

Genetic Discrimination Project Update

May 2005

Welcome to the second Genetic Discrimination Project Newsletter which provides an update on the project.

About The Project

This national research project is a cross-institutional and interdisciplinary study funded for 2002-2004/5 by the Australian Research Council (ARC) Discovery Project Scheme. The full title of the project is *Genetic discrimination in Australia: an exploration of the nature and extent of the phenomenon within the legal and social context*. Further details can be found on the website at www.gdproject.org

The project aims to collect empirical data regarding the experiences and perspectives of key stakeholders associated with the issue of genetic discrimination in Australia. Specifically, data is being gathered from **consumers** (those considered to be at risk as a result of a genetic test result or because of their family history), **third parties**, comprising insurers and employers (recognised as being in a position to discriminate – either positively or negatively – on the basis of a person's genetic status) and also the various organizations within the **legal system** through which complaints of genetic discrimination may be pursued. There is also a **verification** component to the research, where attempts will be made to follow up consumer allegations of genetic discrimination. The aim of the verification sub-project is to gain greater insights into the issues involved for all parties.

The research has been approved in accordance with the National Health and Medical Research guidelines by the Human Research Ethics Committees associated with the researchers' institutions.

Extension of the GDP to June 2005!

Due to various unanticipated and unavoidable delays, the Australian Research Council has agreed to extend the GDP until mid-2005. This means that we can continue to finalise our data collections and analysis into 2005, with the project formally drawing to a close around June 2005.



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Sub-projects of the GDP

- Project A The Consumer Study
- Project B The Third Party Study
- Project C The Legal System Study
- Project D The Verification Study

The Consumer Study

The Consumer Study has been conducted out of the University of Queensland by Sandy Taylor with the dedicated assistance of Sue Treloar and three Research Assistants. There has been a lot of activity in this project since our last newsletter. Firstly, a large survey has been conducted with the help of 15 clinical genetic services throughout Australia to examine the experiences of individuals who have enquired about or presented for a predictive genetic test for a range of genetic disorders and conditions, during the period 1998 to 2003. Almost 1200 people have responded and we are now busy analysing the data. Just over 90 alleged incidents of unfair or disadvantaging treatment on the basis of genetic risk or family history have been reported in this survey. We are following some of these up with individuals who have given their contact details in the hope that some of these alleged incidents may be able to be verified. Secondly, we have conducted a small study which aimed to document the perceptions and experiences of clinical geneticists and genetic counsellors regarding the issue of genetic discrimination. Thirdly, the survey questionnaire has been circulated through genetic support groups to try to reach people who may have genetic risks but have not necessarily attended a clinical genetics service. The questionnaire is also posted on our project website www.gdproject.org for downloading. Finally we have a range of interview and focus group data to analyse that was collected in the early days of the GDP.

Some preliminary findings have already been presented at several conferences in late 2003 and also 2004 and more will be forthcoming once full analysis of all our data has been completed.

A special thank you to all the clinical genetics services and support groups around Australia which have assisted us with this study as well as the many consumers who have contributed!

The Third Party Study

Margaret Otlowski and Mark Stranger are both based at the University of Tasmania's Centre for Law and Genetics. They are responsible for conducting the Third Party Study into the use of genetic information by employers and insurers.

Employers

A Pilot of 50 businesses showed us that achieving an adequate sample was going to be difficult given the demands that are placed upon organisations these days to provide information to government and other bodies, including a considerable number of requests to participate in research surveys. In order to overcome this problem we used the Business Review Weekly's 2001 lists, the Top 1000 and the Fast 100 as the sample for the study. These provided the name and correct title of the Chief Executive Officers (CEOs) for organisations we considered most likely to use employees' genetic information (i.e. they were likely to have the resources and/or were progressive in their outlook). It was hoped that if the CEO could be convinced of the value of participation then the job would be delegated to the appropriate officer. To some extent this tactic was successful, but after following up with a letter it became clear that the survey pack (in bulky A4 envelope) had often not reached them, as many CEOs had not seen the survey and requested a copy. Eventually it was decided that we had achieved as much as possible targeting CEOs and so a new round of requests (and follow-ups) went out to Human Resource Managers. This resulted in a doubling of the number of viable responses to 34% of the sample frame. We have completed data entry and are in the process of analysing the data. Follow up interviews will be undertaken as

appropriate. A separate survey of Occupational Medicine Practitioners will be administered in early 2005.'

Insurers

Data about the use of genetic information by life insurance companies has been collected over the past 3 years for the life insurance industry's peak body, the Investment and Financial Services Association (IFSA) by the Institute of Actuaries of Australia (IAAust). Our

experience with employers indicated that although the industry (through IFSA) had proved to be extremely supportive of the project, it was unlikely that we would get adequate responses to a survey that duplicated in any way the data collected by IAAust. Using the IFSA data seemed a logical option. However, while there was no suggestion that IAAust's interpretation of the data was faulty in any way, nevertheless, it was important for the integrity of our project that we use raw data and not simply accept their analysis of it.

Since the data had been collected with the understanding that it would be kept confidential, IFSA's David Mico (Senior Policy Manager) contacted the members to get their agreement to provide us with the raw data - minus company identifiers. Analysis of this data is underway with input from various actuarial and clinical experts. Clarification of a number of cases of potential interest has been sought from IFSA with the assistance of David Mico.

While life insurers are the most likely to use an applicant's genetic information, two other surveys have also been developed: one for the general insurance industry, and one for insurance brokers. General insurers are being approached to test anecdotal evidence that suggests genetic information has been a factor in insurance products such as travel and income insurance, and brokers are being approached in order to ascertain the role these gatekeepers may play in the collection and use of genetic information.

After feedback from the Insurance Council of Australia (the peak body for general insurers), and the National Insurance Brokers Association (and a number of other related peak bodies), surveys were sent out to all ICA members, and to Brokers (using the Australian Securities Commission database). Follow up letters and surveys will be sent out early in 2005 to ensure adequate response rates.

Further, the industry's complaints bodies, the Financial Industry Complaint Service Ltd (life insurers) and Insurance Enquiries and Complaints Ltd (general insurers), are both collecting data for the project on complaints that come to them relating to a client's family medical history or genetic testing.

These clients are invited to contact us for inclusion in the consumer research and/or the verification phase of the project.

The Legal System Study

Further work has also been undertaken since the last newsletter on the Legal System Study which aims to explore what use, if any, is being made of legal avenues by individuals who feel they have been discriminated against on the basis of their genetic status.

Follow up contact has been made with all tribunals and other legal and quasi-legal bodies that may deal with complaints of this nature (anti-discrimination Tribunals, anti-discrimination commissioners, ombudsmen and industrial tribunals where issues relating to discrimination in employment may be raised) to ascertain whether any cases have arisen in the intervening period. To date this has not yielded any new cases, however we are still in the process of following up a number of cases identified in our initial contact with these bodies.

This legal system research is being augmented by a number of periodic legal data base searches to assist us in monitoring any cases coming before Australian courts or tribunals involving allegations of genetic discrimination. Whilst no cases of direct interest have been identified through these searches to date, there have been a number of cases found within the Family Court's jurisdiction where the issue of genetic status has arisen as a consideration in contested child proceedings.

The Verification Study

The verification study involves following up where possible and appropriate, alleged cases of genetic discrimination with third parties who may have been involved in the discriminatory treatment. Such verification is an important aspect of this research as verified cases of alleged discrimination have rarely been possible before.

It is not too late to tell us about your views or experiences

If you would like to speak to us about these issues, please contact any of the research team members (contact details on front page of Newsletter) or those listed below.

The Consumer Study

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Recent and forthcoming GDP-related publications

Treloar, S, Taylor, S, Otlowski, M, Barlow-Stewart, K, Stranger, M, Chenoweth, K. (2004) "Methodological challenges in the study of genetic discrimination: A review". *Community Genetics* 7:161-168.

Taylor, S, Otlowski, M, Barlow-Stewart, K, Treloar, S, Stranger, M & Chenoweth, K. (2004) "Investigating genetic discrimination in Australia: opportunities and challenges in the early stages". *New Genetics and Society* 23(2): 225-239

Otlowski, M. 'Genetic Discrimination: Meeting the Challenges of an Emerging Issue' (2003) 9 *University of New South Law Journal*, Forum on Genetics & Law 15-18.

Otlowski, M, Taylor, S & Barlow-Stewart, K. (2002). "Major Study Commencing into Genetic Discrimination in Australia". *Journal of Law & Medicine* 10(1): 41-48

Otlowski, M. 'Employers' Use of Genetic Test Information: Is there a Need for Regulation?' (2002) 15 *Aust Journal of Labour Law* 1-39

Otlowski, M. 'Is There Scope for Lawful Genetic Discrimination in Health Insurance in Australia?' (2001) 8 *Journal of Law and Medicine* 427-432

Recent Conference Papers

Barlow-Stewart, K, Treloar, S, Taylor, S, Saleh, M, Muchamore, I & Otlowski, M "Australian views on commercial and government interests in genetic test results: implications for public policy". Poster presentation at the American Society of Human Genetics Meeting. Toronto, November 2004

Barlow-Stewart, K, Weisbrot, D, Taylor, S., Otlowski, M. "Genetic privacy and discrimination in Australia" 7th World Congress of Bioethics, Sydney. 2004

Otlowski, M, Taylor, S. Barlow-Stewart, K, Stranger, M & Treloar, S. "Genetic Discrimination: Overview Of A Major Australian Empirical Research Project". 2004 World Medical Law Congress, Sydney.

Taylor, S, Treloar, S, Barlow-Stewart, K, Stranger, M. & Otlowski, M. "Genetic discrimination in Australia: the perspectives of consumers, genetic counsellors and clinicians". 28th Scientific Meeting of the Human Genetics Society of Australasia (HGSA), Fremantle 2004.

Barlow-Stewart, K, Stranger, M, Taylor, S, Treloar, S, & Otlowski, M. "The use of genetic test results for underwriting by life insurance companies in Australia (1999-2003)". The 28th Annual Scientific Meeting of the Human Genetics Society of Australasia (HGSA), Fremantle 2004.

Stranger, M, Otlowski, M, Taylor, S, Barlow Stewart, K & Treloar, S. 'Genetic Discrimination Project' British Sociological Associations' Medical Sociology Conference, York, UK, September 2003

Otlowski, M & Taylor, S, 'Investigating Genetic Discrimination in Australia: Opportunities & Challenges' 8th Annual Conference of the Australian Institute of Health Law and Ethics, Hobart, 2003.

Stranger, M, Otlowski, M, Taylor, S, Barlow Stewart, K & Treloar S. 'Genetic Discrimination Project' Australian Sociological Association's Annual Conference, University of New England, Armidale, 2003

Thank you to all participants and members of our Expert Reference Group!

We would like to thank all those who have assisted us so far by participating in the various projects associated with the GDP.

We would also like to thank those who have provided valuable input and support for the project at all stages, especially our Expert Reference Group members and special consultants.