**Global Challenges and Opportunities: the Australian Experience**

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# Introduction

Australia has a population of about 22 million, mainly concentrated in the coastal capital cities and regional centre on a large (and largely dry and inhospitable) continent. Australia has a federal system of political organization, with six states, two territories and an overarching Commonwealth government—and a great deal of resulting complexity. For example, each of those nine political entities has a Privacy Act, and three of them also have dedicated health privacy legislation. Australia has a comprehensive, national healthcare system, which includes medical care and pharmaceuticals, and is federally funded—although the operation of hospitals, and thus a considerable portion of service delivery, is a state and territory responsibility.

Given the nature of the comprehensive public healthcare system, private health insurance is not the point of contention and hotspot that it is in the United States. Private health insurance *is* available in Australia—and, indeed, is strongly encouraged by ‘carrot and stick’ Government policies[[1]](#footnote-1)—but it community-rated (rather than individually risk-rated). Thus, an individual can choose from a menu of cascading choices (for example, deciding whether to include physiotherapy and gym membership, or a private hospital room), but the cost of each option is the same whether the person is old or young, super-fit or chronically ill.

In the past decade, Australia has made significant advances in regulating human genetic technologies, including the establishment of a Human Genetics Advisory Committee, reform of privacy and anti-discrimination laws, and—most recently—moves by the Therapeutics Goods Administration (TGA) to regulate direct-to-consumer (DTC) genetic testing. Currently, public and political attention is focused on the validity of gene patents—including a Bill currently before Parliament, a case pending before the Federal Court and a slew of independent reports to which the government is yet to respond. Integral to these reforms are two major inquiries undertaken by the Australian Law Reform Commission (ALRC)—an inquiry on the protection of human genetic information (which reported in 2003) and a 2004 inquiry into gene patents and human health. Issues for the future are likely to include the concerns of Indigenous Australians (eg, about biopiracy and equitable benefit sharing) and strategies for international cooperation and harmonization.

# ALRC-AHEC inquiry: the protection of human genetic information

## Background to the Inquiry

The Australian Law Reform Commission (ALRC) was established in 1973, as an independent statutory authority tasked with reviewing Commonwealth laws, policies and practices referred to it by the federal Attorney-General. In performing its functions, the ALRC must have regard to upholding personal rights and liberties, and promoting consistency with the International Covenant on Civil and Political Rights. In essence, the ALRC operates as Australia’s national ‘legal think tank’ on important socio-legal issues. From its earliest days, the ALRC entrenched the active engagement of the community as part and parcel of its basic approach to law reform. The ALRC committed itself to ensuring, as a matter of basic philosophy, that ‘law reform should be conducted in a transparent way with opportunities for widespread public consultation’.[[2]](#footnote-2) Indeed, its underlying ethos over 35 years has been that ‘law reform is much too important to be left to the experts’.[[3]](#footnote-3)

In February 2001, the Australian Government announced the establishment of a major, two-year inquiry by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC)—a principal committee of the National Health and Medical Research Council (NHMRC)—into the ethical, legal and social implications of rapid advances in genetic science and technology, or what was then commonly referred to as the ‘New Genetics’.

The Terms of Reference directed the ALRC and AHEC to consider, with respect to human genetic information—and the tissue samples from which such information may be readily derived—how best to protect privacy; protect against unfair discrimination; and ensure the maintenance of high ethical standards. These concerns were explored across a wide array of contexts, including such matter as: the oversight of human genetic research; public health planning and administration; the delivery of clinical genetic services; law enforcement uses of DNA; insurance underwriting; employment; sport; immigration; parentage and kinship testing (including communal identity); and the management of genetic databases.

The Inquiry prioritized widespread consultation. It released a substantial Issues Paper and Discussion Paper; conducted a series of 15 highly publicized, geographically dispersed, open forums; initiated over 200 meetings with interested groups; and received about 350 formal written submissions. The Inquiry also established a broad-based, external Advisory Committee—a reference group which included leaders in the fields of genetic research; clinical genetics and genetic counseling; public health; Indigenous health; community and professional education; employment and industrial law; human rights, privacy and anti-discrimination law; and insurance and actuarial practice.

Consultation revealed strong, but conflicting, feelings in the community. There was considerable optimismabout the potential for genetic research to produce important medical breakthroughs. There was also strong support in the community for the use (with proper safeguards) of DNA technology and databases by law enforcement and national security authorities. It was very common in public meetings for participants to declare their altruism, and their willingness to provide tissue for genetic research studies or permanent biobanks. At the same time, however, there was a palpable, underlying anxiety in the community about the pace of change and some doubts about the capacity of public authorities to regulate this area effectively in the public interest. Put another way, Australians were attracted by the glittering vision of an era of personalised genomic medicine, but fearful of a ‘geneticised’ future in which an individual’s potential and drive might be defined to too great an extent by their genetic sequence.[[4]](#footnote-4)

## Essentially Yours (ALRC 96, 2003)

The ALRC/AHEC Report, *Essentially Yours*,[[5]](#footnote-5) made 144 recommendations addressed to the Australian Government *and* to 30 other actors—including, among others, health and medical policymakers (such as the National Health and Medical Research Council (NHMRC), university medical school deans, and state and territory health officials); doctors and allied health professionals; anti-discrimination and privacy officials; regulatory authorities (for consumer protection and regulation of medical devices); insurers; employers and educators.

A threshold question for the Inquiry was whether to embrace notions of ‘genetic exceptionalism’; that is, the idea that genetic information is so fundamentally different from, and more powerful than, all other forms of personal information that it requires different and higher levels of legal protection. The Inquiry rejected genetic exceptionalism, but recognised the special features and challenges of genetics.

In December 2005, the Australian Government issued a formal Whole-of-Government response and accepted *almost* all the report’s recommendations. There has been steady implementation of the accepted recommendations since that time. Some of the more significant steps are discussed below.

## A national standing body (HGAC)

The central recommendation in *Essentially Yours* called for the establishment of a standing advisory body on human genetics to provide high-level, technical and strategic advice to Australian governments and others about current and emerging issues in human genetics, as well as providing a mechanism for the development of policy statements and national standards and guidelines in this area. This recommendation was accepted by the Australian Government, and in 2005, the Government appropriated A$7.6 million over four years to establish a Human Genetics Advisory Committee (HGAC) as a new principal committee of the NHMRC. Similar bodies then existed in the United Kingdom (the Human Genetics Commission), Canada (the Ontario Genetics Advisory Committee) and the United States (the Secretary’s Advisory Committee on Genetics, Health and Society)—but the HGAC has outlasted most of its international counterparts and is still an active part of the NHMRC.

HGAC membership includes persons with expertise in human genetics; community representation; privacy, discrimination and health law; data management and information security; science communication; and the health needs of Indigenous Australians. The HGAC has taken the lead on a number of important issues, including: the education of general practitioners and the broader community; monitoring and working with insurance industry on its underwriting policies and practices; the regulation of the direct-to-consumer genetic testing; and system-wide planning for the implications of the rapidly approaching Whole-Genome-Sequencing era.

## Adapt privacy laws

Responding to the strong concerns raised in consultations, the Inquiry made a number of recommendations to enhance the privacy of genetic information, including inserting into federal privacy legislation a definition of ‘genetic relative’; amending the definition of ‘health information’ expressly to cover genetic information predictive of the health of the individual or a genetic relative; and amending the definition of ‘sensitive information’ to include ‘genetic information about an individual that is not otherwise health information’. The Australian Government implemented these recommendations in 2006.

The Inquiry also recommended that the *Privacy Act* should apply explicitly to human tissue *samples*, above and beyond genetic information. Although there was broad support in consultations and the close analogies between genetic samples and other sources of encrypted personal information covered by the *Privacy Act*, the Government did not support such a change, fearing that this would move the Act too far away from its original ‘data protection’ focus. Instead—and despite the ALRC expressly rejecting this idea—it suggested that ownership interests in genetic samples could be addressed in state and territory Human Tissues Acts.

One issue which remains up for debate in Australia is the desirability of the establishment of a criminal offence for the non-consensual collection and analysis of DNA samples. Given the ubiquity of genetic samples and the growing availability and decreasing cost of DNA analysis, the Inquiry raised concerns about the greatly increased potential for abuse. After considerable internal debate, the Inquiry recommended the creation of a new criminal offence, which would prohibit an individual or a corporation from submitting another person’s sample for genetic testing, or conducting such testing, knowing (or recklessly indifferent to the fact) that this is done without the consent of the person concerned or without other lawful authority—such as a court order, approval by a human research ethics committee, or authorization under police forensics legislation. The Government accepted this recommendation in principle, but referred the matter to the Standing Committee of Attorneys-General (SCAG)[[6]](#footnote-6) for further development. In late 2008, the Model Criminal Law Officers’ Committee of SCAG released a discussion paper entitled *Non-consensual Genetic Testing*,[[7]](#footnote-7) which contained a number of model draft offences. Unfortunately, these were poorly drafted and came under nearly universal criticism for being too vague, overly broad, and failing to come to grips with the nature of DNA and DNA testing. Submissions were called for by 31 January 2009, but there has been no announcement or further action since then, despite questions being asked by the HGAC about the unexplained lack of progress on this matter.

## Adapt anti-discrimination laws

Anti-discrimination legislation exists at the federal, state and territory levels in Australia. Despite some differences in detail, all of anti-discrimination legislation in Australia embodies the same basic paradigm for identifying unlawful discrimination. One requirement for discrimination to be unlawful is that an act or omission be based on one of the grounds or attributes set out in the legislation, such as sex, race, age or disability (but also including, in various jurisdictions, sexual orientation, political views, and pregnancy, among other things).

Experts generally agreed that definitions of disability would cover genetic conditions once symptoms had manifested. However, they questioned whether they would cover discrimination on the basis of genetic status where a person was asymptomatic. For the purpose of clarity and consistency, the Inquiry recommended that antidiscrimination laws should be amended to apply expressly to discrimination based on (real or perceived)[[8]](#footnote-8) genetic status. In contrast to the approach later taken by the United States, the Inquiry rejected calls for a dedicated new ‘Genetic Non-Discrimination Act’, consistent with its general approach to eschewing genetic exceptionalism.[[9]](#footnote-9)

The Inquiry also took a strongly interventionist approach to the use of genetic testing and information in the employment area, expressing concern about the potential to create an unfortunate ‘genetic underclass’ of people who are actually fit to work but might be denied employment on the basis of predispositions to genetic conditions that might never eventuate. The Inquiry recommended that employers be barred from collecting or using genetic information in relation to job applicants and employees *except* where that information is reasonably required for purposes that do not involve unlawful discrimination. The *Disability Discrimination and Other Human Rights Legislation Amendment Act 2009* (Cth) implemented these recommendations.

The Inquiry took a different approach in the context of the use of genetic information in insurance underwriting, concerns about which had been a key factor in the establishment of the Inquiry. Under the federal *Disability Discrimination Act*, *Sex Discrimination Act* and *Age Discrimination Act* (but, notably, *not* the Race Discrimination Act), it is possible for insurance underwriters to make lawful (that is, non-invidious) distinctions among individuals for risk assessment purposes, but only where this is done on a scientifically accurate and actuarially relevant basis.

As noted above, health insurance is community-rated, and not individually risk-rated in Australia, there is a comprehensive public healthcare system, and there is also a compulsory, employment-based, superannuation system[[10]](#footnote-10)—so that only about 30 percent of Australians seek to purchase individually risk-rated products, such as life insurance or income protection insurance. Given that those products are quintessentially about identifying and weighing material risk factors, there are alternative investment strategies available, and there is realistic concern about ‘moral hazard’ in insurance markets if individuals were not required to disclose known health risks, the Inquiry took a less interventionist approach than it did in relation to the employment market.

Instead, the Inquiry pushed for greater public scrutiny to ensure that the insurance industry is living up to its exemption under anti-discrimination laws and is basing its underwriting practices on cutting-edge genetic science and actuarial practices. In order to test this, the Inquiry recommended that: better educational programs be developed for insurance agents, brokers and underwriters regarding genetics; all adverse underwriting decisions (whether refusal, exclusions, or increased premiums) be explained in writing to the applicant; and that dissatisfied applicants or policyholders be able to seek review of any unfavourable decision before an independent, low-cost, dispute resolution body established for this purpose, as an alternative to pursuing a complaint to the Australian Human Rights Commission or litigation in the federal courts.

The HGAC is actively engaged with the insurance industry at present to see that all of these improvements are adopted. The insurance industry also has been very cooperative in permitting an independent,[[11]](#footnote-11) twice-yearly, survey of all risk-rated insurance applications, to identify all instances in which genetic test information was disclosed, and to report on the handling of this information and on the outcomes. This survey information is being used to indentify contentious issues and then to refine and improve industry educational and underwriting practices.[[12]](#footnote-12)

# Human Gene Patents

## ALRC 99: Genes & Ingenuity

Gene patents have the potential to impose a particularly heavy burden on Australian Governments, given Australia’s public healthcare system. A small number of genetic tests are included in the federally-funded Medical Benefits Scheme (MBS), but the bulk of genetic testing and related clinical services are funded by state and territory governments. Attempts by Genetic Technologies (or GTG, which was granted an exclusive licence for Australia and New Zealand by the Utah-based Myriad Genetics) in 2002-03 and briefly again in 2008 to enforce its patent rights over the BRCA1 and BRCA2 genes have led to widespread government and community concerns, and extensive and adverse media coverage—triggering several public inquiries.

On 17 December 2002, the Australian Government asked the ALRC to conduct an inquiry into the relevant laws, international obligations and practices relating to gene patenting and human health. The ALRC’s 700 page report, *Genes and Ingenuity* (ALRC 99, 2004),[[13]](#footnote-13) which again followed an extensive community consultation exercise, was tabled in Parliament in August 2004.

The ALRC was highly critical of the fact that overly broad patents had been granted in Australia and overseas in relation to pure gene sequences—the discovery of which would generally not satisfy the intellectual property requirements for an ‘invention’. The ALRC made 50 recommendations for reform, including amendments to the *Patents Act* (Cth) to upgrade the burden of proving ‘usefulness’ (utility)—and thus to sharpen the distinction between mere ‘discoveries’ and patentable ‘inventions’—and to provide an express ‘experimental use’ exemption for researchers.

The ALRC also recommended a significant upgrading of the skills and resources available to the Patent Office (now ‘IP Australia’) and patent examiners, and called for a more active and strategic approach by federal and state Governments to monitoring and challenging patents where appropriate, seeking to preserve the benefits of publicly-funded research, and using their existing legal powers more effectively (eg ‘Crown use’ rights and compulsory licences).

The ALRC’s findings and recommendations have been validated and adopted (expressly or coincidentally) by virtually all of the major international reports that have followed, including the OECD’s 2006 Guidelines for the Licensing of Genetic Inventions, and the US Government’s Gene Patenting Task Force in 2009.

Remarkably, however, the Australian Government has still not formally responded to the *Genes and Ingenuity* report (despite many false alarms).

In November 2010, the Australian Senate Community Affairs References Committee issued a separate report on gene patents,[[14]](#footnote-14) which expressly recommended that the Government should implement the ALRC’s key recommendations—as well as those similar recommendations from parallel reviews by the Advisory Council on Intellectual Property and IP Australia—and use this response as the basis of future Commonwealth engagement with the patent system.

## Patent Amendment (Human Genes and Biological Materials) Bill

The Patent Amendment (Human Genes and Biological Materials) Bill was introduced as a Private Members Bill by four non-Government Senators[[15]](#footnote-15) on 24 November 2010, with the stated purpose of ‘advance[ing] medical and scientific research and the diagnosis, treatment and cure of human illness and disease by enabling doctors, clinicians and medical and scientific researchers to gain free and unfettered access to biological materials, however made, that are identical or substantially identical to such materials as they exist in nature’.

The Bill proposes to introduce a new limb of s18(2) of the *Patents Act* (dealing with patentable inventions). The amended section would provide that:

The following are not patentable inventions: (a) human beings, and the biological processes for their generation; **and** **(b) biological materials including their components and derivatives, whether isolated or purified or not and however made, which are identical or substantially identical to such materials as they exist in nature.**

The Bill also would amend s18(4) defines ‘biological materials’ to include ‘DNA, RNA, proteins, cells and fluids’.

Although there is widespread sympathy for the general proposition, the specific Bill has provoked heated controversy, including fears that its broad drafting would exclude from patentability a wide range of biological materials that are routinely the subject of patents (for example, virus particles used in vaccines). Consequently, the Bill, in its present form, has been strongly criticised by the Australian Academy of Sciences, the HGAC and others. In any event, as a Private Members’ Bill without Government support, there is no prospect of it becoming law.

Relevantly, the Intellectual Property Amendment (Raising the Bar) Bill 2011 was introduced in Parliament in June 2011, which would, among other changes, raise thresholds for patentability in a technologically neutral manner and establish a broad research use exemption—in keeping with the recommendations of the ALRC’s *Genes and Ingenuity* report.

## Litigation

Mirroring the ongoing patent disputes in the United States, such as the ACLU’s challenge to the Myriad patents, a consortium led by Cancer Voices Australia is challenging the validity of the BRCA1 and BRCA2 patents in the Australian courts. The consortium is arguing that the patent was incorrectly awarded in this case for mere discoveries, not ‘inventions’. The case, *Cancer Voices Australia & Anor v Myriad Genetics & Ors*, ispending in the Federal Court, with the next appearance scheduled for September 2011.

# Direct-to-Consumer Genetic Testing

Compared to the United States, Australia has little in the way of DTC genetic testing. There are 5-6 private labs operating and marketing their services in Australia, but they all require some involvement from a general practitioner (‘yours or ours’). We are aware of one start-up DTC lab (Lumigenix), which is currently seeking to establish itself in Australia. Some additional impetus in this regard came in 2010, when one private health insurer offered a 50% discount to its members to purchase the Navigenics test—but this attracted controversy when it transpired that no warning was provided in relation to potential implications for insurance and other collateral matters.

In July 2010, with almost nothing in the way of public attention or comment, the Therapeutic Goods Administration (roughly, the Australian equivalent of the FDA) announced a new framework for reviewing in-vitro diagnostics (IVDs). Most relevantly, human genetic testing was assessed as posing a potential public health risk based on ‘possible stress and anxiety relating to the information and/or follow-up measures’. Accordingly, the TGA classified genetic testing as a ‘Class 3 IVD’, which permits it to impose marketing and sale restrictions.

Ultimately, however, the ubiquity of the internet means that greatest impact on DTC genetic testing in Australia will stem from regulations imposed elsewhere—in particular, in the United States.

# Future issues

## Concerns of Indigenous peoples:

Indigenous Australians have raised particular concerns about the implications for them of the ‘new genetics’, especially in relation to ethical oversight of genetic research and benefit sharing (or at least the avoidance of further exploitation). Indigenous Australians are severely disadvantaged by all socio-economic and health indicators, despite years of Government attention to the need to ‘bridge the gap’. The NHMRC now has a separate principal committee dedicated to Indigenous health and medical issues. In the Northern Territory, which has the highest proportion of Indigenous people, the two main Human Research Ethics Committees (HRECs) (in Darwin and Alice Springs) each have an Indigenous sub-committee with veto powers over proposed health and medical research. In most other jurisdictions there are requirements for research projects targeting Indigenous Australians to be reviewed by specialised HRECs in addition to the project’s standard HREC review.[[16]](#footnote-16)

There are also considerable fears of biopiracy in Indigenous communities—and many stories, whether real or apocryphal, about fly-in/fly-out medical pillagers who take blood and tissue samples or collect native flora and fauna. One recent example that has generated media attention is a pending patent application by an American cosmetics company making claims over ingredients extracted from the Kakadu plum—a native fruit of Australia’s Northern Territory—for use in cosmetics. Indigenous groups have long used the plum as traditional medicine and as part of traditional legends, and they worry that the patent could prevent them from such use.

Also contentious is the possibly of using DNA testing to constitute ‘Aboriginality’. Unlike the United States and Canada, Australia has not used ‘blood rules’ to determine a person’s Indigenous identity, nor the rights and interests that flow from that (such as the right to make a claim for Native Title over land or water, or live on an Aboriginal Reserve, or vote in an election for representatives to the Indigenous self-determination body, or claim certain financial benefits or scholarships reserved for Indigenous people). Rather, the position in Australia is that if an individual self-identifies as an Aboriginal person and is accepted by that community, then the law (courts, Government agencies etc) will recognise that fact.

The issue that came up during the controversial 1999 Tasmanian election for the Aboriginal and Torres Strait Islander Commission (ATSIC), during which one local Aboriginal activist challenged the bona fides of hundreds of individuals who were on the electoral rolls, having identified themselves as Aboriginal people. Some disputants talked about using genetic testing as a means of proving their Aboriginal descent, but in the end the matter didn’t proceed on this basis. However, issues about the biological meaning of Aboriginality may continue in the future, given the element of ‘descent’, which in combination with self-identification and community recognition comprises the classic legal definition of an Aboriginal person set out by Justice Deane in the leading High Court of Australia decision *Commonwealth v. Tasmania* (1983).

## International and regional cooperation

Australia has always been well-disposed to participate actively in international institutions, such as the United Nations and its constituent agencies—including UNESCO and the World Health Organisation—as well as in other international and regional groupings, including the OECD and APEC. Australia is invariably represented when such bodies consider developing rules, guidelines or policies on genetics, health and society.

Australia and New Zealand formally have a Closer Economic Relations treaty and relationship, which provides generally for free trade, an open labour market, and joint regulation of certain economic markets (such as by Food Standards Australia New Zealand). In the relevant area, there is also considerable informal regional discussion and cooperation, with an annual Australia New Zealand Roundtable on Genetics operating for the last few years, coordinated and supported by the New Zealand Law Foundation.

Australia also has a Free Trade Agreement with the United States (AUSFTA), which attracted controversy in the negotiating stages and early in its life, when the US put considerable pressure on Australia over its Pharmaceutical Benefits Scheme (PBS)—effectively a monopsony (single payer), which delivers inexpensive (or free) drugs to Australians because the Government can negotiate prices with pharmaceutical companies whose products are recommended for inclusion in the PBS by an expert committee(PBAC) that considers efficacy and cost. Given the universally positive feelings about the benefits of the PBS among Australians—and across all party lines—there had to be an exchange of letters by the relevant Australian and American officials to state that the PBS would remain unaffected by the general language promoting free trade and limited Government intervention.

Australia has also been relatively active in international and regional discussions (formal and informal, governmental and non-governmental) that develop on an ad hoc basis around particular issues, such as biobanking (in association with the UK, Singapore, Japan, Canada, China and others) as DTC genetics (in association with the US, UK, EU, Japan and others). Given the ease of transporting genetic samples—and especially genetic information—across national borders, it will become increasingly critical to develop international standards and a high level of cooperation when it comes to protecting human integrity, privacy and other important rights and interests.

1. In order to keep the premiums at an affordable level—and especially to encourage younger and healthier people into the private health insurance pool—the federal Government provides a direct subsidy of more than $2B per annum, plus a number of related tax concessions and penalties. [↑](#footnote-ref-1)
2. . Michael Kirby, “Foreword”, *The Speeches of The Honourable Justice M D Kirby, CMG – Volume 1, 1975-1976* (ALRC, 1986) pp 2-3. [↑](#footnote-ref-2)
3. David Weisbrot, “Michael Kirby and Law Reform, Australian-Style” in Ian Freckelton and Hugh Selby (eds), *Appealing to Future: The Legacy of Michael Kirby* (Thomsons, 2009) Ch 24, 607-637. [↑](#footnote-ref-3)
4. The geneticised future depicted in the popular film ‘Gattaca’ was often referred to in consultations. [↑](#footnote-ref-4)
5. Australian Law Reform Commission, *Essentially Yours: the Protection of Human Genetic Information in Australia* (ALRC 96, 2003), available at <<http://www.alrc.gov.au/publications/report-96>> (accessed 4 July 2011). [↑](#footnote-ref-5)
6. SCAG is comprised of representatives from each state and territory and from the Commonwealth; on relevant issues, the Attorney-General of New Zealand is also represented. [↑](#footnote-ref-6)
7. Available at <http://www.ag.gov.au/www/agd/agd.nsf/Page/Modelcriminalcode\_Non-ConsensualGeneticTestingDiscussionPaper> (accessed 4 July 2011) [↑](#footnote-ref-7)
8. The Inquiry heard concerns about alleged discrimination against individuals who, for example, were from a ‘known Huntington’s disease family’, whether or not the particular individual shared this familial predisposition. [↑](#footnote-ref-8)
9. The Inquiry recommended that that the federal *Disability Discrimination Act* be renamed the Genetic and Disability Discrimination Act, however—but this has not happened. [↑](#footnote-ref-9)
10. To which employers must contribute at least an additional nine percent of an employee’s annual salary. [↑](#footnote-ref-10)
11. Carried out by the Australian Institute of Actuaries. [↑](#footnote-ref-11)
12. For example, underwriting practices in relation to haemochromatosis have been radically revamped, and the practices in relation to positive tests for the BRCA 1 and 2 mutations are being reviewed. [↑](#footnote-ref-12)
13. Australian Law Reform Commission, *Genes and Ingenuity: Gene Patenting and Human Health* (ALRC 99, 2004), available at <http://www.alrc.gov.au/publications/report-99> (accessed 4 July 2011). [↑](#footnote-ref-13)
14. Australian Senate, Community Affairs References Committee, *Gene Patents* (November 2010), available at <(<http://aph.gov.au/senate/committee/clac_ctte/gene_patents_43/report/index.htm>> (accessed 4 July 2011). [↑](#footnote-ref-14)
15. Two Liberal Senators, one from the Greens and one Independent. [↑](#footnote-ref-15)
16. See, eg, <http://www.ahmrc.org.au/Ethics%20and%20Research.htm> for New South Wales; <http://www.aboriginal.health.wa.gov.au/ethics/index.cfm> for Western Australia; <http://www.ahcsa.org.au/content/research-ethics> for South Australia. [↑](#footnote-ref-16)