 1998; Otlowski et al. 2002), a small number only of respondents reported that employers or potential employers had requested genetic information or that it was required in pre-employment medical assessments; where mentioned, public rather than private sector employers were nominated. The benefits for several respondents of employers knowing genetic information were also noted. The lack of employers' use of genetic information reported in the survey concurs with findings from the recent national inquiry (ALRC/AHEC 2003) which concluded that Australian

employers were not seeking, or using, genetic information for employment-related purposes on any large scale, in spite of it being currently not illegal for them to do so. However several respondents did report accounts of employment-related experiences at follow up interview. The ALRC/AHEC (2003) has recommended that employers should not be permitted to collect or use genetic information regarding workers or potential workers except where it specifically relates to health and safety). Survey respondents also expressed equal concern about both employers and insurers having legally-sanctioned access to genetic information; such attitudes are consistent with those of the broader Australian community (Barlow-Stewart et al. 2005).

It should be noted that there were several limitations in our study. Findings are based on cross-sectional data and self-reported perceptions and experiences relating to a specified time period, that is pre-2003 Australian context. The asymptomatic status of respondents was not able to be independently verified although the sample was based on most recent clinical assessment of asymptomatic status by genetics clinicians and rigorous exclusion criteria were applied to the data prior to its analysis. Sampling through clinical genetics services in Australia is likely to have resulted in respondents who were positively oriented towards predictive genetic testing and who had other characteristics that are unlikely to be representative of the broader at risk populations. The survey questionnaire was also quite complex and there was some evidence that non-specific wording and use of the term 'risk' may have resulted in individuals with negative test results self-selecting out of the study or a section of the questionnaire because they erroneously believed it did not apply to them. Finally, while the term 'genetic discrimination' was not explicitly used in the questionnaire in order to minimise bias, its inclusion in the approach letter and information sheet might have had an unknown effect on response.

Conclusion

The perceptions and experiences of Australian consumers constitute a significant perspective regarding the complex phenomenon of genetic discrimination or negative treatment based on genetic information acquired from family history or genetic testing. The full public and preventive health benefits associated with the increasing availability of genetic testing will not be fully realised unless individuals can freely engage with genetic testing without fear of negative treatment as a result of it. Individuals and families are now reporting experiences of both coercion and negative treatment and are developing strategies to minimise or pre-empt anticipated occurrences. Coercion to undertake testing can occur subtly within a range of contexts including family, health, clinical genetics, and insurance and employment contexts. The potential impact on individuals and families of coercion as well as post-test negative treatment is substantial. It is imperative that the community and all relevant sectors be informed about these issues, that individuals are not openly or covertly coerced into undertaking genetic testing and that the potential for negative treatment in contexts like insurance and employment is monitored and pro-actively addressed.

Endnotes

¹ For detailed information about genetic conditions, modes of inheritance, treatment and genetic testing, see the website of The Centre for Genetics Education: <http://www.genetics.com.au>

² GDP website www.gdproject.org

³ Missing data were high on this question because some respondents, mostly those with a negative test result, may have misinterpreted an instruction in this section of the questionnaire and mistakenly skipped several questions

⁴ Predictive testing for Huntington disease was first offered in Australia in the mid 1980s, significantly earlier than for many other conditions regarding which testing has more recently become available

⁵ A small percentage of test results for Huntington Disease cannot be interpreted with certainty; such test results are described as being in the 'intermediate' range rather than represent a definitive result. Individuals receiving intermediate test results are unlikely to ever develop symptoms of HD themselves but their children may face an increased risk (Langbehn et al. 2004).

Acknowledgements

Financial support for this work has come from the Australian Research Council #DP0208853. Sincere thanks goes to all members of the Expert Reference Group that advised the researchers, as well as to all those individuals who participated in the study. Ms. Kellie Chenoweth and Ms. Bree Ryan provided valuable research assistance to the project. We also thank Meg Tighe and Warren Laffan of the University of Queensland's Social Research Centre for advice and assistance in the conduct of the survey and data entry and management. In addition, we acknowledge the following staff within clinical genetics services around Australia who facilitated the distribution of the questionnaire to eligible clients: Associate Professor John MacMillan at Queensland Clinical Genetics Service and Professor Lawrie Powell and Sr Jeannette Dixon at Queensland Institute of Medical Research, in Queensland; Dr Meredith Wilson and Ms Fiona Richards at The Department of Clinical Genetics at The Children's Hospital at Westmead, Associate Professor Judy Kirk and Ms Anna Silvester at The Familial Cancer Service at Westmead Hospital, Dr Anne Turner at The Dept of Medical Genetics at the Sydney Children Hospital, Sydney and Dr Matthew Edwards, Ms Sarah Bennett and colleagues at Hunter Genetics in Newcastle, in New South Wales; Dr Martin Delatycki and Ms Roslyn Tassicker at Genetic Health Services Victoria at the Royal Children's Hospital Melbourne and Associate Professor Geoffrey Lindeman, Dr Clara Gaff and colleagues at The Familial Cancer Centre, and Professor Finlay Macrae at Colorectal Medicine & Genetics at the Royal Melbourne Hospital, in Victoria; Associate Professor Eric Haan and Ms Janet Goldstone at The South Australian Clinical Genetics Services and Dr Graeme Suthers at The Familial Cancers Unit at the South Australian Clinical Genetics Services, in South Australia; Dr Carmela Connor and Ms Kate Frenchman at The Neurosciences Unit at Graylands Hospital and Dr Jack Goldblatt, Ms Karen Harrop, Ms Julia Mansour and colleagues at The Genetic Services of Western Australia, in Western Australia; and Dr David Amor and Dr Jo Burke at The Tasmanian Clinical Genetics Service at the Royal Hobart Hospital and Dr Kurt Fisher and Ms Pam Marshall at The Department of Psychiatry, Launceston General Hospital, in Tasmania.

References

- AIHW (Australian Institute of Health and Welfare) (2004) 'Australia's Health 2004' <http://www.aihw.gov.au> Accessed July 2005.
- ALRC/AHEC (Australian Law Reform Commission & Australian Health Ethics Committee of the National Health & Medical Research Council NHMRC) (2003) *Essentially Yours: The Protection of Human Genetic Information in Australia*, Sydney: Commonwealth of Australia.
- Barash, C.A. (2000) 'Genetic Screening for Hemochromatosis: Then and Now' *Genetic Testing*, Vol. 4, No.2: pp. 213-218.
- Barlow-Stewart, K.K., Taylor, S.D. & Otlowski, M.F. (2005) 'Knowing your genes: freedom, burden or power?' in Wilson, S., Meagher, G., Gibson, R., Denmark, D. & Western, M. (eds) *Australian Social Attitudes: The First Report*, Sydney, UNSW Press.
- Barlow-Stewart, K. & Keays, D. (2001) 'Genetic discrimination in Australia' *Journal of Law & Medicine*, Vol. 8, pp. 250-262.
- Billings, P.M., Kohn, M., de Cuevas, J., Beckwith, J., Alper, J.S. & Natowicz, M.R. (1992) 'Discrimination as a Consequence of Genetic Testing' *American Journal of Human Genetics*, Vol. 50, pp. 476.
- Bombard, Y., Pensiner, E., Decolongon, J., Klimek, M.L.M., Creighton, S., Suchowersky, O., Guttman, M., Paulsen, J.S., Botorff, J.L. & Hayden, M.R. (2007) 'Managing genetic discrimination: Strategies used by individuals found to have the Huntington disease mutation' *Clinical Genetics*, Vol. 71, pp. 220-231.
- Broom, D. (2002) 'Gender and health' In: Germov, J. (ed) *Second Opinion: An Introduction to Health Sociology* Melbourne: Oxford, pp. 95-111.
- Brown, S., Bruinsma, F., Darcy, M.A., Small, R. & Lumley, J. (2004) 'Early discharge: no evidence of adverse outcomes in three consecutive population-based Australian surveys of recent mothers, conducted in 1989, 1994 and 2000' *Paediatric and Perinatal Epidemiology*, Vol. 18, pp. 202-213.
- CGE (Centre for Genetics Education) (2003) 'Genetic Information and Life Insurance Products in Australia' <http://www.genetics.com.au/pdf/pubs/lifeinsurance.pdf> Site accessed March 2007
- Chapman, E. (2002) 'Ethical Dilemmas in Testing for Late Onset Conditions: Reactions to Testing and Perceived Impact on Other Family Members' *Journal of Genetic Counseling*, Vol. 11, pp. 351-367.
- Chapman, P.D. & Burn, J. (1999) 'Genetic predictive testing for bowel cancer predisposition: The impact on the individual' *Cytogenetics and Cell Genetics*, Vol. 86, No. 2, pp. 118-124.
- Commonwealth Department of Health & Ageing (2005) 'Establishment of a human genetics advisory committee' <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact6.htm> Date accessed May 26, 2005
- Cox, S.M. & McKellin, W. (1999) "'There's this thing in our family'": predictive testing and the construction of risk for Huntington Disease' *Sociology of Health and Illness*, Vol. 21, No. 5, pp. 622-646.

- Gandolfi, A.S. & Miners, L. (1996) 'Gender-Based Differences in Life Insurance Ownership' *Journal of Risk and Insurance*, Vol. 63, No. 4, pp. 683-693.
- Geller, L.N. (2002) 'Current developments in genetic discrimination', in Alper, J.S., Ard, C., Asch, A., Beckwith, J., Conrad, P. & Geller, L. (eds) *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society* Baltimore: John Hopkins University Press, pp. 267-285.
- Geller, L.N., Alper, J.S., Billings, P.R., Barash, C.I., Beckwith, J. & Natowicz, M.R. (2002) 'Individual, family, and societal dimensions of genetic discrimination: a case study analysis', in Alper, J.S., Ard, C., Asch, A., Beckwith, J., Conrad, P. & Geller, L. (eds) *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society* Baltimore: John Hopkins University Press, pp. 245-266.
- Geller, L.N., Alper, J.S., Billings, P.R., Barash, C.I., Beckwith, J. & Natowicz, M.R. (1996) 'Individual, family, and societal dimensions of genetic discrimination: a case study analysis' *Science and Engineering Ethics*, Vol. 2, pp. 71-88.
- Gutiérrez, C. & MacDonald, A. (2004) 'Huntington's Disease, Critical illness insurance and life insurance' *Scandinavian Actuarial Journal*, Vol. 4, pp. 279-313.
- Haan, E.A. (2003) 'The clinical geneticist and the "new genetics"' *Medical Journal of Australia*, Vol. 178, No. 9, pp. 458-462.
- Hall, M.A., McEwen, J.E., Barton, J.C., Walker, A.P., Howe, E.G., Reiss, J.A., Power, T.E., Ellis, S.D., Tucker, D.C., Harrison, B.W., McLaren, G.D., Ruggiero, A. & Thomson, E.J. (2005) 'Concerns in a primary care population about genetic discrimination by insurers' *Genetics in Medicine*, Vol. 7, No. 5, pp. 311-316.
- Hallowell, N. (1999) 'Doing the right thing: genetic risk and responsibility' *Sociology of Health & Illness*, Vol. 21, No. 5, pp. 597-621.
- Hendricks, A. (1997) 'Genetics, human rights and employment: American and European perspectives' *Medical Law*, Vol.16, pp. 557-565.
- HGSA (Human Genetics Society of Australasia) (1999) 'Predictive Genetic Testing and Insurance' <http://www.hgsa.com.au> Site last accessed March 2007.
- IFSA (Investment and Financial Services Association) (2002) 'Life Insurance and Genetic Testing in Australia 2002' <http://www.ifsa.com.au/index.aspx> Site accessed March 2006.
- Knoppers, B.M., Lemmons, T., Godard, B., Joly, Y., Avar, D., Clark, T., Hamet, P., Hoy, M., Lanctôt, S., Lowden, S., Martin, H., Maugard, C., Millett, Y., Simard, J., Vachon, M. & Zinatelli, F. (2004) 'Genetics and life insurance in Canada: points to consider' www.cmaj.ca/cgi/content/full/170/9/1421/DC2 Site accessed September 2005
- Langbehn, D., Brinkman, R., Falush, D., Paulsen J. & Hayden M. (2004) 'A new model for prediction of the age of onset and penetrance for Huntington's disease based on CAG length' *Clinical Genetics*, Vol. 65, pp. 267-277.
- Lapham, E.V., Kozma, C. & Weiss, J.O. (1996) 'Genetic discrimination: perspectives of consumers' *Science*, Vol. 274, pp. 621-624.
- Lemke, T. (2005) 'Beyond genetic discrimination: Problems and perspectives of a contested notion' *Genomics, Society & Policy*, Vol. 1, No. 3, pp. 22-40.

- Lemmens, T. Joly, Y. Knoppers, B. M. (2004) 'Genetics and Life Insurance: A Comparative Analysis' *GenEdit*, Vol. 2, pp. 1-14.
- Low, L., King, S. & Wilkie, T. (1998) 'Genetic discrimination in life insurance: empirical evidence from a cross sectional survey of genetic support groups in the United Kingdom' *British Medical Journal*, Vol. 317, pp. 1632-1635.
- Lynch, E.L., Doherty, R.J., Gaff, C.L., Macrae, F.A. & Lindemann, G.J. (2003) 'Cancer in the family and genetic testing: implications for life insurance' *Medical Journal of Australia*, Vol. 179, No. 9, pp. 480-483.
- Markman, M. (2004) 'Genetic discrimination arising from cancer risk assessments: A societal dilemma' *Cleveland Clinic Journal of Medicine* Vol. 71, No. 1, pp. 12-18.
- Marteau, T. & Richards, M. (1996) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* Cambridge: Cambridge University Press.
- Meiser, B. & Dunn, S. (2000) 'Psychological impact of genetic testing for Huntington's disease: an update of the literature' *Journal of Neurology, Neurosurgery & Psychiatry*, Vol. 69, pp. 574-578.
- Nowlan, W. (2003) 'A scarlet letter or a red herring?' *Nature*, Vol. 421, p. 313.
- Otlowski, M.F. (2005) 'Exploring the Concept of Genetic Discrimination' *Journal of Bioethical Inquiry*, Vol. 2, pp. 165-176.
- Otlowski M.F. (2002) 'Employers' use of genetic test information: is there a need for regulation?' *Australian Journal of Labour Law*, Vol.15, pp. 1-39.
- Otlowski, M. (2001) 'Is there scope for lawful genetic discrimination in health insurance in Australia?' *Journal of Law & Medicine*, Vol. 8, pp. 427-432.
- Otlowski, M.F., Barlow-Stewart, K.K., Taylor, S.D., Stranger, M. & Treloar, S.A. (2007a) 'Investigating genetic discrimination in the Australian life insurance sector: use of genetic test results in underwriting 1999-2003' *Journal of Law & Medicine*, 14(3): 367-396.
- Otlowski, M.F., Taylor, S.D., Barlow-Stewart, K.K., Stranger, M. & Treloar, S. (2007b, in press) 'The use of legal remedies in Australia for pursuing allegations of genetic discrimination: Findings of an empirical study' *International Journal of Discrimination*, Vol. 9, pp. 3-35.
- Otlowski, M.F., Taylor S. D. & Barlow-Stewart, K. K. (2002) 'Australian empirical study into genetic discrimination' *Genetics in Medicine*, Vol. 4, Issue 5, pp. 392-395.
- Petersen, A. & Bunton, R. (2002) *The New Genetics and the Public's Health* Routledge, London.
- Peterson, E.A., Milliron, K.J., Lewis, K. E., Goold, S.D. & Merajver, S.D. (2002) 'Health insurance and discrimination concerns and BRCA1/2 testing in a clinic population' *Cancer Epidemiology, Biomarkers & Prevention*, Vol. 11, pp. 70-87.
- Richards, M. (1996) 'Families, kinship and genetics' in Marteau, T. & Richards, M. *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* Cambridge: Cambridge University Press.

- Sale, M.M., Hazelwood, K., Zimmet, P.Z., Shaw, J.E., Stankovich, J.M., Greenaway, T.M. & Dwyer, T. (2004) 'Trends in diabetes management practices of patients from an Australian insulin-treated diabetes register' *Diabetic Medicine*, Vol. 21, pp. 165-170.
- Sandberg, P. (1995) 'Genetic information and life insurance: a proposal for an ethical European policy' *Social Science & Medicine*, Vol. 40, pp. 1549-1559.
- SPSS Inc. (Statistical Package for the Social Sciences) (2004) *SPSS 12.0 for Windows 2004*, <http://www.spss.com/spss/> Illinois, USA. Site accessed June 6, 2005.
- Steginga, S.K., Occhipinti, S., McCaffrey, J. & Dunn, J. (2001) 'Men's attitudes toward prostate cancer and seeking prostate-specific antigen testing' *Journal of Cancer Education*, Vol. 16, pp. 42-45.
- Taylor, S.D. (2005) 'Gender differences in attitudes amongst those at risk for Huntington's disease' *Genetic Testing*, Vol. 9, No. 2, pp. 152-157.
- Taylor, S.D. (2004) 'Predictive genetic test decisions for Huntington's disease: Context, appraisal and new moral imperatives' *Social Science & Medicine*, Vol. 58, No. 1, pp. 137-149.
- Taylor, S. (1998) 'A case study of genetic discrimination: Social work and advocacy in a new context' *Australian Social Work*, Vol. 51, pp. 51-58.
- Taylor, S. (1994) 'Demand for predictive genetic testing for Huntington's disease in Australia, 1987 - March 1993' *Medical Journal of Australia*, Vol. 161, No. 6, pp. 351-355.
- Taylor, S., Treloar, S., Barlow-Stewart, K., Stranger, M. & Otlowski, M. (2007, manuscript in review) 'Investigating genetic discrimination in Australia: A large-scale survey of clinical genetics clients' perceptions and experiences' submitted May 2007.
- Taylor, S. D., Otlowski, M.F., Barlow-Stewart, K.K., Stranger, M. & Chenoweth, K. (2004) 'Investigating genetic discrimination in Australia: opportunities and challenges in the early stages' *New Genetics and Society*, Vol. 23, No. 2, pp. 225-239.
- Treloar, S.A., Morley, K.I., Taylor, S.D. & Hall, W.D. (2007) "Why do they do it?" A pilot study towards understanding participant motivation and experience in a large, genetic epidemiological study of endometriosis' *Community Genetics*, Vol. 10, pp. 61-71.
- Treloar, S.A., Taylor, S.D., Otlowski, M.F., Barlow-Stewart, K.K., Stranger, M. & Chenoweth, K. (2004) 'Methodological considerations in the study of genetic discrimination' *Community Genetics*, Vol.7, pp. 161-168.
- Turner, D.R., Haan, E.A., Jacka, E., Kalucy, R.S., Burns, R.J., Willoughby, J.O. & Crabb, R. (1988) 'Prenatal and adult presymptomatic testing for Huntington's disease' *Medical Journal of Australia*, Vol. 148, pp. 567-573.
- Wertz, D.C. (2002) 'Genetic discrimination – an overblown fear?' *Nature Review Genetics*, Vol. 297, pp. 196-197.
- Zick, C.D., Smith, K.R., Mayer, R.N. & Botkin, J.R. (2000) 'Genetic testing, adverse selection and the demand for life insurance' *American Journal of Medical Genetics*, Vol. 93, pp. 29-39.