Employer-endorsed DNA sampling schemes:

*A Chasm for Protection of Employee Rights and Liberties*

**KARLIE BROWN**

From a 2008 ANU Law internship project

Anthony Williamson, Professional Supervisor (Director, Civil Liberties Australia, CLA)
Peter Ford, Academic Supervisor (ANU College of Law)

In late 2007 Civil Liberties Australia undertook to provide supervision for a research project that it had proposed concerning the law governing the collection and use of DNA samples in employment relationships. This research project was initiated as a result of concerns raised in relation to potential mandatory DNA sampling of employees within the Australian Federal Police. The project was undertaken as part of an undergraduate subject within the College of Law at the Australian National University, on behalf of Civil Liberties Australia, a national, non-party political organisation with headquarters in Australia’s capital city, Canberra. Any references to Civil Liberties Australia, or CLA, within this report are references specifically to that organisation only.
EMPLOYER ENDORSED DNA SAMPLING SCHEMES:
A chasm for protection of employee rights and liberties.

This paper, also authored by Ms Brown and a close adaptation of the academic work, makes clear recommendations for the legislative/community responses that are needed, CLA believes.

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<td>DNA</td>
<td>Deoxyribonucleic acid</td>
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<td>Information Privacy Principle</td>
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SUMMARY OF RECOMMENDATIONS

Recommendation 1: That ALRC96 be revisited by the recently elected Rudd Labor Government; a comprehensive response to that report be re-issued and further implementation of its recommendations undertaken.

Recommendation 2: That mandatory collection of DNA for employment related purposes be prohibited.

Recommendation 3: That mandatory professional standards be developed, setting minimum standards for gaining voluntary informed consent of employees where employers endorse DNA sampling programmes.

Recommendation 4: That an offence of prejudicial treatment of employees on the basis of refusing to give a DNA sample be created.

Recommendation 5: That mandatory professional standards be developed, setting minimum requirements of DNA storage security.

Recommendation 6: That explicit protection against unsolicited genetic testing of DNA samples be adopted by way of:

(a) Legislative provisions specifically affording equivalent privacy protection to human biological and DNA samples.

(b) The creation of an offence of non-consensual DNA/genetic testing

Recommendation 7: That all employment related collection of DNA samples be immobilised until explicit protections against non-consensual uses of DNA be developed and implemented.
INTRODUCTION

1. In late 2007, several media outlets reported that the Australian Defence Force (ADF) had announced its intention to commence voluntary DNA sampling of new recruits, for the purpose of disaster victim identification (DVI). The program, which had been contemplated for several years, followed a “review of current operating procedures” in the ADF. It was quickly mooted as a preliminary scheme which would later be expanded to a mandatory sampling scheme for all ADF employees. In the preceding 18 months, the Australian Federal Police (AFP) had already begun to implement a similar scheme of DNA sampling for the purpose of excluding DNA samples of police officers from those found at crime scenes.

2. This report presents an analysis of how DNA sampling schemes such as those proposed and implemented by the ADF and AFP fit within the Australian legal context. It does so in light of the recommendations of the 2003 ALRC/AHEC inquiry into the protection of human genetic information in Australia. In considering the legal context of DNA sampling schemes, the report also describes and evaluates the legislative protections afforded to employees affected by such schemes, and makes recommendations in support of robust protections of individual rights and liberties.

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3 ‘Plan to Collect Defence Force DNA’ above n 1.

4 Ibid.

DNA SAMPLING SCHEMES IN AUSTRALIA

**Australian Defence Force**

3. As outlined above, the ADF announced its intention to commence voluntary DNA sampling of service members for the purpose of DVI in late 2007. The program, which was said to follow a “review of current operating procedures” in the ADF, had been contemplated for several years, and in effect subsumed a previously established voluntary DNA repository maintained by the Air Force.

4. Those media reports were largely based on information found in two requests for tender released by the Department of Defence. The first was open from 16 May to 7 June 2007, seeking “offers to establish a DNA Repository for the voluntary collection and storage” of ADF DNA samples, within a National Association of Testing Authorities (NATA) accredited facility. The second request for tender was open from 20 October to 20 November 2007, and

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6 Nolan, above n 1.
7 ALRC96 above n 2, [29.30].
8 Nolan, above n 1.
sought provision of a “secure storage facility for up to about 60 000 DNA samples with the possibility to increase to about 90 000 samples.” It stated that the samples would be held as blood spots on special blotting paper, in tamper evident sealed bags, with no sample analysis to be performed, and the contract said to commence February 2008.\textsuperscript{11}

5. Tender documents and statements released by defence personnel made it clear that the scheme is intended to become mandatory in its mature form, but that mandatory sampling was not able to go ahead without legislative changes.\textsuperscript{12} Within days of the media attention however, leaders of both major political parties had rejected the possibility that legislation would change to enable mandatory sampling.\textsuperscript{13}

\textit{ADF Legislative Basis}

6. The ADF DNA sampling scheme is, at present, not established by legislation, and remains a voluntary scheme. As stated above, however, ADF personnel have indicated that, in order for the scheme to proceed to its intended mandatory form, amendments to the \textit{Defence Act 1903} (Cth) conferring the power to enforce such a scheme will be sought.\textsuperscript{14}


\textsuperscript{13} Nolan, above n 1.

\textsuperscript{14} Barry Rollings, above n 12, 8.
Australian Federal Police

7. In January 2006, the ABC reported on a proposal by the AFP that voluntary DNA samples would be taken for the purposes of DVI, comparison against DNA samples found at crime scenes as well as comparison against the National Criminal Investigation DNA Database (NCIDD) prior to employment to ensure the integrity of new recruits. The proposal followed the development of DNA sampling policies by the Police Commissioners’ Policy Advisory Group over 2004-2005 and endorsement by the Police Commissioners’ Conference in March 2005.

8. The Australian Federal Police Association initially stated that the guidelines associated with sampling were not strict enough, and could lead to their misuse. In response, the AFP stated that officers were not being asked any more than to provide DNA samples under volunteer provisions in the Crimes Act. As a result, officers would be afforded the same protections as civilian volunteers under the same provision. The AFPA was reported as giving its support for the mandatory sampling of AFP officers, conditioned on heavy safeguards to prevent the profiling and misuse of samples.

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16 Question No 163, above n 5.
17 Union Concerned over DNA Profiling of AFP Officers, above n 15.
18 Crimes Act 1914 (Cth).
20 Ibid.
9. AFP voluntary DNA sampling began in November 2005 with samples provided by Police Commissioner Mick Keelty, and National Manager of Human Resources, Mark Ney. On the 23 December 2005, AFP staff were advised via email of an AFP National Guideline on Scientific Identification of Employees, providing for the voluntary provision of DNA samples for the purposes of differentiating AFP employee forensic material from other material found at crime scenes and DVI.\textsuperscript{21}

10. A similar DNA sampling scheme has been in place within the Tasmanian Police Force for several years. In 2002 it was announced that Tasmanian police officers would be given the opportunity to voluntarily contribute DNA samples with the eventual aim of creating a DNA database of police officers for exclusionary purposes.\textsuperscript{22} Subsequent to protest from the Police Federation of Australia, legislation to ensure the privacy of officer samples was drafted.\textsuperscript{23} In submission to the ALRC\textsuperscript{96} Inquiry, the Police Commissioner indicated that if police were not voluntarily submitting to sampling, he would ask the Tasmanian government to implement legislation to make sampling compulsory.\textsuperscript{24} Although existing officers were given the opportunity to voluntarily submit to DNA sampling, new recruits now give samples as a condition of employment, although samples are only held for the duration of officers’ employment. Similarly, the Western Australia Police Commissioner has been able to require a DNA sample from any member of the WA Police Force since 2002,\textsuperscript{25} but has rarely used the power.\textsuperscript{26}

\textsuperscript{21}Question No. 163 above n 12.
\textsuperscript{22}Danny Rose, ‘Chief’s plea on DNA database’ The Mercury, 9 July 2002, 7.
\textsuperscript{23}Ibid.
\textsuperscript{24}ALRC\textsuperscript{96} above n 2, [29.27].
\textsuperscript{25}Criminal Investigation (Identifying People) Act 2002 WA, s. 22
\textsuperscript{26}ALRC\textsuperscript{96} above n 2 [29.29].
**AFP Legislative Basis**

11. The AFP DNA sampling scheme is sanctioned by the *Crimes Act 1914 (Cth)* which provides in Division 6B for the forensic sampling of volunteers. Forensic samples may be taken from a person who, with informed consent, volunteers to have that sample taken, provided that the procedure is necessary, or incidental to, the performance of an AFP function;\(^\text{27}\) where an AFP function is one defined by the *Australian Federal Police Act.*\(^\text{28}\) Where police officers volunteer to submit to forensic sampling, they are afforded the same protections as other members of the community who similarly volunteer forensic samples.

12. Where state police forces take DNA samples from their members, each scheme requires legislative authority in that state. In Tasmania, for example, the power to take samples is conferred in the *Forensic Procedures Act 2000* provisions for sampling of volunteers.\(^\text{29}\)

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\(^{27}\) *Crimes Act 1914 (Cth)* s 23XWQ.
\(^{28}\) *Australian Federal Police Act 1979 (Cth)* s 8.
\(^{29}\) *Forensic Procedures Act 2000 (Tas)* s 29.
Newborn Screening Programmes

13. Perhaps the most comparable system of routine DNA sampling undertaken in Australia is the Newborn Screening Programme (NBSP). The NBSP is a public health programme that screens blood samples of newborn babies for an array of diseases which are relatively easy to treat; and for which early detection has enormous benefits to the individual, their family and the public health system.\(^\text{30}\) Despite the enormous public health value of the NBSP, it represents a major example of the concerns associated with DNA sampling, in particular that advances in genetic technology may lead to previously unforeseen uses of samples in the absence of appropriate protection.

14. After testing, newborn blood samples are stored for quality assurance purposes for two years.\(^\text{31}\) Depending on health policy of the state in which samples are held, they may be made available for secondary purposes such as scientific research after that period.\(^\text{32}\) In New South Wales and Victoria, the police have limited access to samples as outlined by a Memorandum of Understanding between the health department of each state and the police.\(^\text{33}\) Although the issues associated with the NBSP are not dealt with at length in this paper, CLA notes that whilst the public health benefits are undeniable, CLA opposes all unauthorised police access to NBSP cards, and urges the Government to adopt greater regulation of access to newborn screening samples in accordance with recommendations 19-1 and 19-2 of ALRC96.


\(^{31}\) As required by NPAAC, ‘Requirements for the Retention of Laboratory Records and Diagnostic Material’ 2007 (Released 2007, effective 1 January 2008).


THE CURRENT REGULATORY FRAMEWORK

15. The proposed schemes of DNA sampling in two large Commonwealth agencies present specific concerns for the protection of employees.

16. The nature of the relationship between employee and employer is inherently unequal. In the workplace, the employee is frequently vulnerable to their employer’s decisions. Various pieces of legislation at both federal and state level attempt to balance the inequality in the employee-employer relationship, by restricting the decision-making capacities of employers in respect of issues to which employees are particularly susceptible. The unique nature of genetic information, however, lends itself to even greater vulnerability where it is accessible to an employer.

17. When DNA samples are taken as a condition of employment, the employee, already in a disadvantaged bargaining position, is asked to consent to the removal of a bodily sample, and to donate that sample into their employer’s possession. As will be discussed further below, their ability to give voluntary informed consent is compromised because the immediate threat of harm to their employment prospects (if they refuse consent) must be weighed against the long term threat of improper or discriminatory uses of their DNA sample. In consenting to the removal of a DNA sample from their body, the employee relinquishes control over that sample, and its possible future uses.

18. While a great deal of research examining the issues associated with donation of genetic samples has been conducted, much of it has focussed on DNA sampling for research or clinical purposes.34 In general, for such purposes,

donors of tissue have no property rights over the sample, and, once donated, ownership and control of it will lie with the institution they are donated to.\textsuperscript{35} Despite this, donation occurs because the individual generally expects some health benefit in return. Within employment, however, the collection of genetic samples presents less of an immediate benefit on behalf of the individual. Because property rights are likely to vest in the institution to which the DNA is donated, employees become increasingly vulnerable to the protections afforded them by their employers.

19. In the case of the AFP and ADF proposals, it has been made clear that the implementation of voluntary schemes is intended to forge the way for an expansion to mandatory sampling of all employees. Vulnerability of employees is particularly stated when the submission of DNA samples becomes a mandatory condition of employment. Individuals are denied the option of giving voluntary consent to such a procedure, and their autonomy is disregarded.

20. Although neither scheme purports to use the DNA for primary purposes other than verification or exclusion of identity, the ‘bio-banking’ of large quantities of DNA samples has been seen in the NBSP to lead to the samples being made available for secondary purposes.\textsuperscript{36} Should this happen, perhaps the greatest concern is that the samples will be made available for genetic testing, and may lead to genetic discrimination.

21. In light of the above issues, it is clearly appropriate to consider the current legislative and regulatory framework in which the ADF and AFP have implemented DNA sampling of employees. At present, regulation of

\textsuperscript{35} \textit{Ibid.}

\textsuperscript{36} ABC TV Science, ‘Guthrie Cards’, Catalyst, 29 May 2003 \textless http://www.abc.net.au/catalyst/stories/s867619.htm\textgreater at 1 November 2007; Skene above n 34, 69.
biomedical research and biological products remains largely governed by law that is primarily directed to other purposes,\textsuperscript{37} resulting in a miscellany of legislation which may or may not regulate either scheme. The following discussion will consider the federal and state legislation, regulations, official guidelines, professional ethics and other persuasive influences which may afford protection to employees. It will evaluate the effectiveness of such protection and make recommendations in support of robust protections of individual rights and liberties.

**NATIONAL INQUIRY**

22. In February 2001, the Australian Government commissioned an inquiry into the protection of human genetic information in Australia, to be jointly undertaken by the Australian Law Reform Commission and the Australian Health Ethics Committee (a subsidiary of the National Heath and Medical Research Council). After two years of extensive consultation the final report, *ALRC/AHEC96 Essentially Yours: The Protection of Human Genetic Information in Australia* was launched in the Australian Parliament on 29 May 2003.\textsuperscript{38}

23. Since its release, the *Essentially Yours* report has been heralded as the most comprehensive inquiry into the protection of human genetic information, both here and internationally.\textsuperscript{39} It is regarded as having put Australia at the forefront in dealing with the social, ethical, legal and practical issues associated with the use of human genetic information.\textsuperscript{40}

24. On 9 December 2005, the Australian Government released its official response to the 2003 report, accepting many of the 66 recommendations specifically


\textsuperscript{38} Weisbrot, David, ‘Policy Transparency, Genetic Counselling and the Required Legal Infrastructure’ (Paper presented at the Symposium on ‘The Legal Implications of Biobanking: An Initial Review of the Legal Infrastructure development of Taiwan’s Pilot Project’ 8 August 2005).

\textsuperscript{39} Australian Law Reform Commission, ‘Australia ‘Well placed’ to lead world in protecting genetic information’ (Media release, 9 December 2005).

\textsuperscript{40} *Ibid.*
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directed towards it,\textsuperscript{41} and recommending many others to be considered by State governments and other bodies.\textsuperscript{42} To date, however, the Government has acted upon only few recommendations. In particular, the Human Genetics Advisory Committee was established in 2005, as a principal body of the NHMRC, implementing several of the central recommendations of the report.\textsuperscript{43} Additionally, the \textit{Privacy Legislation Amendment Act 2006} (Cth) amended the \textit{Privacy Act 1988}, implementing several recommendations. The NHMRC has implemented changes to ethical guidelines, and several parliamentary bodies are in the process of reviewing other recommendations.\textsuperscript{44}

25. ALRC96 recognised the unique quality of genetic information. It suggested that while genetic information did not need a separate and unique regulatory scheme to oversee its use, multiple changes to existing regulatory schemes were required in order to address the perceived risks of advances in human genetic technology. The government response to that report supported the view that a unique regulatory scheme was not necessary to regulate the use of human genetic technology, and went on to accept in principle, many of the recommendations that had been made.\textsuperscript{45} In the four years since that report was published, however, many of those recommendations have not been implemented.\textsuperscript{46}

26. The recent change in Federal Government in Australia presents a unique opportunity for a reassessment of the ALRC96 report. Given that now, almost five years after its release, Australian employees continue to become increasingly susceptible to improper use of genetic technology, CLA urges the

\textsuperscript{41} ALRC96 above n 2, Implementation Schedule.
\textsuperscript{43} ALRC96 above n 2, Recommendations 5.1 – 5.9.
\textsuperscript{44} See http://www.alrc.gov.au/inquiries/title/alrc96/implementation.htm
\textsuperscript{45} Government Response to Recommendations, above n 42.
\textsuperscript{46} See http://www.alrc.gov.au/inquiries/title/alrc96/implementation.htm
Rudd Labor Government to re-issue a comprehensive response to ALRC96, and to reconsider further implementation of its recommendations.

27. In the context of the AFP and ADF DNA sampling schemes, it will be seen below that, despite the recommendations of ALRC96, the Australian employee is still vulnerable to the threats posed by genetic technology. Whilst it is unrealistic to propose that the extensive consultation process taken in developing ALRC96 be undertaken again, further action needs to be taken in order that Australian employees may be better protected.

Recommendation 1: That the highly esteemed ALRC96 be revisited by the recently elected Rudd Labor Government; a comprehensive response to that report be re-issued and further implementation of its recommendations undertaken.

JUSTIFYING SAMPLING AS A CONDITION OF EMPLOYMENT

28. Many commentators have recognised that forensic DNA collection is seen by the public “as the ultimate crime-fighting tool rather than a potential threat to liberty.” Collection of DNA, however, is seen in a different light when viewed in the context of employment. Where DNA is collected from convicted or alleged criminals, it is for the purported safety of the community. In contrast, where DNA is collected from current or potential employees, by their employer, it would appear to be primarily for the administrative purposes of the employer, and must be questioned.

29. The ADF has promoted their proposed DNA repository on the grounds that advanced weaponry in international operations may make it difficult to identify victims using traditional non-DNA means. The only means of identifying victims then may be “to compare samples of ante-mortem and

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post-mortem DNA.”48 The ADF has stated that in such an event, the absence of reliable ante-mortem DNA samples forces coronial investigations to intrude on grieving families in order to procure such samples.49

30. By contrast, the AFP collects DNA from officers under the provisions for voluntary forensic sampling found in the Crimes Act. The primary purpose stated is for comparison against samples collected from crime scenes in order to prevent contamination of evidence. The AFP does indicate, however, that the samples are kept on record for identification purposes in case of an officer’s death. It has also been suggested that samples collected from new recruits might be compared against the NCIDD as an ‘integrity test’ to ensure that samples taken from previous crime scenes were not left by individuals applying for positions in the police force.

31. In considering whether the ADF and AFP proposals are appropriate, the purported benefits of the schemes for both the employee and administration are weighed against the interest of the individual in protecting their personal DNA samples. CLA supports the view that compulsory collection ought not to occur unless there is a significant avoidable risk posed to the individual.50

32. Where the collection of DNA is for the purpose of DVI, it admittedly improves administrative ease but, importantly, relieves a burden from grieving relatives in the event of an employee’s death. CLA considers that it is for the individual to weigh these benefits against the security and protection of their DNA sample, and therefore supports voluntary consent.

33. Where the collection of DNA is for widespread forensic purposes, CLA supports the view that collection should be limited to what is reasonably

48 Rollings, above n 12.
49 Ibid.
50 Privacy Victoria, Submission to the Victorian Parliament Law Reform Committee on its Inquiry into Forensic Sampling and DNA Databases (2002), [80].
necessary for law enforcement functions.\textsuperscript{51} CLA supports the view that routine contamination of crime scenes is an issue that should be dealt with by improved training, rather than increased forensic procedures. CLA prefers that collection of AFP officer DNA be limited to the collection of DNA for the purpose of one-off forensic comparison against a specific crime-scene sample, but supports the voluntary consent of the individual to either scheme.

34. CLA opposes the pre-employment collection of DNA from new recruits for the purpose of “integrity testing”. A positive result of such testing (i.e. that a recruit DNA sample should match a previous crime-scene sample) is an instrument of mere circumstance, and should not be relied upon for evidence of criminal behaviour in the absence of actual conviction.

35. CLA believes no Australian should be compelled to give up their DNA unless they are subject to formal, serious criminal allegations, and therefore opposes mandatory DNA sampling as a condition of employment. CLA considers that the administrative aims of the AFP and ADF are not so imperative as to outweigh the individual’s rights to autonomy and liberty. Mandatory collection of DNA samples is not required to achieve the administrative aims of the ADF/AFP. Further, in the absence of significant avoidable risk to the individual, it is difficult to conceive of administrative requirements that would outweigh the interests of the individual sampling. CLA therefore opposes any employment related collection of DNA samples without the voluntary informed consent of the individual.

\textit{Recommendation 2: That mandatory collection of DNA for employment related purposes be prohibited.}

\textsuperscript{51} \textit{Ibid.} [60].
CONSENT

36. Legally, consent is a necessary requirement before any medical procedure is conducted on a person. The standard generally required is that the patient gives voluntary, informed consent.\(^{52}\) If the appropriate standard of consent is not required before undertaking a medical procedure, or, as here, obtaining access to a person’s bodily tissues, the fundamental autonomy of the individual and integrity of their person is compromised, and the medical practitioner may leave themselves open to actions in negligence. The following discussion will highlight the problems that CLA perceives with regards to the status of voluntary consent given by employees to a request for DNA sampling by their employer.

**Regulation of Consent Giving**

*Human Tissues Acts*

37. Each State of Australia has now enacted some variation of human tissue or medical treatment legislation. For the most part, the Acts were developed to protect organ donors and recipients, however they also deal in part with the removal of human tissue for research purposes. Given that they stipulate the necessity for consent prior to removal of tissue samples, *Human Tissues Acts* may afford some protection to employees whose DNA samples are requested by employers subject to State legislation.

\(^{52}\) *Rogers v Whitaker* (1995) ALR 625.
**Forensic Procedures Acts**

38. Forensic Procedures Acts at state levels regulate the consent required for collection of DNA samples from volunteers in each state, and therefore may regulate the forensic sampling of State police forces, as seen in Tasmania (as discussed above).

**Common Law**

39. At common law in Australia, the Rogers v Whitaker standard of informed consent requires that a patient be informed of “material risks” of a procedure, where a risk is “material” if “a reasonable person in the patient’s position … would be likely to attach significance to it.”  

53 This may require that, for informed consent to DNA sampling to be valid, the person be informed of the purpose for taking the sample, and its likely uses and risks to the individual.

40. An employee whose DNA sample is taken without their consent may also be able to pursue a civil action, in trespass or assault, against their employer in respect of the interference with their personal autonomy. In the absence of case law, however, it is unclear how difficult it would be for an employee to prove such an action, and what protection that action might afford.

**Regulations**

41. The NHMRC ‘National Statement’ was revised as a result of ALRC96, and re-released in 2007. It deals with ethical conduct in human research, and, while not generally enforceable, sets ethical standards which must be met under NHMRC research grants, and so has significant persuasive authority. In the context of DNA samples taken as a condition of employment, it can be viewed


as a useful statement on the ethical position, as it sets out the minimum requirements for consent, and deals specifically with consent giving in unequal relationships.55

42. It should also be noted that the AFP has suggested they will produce independent regulatory guidelines for their identification scheme.56

**International Instruments**

43. The UNESCO Universal Declaration on the Human Genome and Human Rights (1997) provides at Article 5 that in all cases of research, treatment or diagnosis relating to an individual’s genome, “the prior, free and informed consent of the person shall be obtained”, and at Article 9 that:

“limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of … the international law of human rights.”

44. In addition, the International Declaration on Human Genetic Data (2003) defines consent to include “agreement of the individual to his or her genetic data being collected, processed, used and stored;”57 Further, it provides that free, informed and express consent should be obtained for all collection of human genetic data without inducement, and that limitations on that principle should only be prescribed by domestic law for compelling reasons,58 and that a person should be able to withdraw their consent without disadvantage or penalty.59

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55 National Health and Medical Research Council, National Statement on Ethical Conduct in Human Research 2007 [4.3].
56 Question No. 163 above n 5.
45. The above two instruments are the only current international points of reference on bioethics. They must, however, be read in conjunction with the broader international instruments that confer the right to liberty and security of person,\textsuperscript{60} and to not be subjected to medical or scientific experimentation without free consent.\textsuperscript{61}

46. Although these international instruments are significant as normative statements, they are not of binding force at the Commonwealth level in Australia. At the State level, however, the implementation of Human Rights Acts in ACT and Victoria now allow judicial interpretation to have reference to human rights.\textsuperscript{62}

**Analysis**

47. Ethical principles of autonomy underlie judicial statements in the Western world, particularly where medical procedures are relevant. Although the taking of DNA samples is not itself for the purposes of a medical procedure, in these cases it is useful to refer to the requirement for consent in that context. In order for consent to be effective it must be free and voluntary, not induced by any undue pressure or coercion. In the case of voluntary DNA collection instigated by an employer, the nature of the employee-employer relationship, as discussed previously, means that consent will rarely be free from outside pressures.

48. The National Statement discusses the issue associated with gaining voluntary consent from people in unequal relationships. It considers that being in an unequal relationship may influence a person’s decision-making regarding consent, and that researchers faced with such a position must identify and

\textsuperscript{60} Universal Declaration of Human Rights (1948) Art 3.

\textsuperscript{61} International Covenant on Civil and Political Rights (1966) Art 7.

\textsuperscript{62} Human Rights Act 2004 (ACT).
take steps to minimise the detrimental effects of the relationship. ALRC96 also recognised that the consent given by job applicants and employees may be compromised by the unequal bargaining power of the workplace.

49. If an individual perceives their employment prospects to be ‘at risk’ or dependent on the provision of DNA sample, consent is more likely to be given as a result of real or perceived pressures exerted upon them. Where DNA sampling programmes are endorsed by employers, there is likely to be a perception, on the behalf of the employee, that refusal to consent will negatively affect their position in the workforce. It must therefore be questioned as to whether consent to sampling can be truly voluntary when advocated by an employer.

50. At present, it is unclear whether the requirement for voluntary and informed consent at law applies in respect of sampling for employment, and, as will be seen, there is little protection for the employee should they refuse consent.

**Recommendations**

51. CLA believes voluntary informed consent should be required for all collection of DNA samples. Given that informed consent is a general requirement in medical, research and forensic contexts, CLA recommends that mandatory professional standards as to the minimum requirements for gaining voluntary informed consent to DNA sampling of employees should be developed. CLA considers the protection of the employee in such an unequal relationship to be crucial. In order that employees are able to give free consent to DNA sampling, CLA insists that prejudicial treatment of employees on the basis of refusing to give a DNA sample be made an offence.

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63 ‘National Statement’, above n 41, 59
64 ALRC96, above n 2, [29.46].
Recommendation 3: That mandatory professional standards be developed, setting minimum standards for gaining voluntary informed consent of employees where employers endorse DNA sampling programmes.

Recommendation 4: That an offence of prejudicial treatment of employees on the basis of refusing to give a DNA sample be created.

STORAGE AND SECONDARY USES

52. The issue of storage of DNA samples is closely intertwined with the issues of secondary purpose usage of DNA and will therefore be dealt with as an independent topic only in discussion of regulation. In both of the proposed ADF and AFP schemes, DNA samples are intended to have a future analytical purpose, and are therefore intended to be stored. It is unclear, however, under what conditions the samples are intended to be stored, and what security protections will prevent unauthorised access to the samples. Inappropriate levels of security could lead to compromised protection of individual samples and information, and is therefore to be avoided.

53. It has been seen already that where large collections of DNA samples are kept, as in the NBSP, they have become a source of information for researchers and law enforcement authorities.\(^6\) In the context of employment-based sampling, concern about the availability of samples to third parties is compounded by the possibility that the employers themselves might use the samples for secondary purposes, by subjecting them to genetic testing without the individual’s consent. Although the statements made by the AFP and ADF state only limited uses for the samples, unless these statements are interpreted as strict contractual clauses, it is necessary to turn to legislative and regulatory protections to prevent further uses.

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While Australian employers do not routinely test genetic samples, there is evidence of reliance on genetic information in the form of family medical histories. Theoretically, reliance on medical history in the workplace allows employers to reduce sick leave and improve productivity by changing working conditions to prevent likely illness or by screening high-risk individuals out of the workplace. Should genetic tests with reliable predictability become available, employers will be able to exclude at-risk individuals in order to reduce both sick leave and potential workers’ compensation claims.

The AFP and ADF are already two of the biggest pre-employment users of medical information and family history. It seems logical then, that once genetic tests are available, they will have the opportunity and interest to take part in genetic tests. It has long been noted that genetic discrimination within the workplace is a particularly alarming possibility. In the USA, genetic testing has been taken up in the workplace and has given rise to incidents of genetic discrimination largely because employers provide health insurance for their employees. As health insurance is community rated in Australia, genetic discrimination in employment is a greater concern in respect of life insurance, and the possibility of the creation of a generally unemployable “genetic underclass.” Genetic testing, therefore, will be discussed independently as the main secondary purpose use of DNA.

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54. ALRC96, above n 2, p 763.
55. Ibid, pp 764-765.
Regulation of Storage

Forensic Procedures Acts

56. State Forensic Procedures Acts, and the Commonwealth Crimes Act, provide for the destruction of forensic materials taken under those provisions, but do not provide for the storage conditions of those samples.

Regulation

57. The ADF requests for tender required tenders to be accredited by the National Association of Testing Authorities (NATA). Additionally, the NATA website recognises the AFP as an accredited DNA analysis service provider.\(^{70}\) A Memorandum of Understanding between NATA and the Commonwealth states that the Commonwealth and its agencies will, wherever possible, use NATA accredited facilities to fulfil its purposes. As a result, the facilities are subject to NATA licensing regulations.

58. The National Pathology Accreditation Advisory Council also produces guidelines on genetic testing, and in particular, the retention of laboratory records and diagnostic materials.\(^{71}\) Such guidelines require that the storage and future uses of samples comply with relevant local jurisdictional regulations (i.e. human tissue Acts) and guidelines, and requires that the individual give consent to storage, either explicitly or implicitly. They also set out minimum retention times and conditions for particular types of samples. Where the laboratory used to collect or store DNA samples is accredited by the NPAAC, such guidelines may apply.


\(^{71}\) NPAAC Requirements for the Retention of Laboratory Records and Diagnostic Material (2007).
Secondary-use Regulation

Privacy Act 1988 (Cth)

59. The collection and use of private information by a public agency must comply with the Information Privacy Principles, as required by the Privacy Act. The IPPS provide for minimum standards of protection for the individual in relation to the manner in which personal information may be collected, used and stored by an agency.

60. In 2006, the passage of the Privacy Legislation Amendment Act implemented several recommendations of ALRC96. The legislation expanded definition of health information to include “genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual.” In addition, the definition of sensitive information was extended to include at (c) genetic information about an individual that is not otherwise health information.72

61. These amendments, however, do not afford protections to stored genetic samples such as those collected by the AFP and ADF. Although it may be argued that a genetic sample is genetic information, it was made explicit in the Government response to ALRC96 that the Government considered the Privacy Act an inappropriate mechanism for protecting genetic samples and intended genetic samples to be protected in another legislative form. It must be noted, however, that although the Commonwealth agencies discussed here are subject to the Commonwealth Privacy Act, each state also has privacy legislation, and may deal with genetic samples differently. NSW legislation in particular, explicitly protects biological samples.73

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72 Privacy Act 1988 (Cth) s 6.
73 Privacy and Personal Information Protection Act 1998 (NSW).
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Biometrics Institute Privacy Code

62. The Biometrics Institute Privacy Code is an approved regulation under s.18BB(2) of the Privacy Act 1988 which protects the privacy of biometric information (that is, any data which can be used to identify an individual on the basis of a biological or behaviourally unique characteristic). Its application, however, only extends so far as workplaces that subscribe to its regulations, and therefore affords protection to the employee only at the will of the employer.

Common Law

63. In Australia, there is a common law duty of confidentiality which may be breached where information of a confidential character, which is specifically identified, and imparted in circumstances so as to indicate its confidential nature is used to the detriment of the individual. A breach in that duty may result in damages in tort, contract or equitable breach of confidence at common law. A breach of confidentiality at common law, however, is difficult to establish, and affords protection only in the assessment of damages where some loss occurs, rather than in broad terms. Because DNA samples are unlikely to be considered information, and the breach is so difficult to prove, common law confidentiality is unlikely to afford strong protections to employees.

64. In some overseas jurisdictions, a tort of privacy also exists. Although Australian common law has not yet evolved to include such a tort of privacy, the High Court has explicitly recognised the possibility, without ruling as to whether it exists.  

75 ABC v Lenah Game Meats Pty Ltd [2001] HCA 63.
International Instruments

65. Further to the discussion of international instruments above, the UNESCO bioethical declarations provide that genetic data must be held confidential in the conditions set by law,\textsuperscript{76} and that consent should be obtained for all subsequent uses of DNA.\textsuperscript{77} Additionally, the UDHR provides for a human right to privacy.\textsuperscript{78}

Genetic Discrimination Regulation

Disability Discrimination Acts

66. All Australian jurisdictions have enacted anti-discrimination legislation preventing discrimination on the grounds of disability. At the Commonwealth level there are several relevant pieces of legislation. In particular, the Disability Discrimination Act 1992 (Cth) prohibits discrimination in employment on the basis of disability.\textsuperscript{79} ALRC96 recognised that it was not clear whether the definition of disability included a genetic result which may indicate a predisposition to future disability. In the Government’s response to ALRC96, the Government recommended that an advisory note be inserted to clarify that disability also includes a genetic predisposition to disability. This amendment has not yet been applied, however.\textsuperscript{80}

67. Anti-discrimination legislation, however, is based on a model of exceptions, such that it prohibits discrimination broadly, but sets out exceptions to which

\textsuperscript{76} UNESCO Universal Declaration on the Human Genome and Human Rights (1997) Art 7.
\textsuperscript{77} International Declaration on Human Genetic Data (2003) Art 8.
\textsuperscript{78} Universal Declaration of Human Rights (1948) Art 3.
\textsuperscript{79} Disability Discrimination Act 1992 (Cth) s 15.
the legislation would not apply.\textsuperscript{81} In particular, the above provision does not apply to ADF or AFP members on selection for peacekeeping duties.\textsuperscript{82} More broadly, the legislation also contains an exemption where the individual’s disability prevents them from being able to fulfil the ‘inherent requirements’ of the job.\textsuperscript{83}

\textit{Workplace Relations Act}

68. The \textit{Workplace Relations Act 1996} (Cth) is the main source of legislative regulation of the employee-employer relationship. It provides that most conditions of employment, including awards,\textsuperscript{84} may not include discriminatory clauses and lists in its principal objects, the prevention of discrimination on the basis of disability.\textsuperscript{85} Despite emphasising the importance of anti-discrimination legislation throughout, the Act applies a similar ‘inherent requirements’ exception to that of the \textit{Disability Discrimination Act} described above. It allows discrimination to form the basis of termination of employment if the discriminatory reason is based on the inherent requirements of the position.\textsuperscript{86}

\textit{Occupational Health and Safety Acts}

69. Occupational health and safety legislation is implemented at both a Commonwealth and State level. In some states OH&S legislation allows employers’ actions to contravene anti-discrimination legislation, if it is considered ‘necessary’ for the protection of employees. Commentators have suggested this may encourage employers to undertake genetic testing in order to exclude individuals with a susceptibility to workplace illness, rather than

\textsuperscript{81} Otłowski, above n 68.
\textsuperscript{82} Disability Discrimination Act 1992 (Cth) ss 53, 54.
\textsuperscript{83} Disability Discrimination Act 1992 (Cth) s 15(4).
\textsuperscript{84} Workplace Relations Act 1996 (Cth) s.517.
\textsuperscript{85} Workplace Relations Act 1996 (Cth) s 4.
\textsuperscript{86} Workplace Relations Act 1996 (Cth) s.659(3).
making the workplace safer. In response, other commentators have suggested that a court is unlikely to allow discrimination as a ‘necessary’ outcome where there are non-discriminatory alternatives.\(^{87}\)

**International Instruments**

70. The international instruments relevant to bioethics, as discussed above, are explicit on the issue of genetic discrimination. Both provide, in different language, that genetic characteristics should not be used as a basis for discrimination “that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity…”\(^{88}\)

**Genetic Information and Non-Discrimination Bill 1998**

71. In 1998, Senator Natasha Stott Despoja introduced the *Genetic Privacy and Non-Discrimination Bill* to Australian Parliament. The bill sought to enact legislation that would prohibit genetic discrimination in Australia. The Senate Legal & Constitutional Affairs Committee recommended it was premature to legislate while the genetic technology was still so rapidly developing, and the Bill did not go ahead. As such it is not law, but represents the only attempt in Australia to deal with genetic information in its own right, rather than within a scheme which is primarily directed at other purposes.

**Analysis**

72. It is unclear under what level of security DNA samples collected by employers are kept. Presumably, collection and storage, as in both cases above, occur at accredited laboratories, and are therefore subject to

\(^{87}\) ALRC96 above n 2, Chapter 90.  
professional rules and guidelines. In light of this ambiguity, CLA advocates transparent requirements for security of sample storage, and recommends the development of mandatory professional standards which prescribe the minimum requirements of DNA storage security.

Recommendation 5: That mandatory professional standards be developed, setting minimum requirements of DNA storage security.

73. As discussed above, the Privacy Act 1988 does not protect or regulate the use of genetic samples taken from individuals, although some state privacy legislation might afford that protection. Where the DNA samples are taken for research or medical purposes, there are stronger protections available; however in the context of employment, there is no legislation clearly and unequivocally preventing the sharing of DNA samples. Individuals, therefore, have little assurances in the way of legislative protection against their samples being put to uses other than those originally proposed.

74. The NBSP has shown that, where large collections of DNA samples are retained, those samples have been made available for research and forensic purposes. It must be acknowledged, however, that where those samples were obtained for research purposes, they were first anonymised, and their use was subject to strict NHMRC ethical guidelines. Police seizure of such samples, however, has been seen in some states to be much less regulated. It is foreseeable that, given the lack of protection afforded to employee DNA sample collections, such secondary uses will eventually be proposed.

75. A particularly concerning secondary application of those DNA samples is their non-consensual genetic testing. It is unclear whether the Disability Discrimination or Workplace Relations Acts would afford any protection to individuals who might be discriminated against as a result of genetic results, as neither specifically includes genetic predisposition within the definition of
disability. Further, the ‘inherent requirements’ exception gives employers the ability to broadly construe the requirements of a position so as to exclude any predispositions that might arise.

76. Moreover, it has been recognised that it is probable that circumstances where a person might be discriminated against on the basis of genetic status may arise, without that person being aware. Given the unequal distribution of power in the employment relationship, it is foreseeable that an employer who wished to terminate the employment of a person with a genetic susceptibility would be able to construct an unrelated reason for that termination. Although there may be limited protections against genetic discrimination afforded by legislation, the inherently disadvantaged position of the employee means they may not realise or be able to prove that actions taken against them are as a result of discrimination on the basis of their genetic status.

77. CLA supports the view that human genetic databanks remain inadequately regulated while the ALRC/AHEC recommendations fail to be addressed. CLA contends that the provision of limited remedies to genetic discrimination is inadequate protection for employees. Greater protection needs to be afforded to employees by way of preventing unsolicited genetic testing, and thereby preventing the discrimination that may result. CLA contends that the collection of employee DNA samples should be immobilised until there are greater assurances and protections to prevent DNA from being subjected to secondary purposes.

Recommendation 6: That explicit protection against unsolicited genetic testing of DNA samples be adopted by way of:

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89 Otlowski, above n 68.
90 Stranger, above n 37.
(a) Legislative provisions specifically affording equivalent privacy protection to human biological and DNA samples.

(b) The creation of an offence of non-consensual DNA/genetic testing

Recommendation 7: That all employment related collection of DNA samples be immobilised until explicit protections against non-consensual uses of DNA be developed and implemented.

CONSEQUENCES FOR IMPROPER USE OF DNA SAMPLES

78. As has been outlined throughout this paper, DNA samples surrendered by employees to a scheme endorsed by their employer might be used improperly in a number of ways. This includes using the DNA for a purpose which was not consented to; inappropriate testing or comparison of DNA samples, for either forensic or medical purposes; or relinquishing DNA samples to the custody of a third party for forensic, research or medical purposes.

79. Outlined above, are several varied pieces of legislation and other forms of regulation that may offer the individual some protection from such improper uses. The protection they offer, however, is very limited. For the most part, each piece of legislation is directed to a different purpose, and only incidentally protects against the improper use of DNA samples.

80. If improper use is conducted by the employer, it seems that protection for the individual is limited, unless it results in genetic discrimination, or the passing on of genetic information after testing DNA samples. As the donation of genetic samples is viewed in other contexts as relinquishing control over that sample, it can be extrapolated that in this circumstance, if consent is valid, the employee relinquishes control over their DNA samples to their employer. Where consent is not valid, the employee may have recourse against the
procedure as a matter of common law, but only if material damage can be shown.

81. If the employer’s action involves the testing of samples, the individual will have recourse against the employer should the employer use that information either by passing it on, or by discriminating against the employee. In the application of both the Privacy Act, and anti-discrimination legislation, however, it has been seen above that the protection of the individual is not without exception.

82. If improper use is conducted by a third party, it is unlikely that there is available recourse against the employer for relinquishing those samples, unless contractual obligations which prevent such behaviour exist.

83. Other protections, such as common law trespass and confidentiality actions are time-consuming and difficult to establish, and require the demonstration of material damage before action can be taken and are therefore unlikely to adequately protect the individual.

ADEQUACY OF EXISTING SAFEGUARDS

84. A strong theme of this paper has been the inherently unequal nature of the employee-employer relationship. Because of the nature of that relationship, the employee is dependent upon legal protection to avoid the negative consequences any misconduct of their employer might have on them. Where the special nature of genetic information is concerned, the employee becomes especially vulnerable to any such employer behaviour.

85. The discussion above highlights the fundamentally inadequate protection of employee DNA samples collected for workplace purposes. Any existing
protections against improper collection, storage and use of DNA samples and any information gained from them, are limited most often to provisions developed for an unrelated purpose, but which coincidentally also cover the collection of DNA samples in the workplace. Any available recourse against inappropriate collection, storage or use of DNA samples is likely to be difficult to prove, and inadequate in restoring the individual’s position.

86. ALRC96 recommended at Chapter 12 the creation of a criminal offence of non-consensual DNA protection. That recommendation was referred to the Standing Committee of Attorneys General, but has not yet been implemented. Its creation and implementation is likely to provide further specific protection for the individual, both in providing a tangible means of discouraging employers from attempting such testing and in affording the individual with a means of recourse against inappropriate use of DNA. CLA strongly supports the creation of such an offence, and has included it above.91.

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91 See above, at recommendation 6.
CONCLUSION

87. In a society that embraces rapidly advancing genetic technology, appropriate protection of DNA samples is essential if the liberty, privacy and autonomy of employees is to be adequately protected in the workplace. DNA sampling schemes such as those proposed and implemented by the ADF and AFP will become more commonplace as the technology to implement them becomes more readily available. As that happens, the employee, already in an inherently weakened position in the workplace, will depend on legislative protection to circumvent inappropriate use of their DNA by their employer. As has been seen here, the regulation of such schemes is, at present, clearly inadequate. Further consideration and implementation of ALRC96 will afford greater protection to employees, but adequate protection will only be achieved with much greater regulation and oversight of such schemes.
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A chasm for protection of employee rights and liberties.

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