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Senate Legal
& Constitutional
Committee

The Cancer Council
New South Wales

Building a
Cancer Smart
Community

28 January 2005

Committee Secretary
Senate Legal and Constitutional Committee
Department of the Senate
Parliament House
Canberra ACT 2600

By email:
legcon.sen@aph.gov.au

Dear Sir/Madam

Inquiry into the Privacy Act 1988

I refer to the announcement of an Inquiry into the Privacy Act 1988 by the Senate Legal and Constitutional Committee. The Cancer Council Australia has forwarded a letter of invitation for submissions dated 14 December 2004 to us which was sent by the acting committee secretary. Accordingly we are pleased to provide comments to the committee from the perspective of a health consumer organisation in the field of cancer.

Of particular interest to us in the terms of reference for the Inquiry is part (a)(ii)(C) "genetic testing and the potential disclosure and discriminatory use of such information".

Genetic testing in Australia

From a cancer perspective, genetic information is increasingly important for understanding this difficult and life-threatening disease and highly sensitive for health consumers who may have undertaken a genetic test. Genetic technology is a new science which is constantly evolving and since the completion of mapping the human genome, discovery of the role of individual genes has been subject to concerted research investigation and discovery. Nevertheless the functions of around 50% of the identified 30,000 genes are still unknown although this is constantly changing[1].

General practitioners order medical genetic tests and individuals in most circumstances cannot obtain direct access to testing. Currently most medical genetic testing is provided through state and territory genetic

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[1] The Human Genome Project:
http://www.ornl.gov/sci/techresources/Human_Genome/project/journals/insights.html

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services and public sector laboratories associated with these services[2]. There are also a few private sector laboratories offering genetic tests.

In Australia, genetic testing is available through 43 laboratories and some 220 tests are available from them[3]. The Medical Benefits Schedule (MBS) has only six items which encompass genetic testing and there are for the specific conditions of haemochromatosis, factor V Leiden, protein C or S deficiencies, antithrombin 3 deficiency and the fragile X syndrome[4]. As the pace of discovery continues, there will be pressure to expand the number of genetic testing items on the MBS. As an example, some 37,000 genetic tests were performed for haemochromatosis between 1987 (when it was added to the MBS) and 2001.

In Australia, in addition to public sector testing laboratories, some private companies offer a range of DNA tests for cancers including breast and ovarian cancers; bowel cancer and melanoma, as well as for many other diseases including heart disease, memory loss; metabolic disorders; and multiple other disease types. There has even been an expansion of genetic testing into sports performance testing thus increasing the level of information being harnessed.

Access to genetic testing information

Public interest in genetics has started to grow due to increased awareness in the community that genetic testing is available and may have significant health importance and benefits. The move by some private sector companies to market their services further adds to this awareness and most likely will increase the public demand for testing services.

With the growth in the amount of genetic information being obtained, an increasing number of people and organisations have or will have access to genetic test results: health consumers, general practitioners, life insurance companies, public and private testing laboratories, and superannuation funds offering death and disability insurance. Although there are very detailed state laws dealing with genetic information, a comprehensive and harmonised regulatory structure across all jurisdictions remains the important goal.

As an example of the management of access to genetic information, The Cancer Council NSW maintains the NSW & ACT Hereditary Cancer Registers (HCR) which includes genetic data. The HCR is a voluntary register for people at increased risk of cancer due to a hereditary bowel cancer syndrome. Individuals listed on the HCR provide their written, informed

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[2] 'Genes and Ingenuity – Gene Patenting and Human Health' Report No 99, Australian Law Reform Commission (ALRC), June 2004, p486

[3] A register of laboratories and the genetic tests available from them is available from the Human Genetics Society of Australasia. Website reference http://www.hgsa.com.au/, accessed 17 December 2004

[4] http://www.health.gov.au/pubs/mbs/index.htm.

consent to be registered with the HCR. The information is kept confidential and is not released in a form that could identify an individual (or child/dependant) except when needed by a doctor, accredited genetic testing laboratory, family cancer clinic or another hereditary cancer register to assist in providing care to the person registered or their child/dependant or other members of their family.

The HCR abides by the NHMRC Guidelines for Genetic Registers and Associated Use of Genetic Material. The HCR sits within NSW and is subject to the Privacy laws in this state, i.e. Health Records and Information Privacy Act (NSW) 2002. Accordingly, the staff of the HCR have been consulted in the discussion around the changes to Privacy in practice in NSW, with the NSW Department of Heath. We believe that genetic information held in cancer registries is sufficiently secure to not pose a risk in terms of inappropriate disclosure to unauthorised parties.

Genetic Information, Insurance and the potential for Discrimination

The Australian Law Reform Commission (ALRC) undertook a substantial inquiry into the protection of human genetic information and issued a final report titled "Essentially Yours: The Protection of Human Genetic Information in Australia". The Report contained *inter alia* 16 recommendations specifically addressing insurance and genetic information however while it is known that some recommendations from the Final Report have been acted upon, not all have been resolved. This is, in part, due to the fact that one of the primary recommendations, to establish a Human Genetics Commission of Australia with a specific role and tasks, has not as yet occurred if indeed the Australian Government agrees with this recommendation.

It may well be beneficial for the Senate References Committee to ascertain the state of progress with specific recommendations of this ALRC report dealing with discrimination matters.

Related to the various matters covered by the ALRC, a major issue for us is insurance and the potential discriminatory use of genetic information. We are particularly concerned with the possible conclusion of the 2-year extension granted by the Australian Competition and Consumer Commission (ACCC) to the Investment and Financial Services Association (IFSA) genetic testing policy. The IFSA policy is an agreement between life insurers which provides that they will not require applicants for life insurance to undergo a genetic test. The agreement, approved by the ACCC, has been in force since November 2000 and was extended for two years from December 2003 until December 2005.

The access to and use of genetic information by insurers is a matter which is has a clear concern for us. We believe the current state of research with genetics in many conditions, including cancer, still has a high level of uncertainty and hence risk assessment used in underwriting will not be accurate. Accordingly the collection of genetic information by the insurance industry should still be subject to restriction.

While the very nature of underwriting calls for discrete predictive values to be attached to genetic information, genetic tests in general terms are not yet reliable enough to be used in such a context. Unlike conventional risk assessment which is based on actuarial statistics, such as actual deaths and disabilities, genetic testing risk assessment must rely upon actuarial interpretation of medical research data. Illustrative of the early stage of understanding of genetic factors, the percentage of women who will develop breast cancer as a result of an inherited genetic mutation has repeatedly been revised down since the discovery of the association.

Added to this aspect, is the fact that cancer and the majority of other genetic disorders are multi-factorial. This added complexity and the number of confounding variables means that the probative value of genetic information is even more restricted.

In our view, the current voluntary approach by IFSA which prevents genetic tests being a requirement for insurance should remain in place. If it is lifted, we believe a specific regulatory approach will be needed and this may need to be placed within the context of amending the Privacy Act preventing compulsory use of genetic tests at this time.

There is already evidence that those with illnesses such as cancer face potential discrimination from the insurance industry even where the illness in question poses little risk for underwriting and is easily defined. Such an example occurred with QBE Travel Insurance vs Denice Basselli. Ms Basselli, who was diagnosed with cancer, was refused travel insurance from QBE even though her condition actually posed little risk to the insurer. She subsequently obtained travel insurance from another company and successfully sought damages from QBE Insurance which was upheld by the Federal Court in April 2004.

Access to genetic data which only shows possible links to cancer and has many more variables and uncertainties, we believe will only exacerbate this potential for discrimination.

Should any further information be required please do not hesitate to contact me (02 93341934) or our Senior Policy Officer, Mr Charles Latimer (02 9334 1749).

Yours sincerely

Andrew G Penman
Chief Executive Officer