

# List of Proposals and Questions of Discussion

## Paper 66 from alrc

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### 3. A Standing Advisory Body on Human Genetics

**Proposal 3-1.** A Human Genetics Commission of Australia (HGCA) should be established under federal legislation as an independent, stand-alone, statutory authority with sufficient resources to fulfil its mission.

**Proposal 3-2.** As a general matter, the role of the HGCA should be to provide:

- on-going, high-level technical advice to Australian governments about existing and emerging issues in human genetics;
- similar high-level advice on the ethical, legal and social implications arising from these developments;
- national leadership in managing the process of change, including engagement of the public on these issues;
- direct expertise and a consultative mechanism for the development of policy statements and national guidelines in this area, where appropriate in association with other governmental agencies or the relevant industries and organisations;
- assistance with the development of community, school, university and professional education about human genetics; and
- a focus for the coordination and integration of various national — and perhaps regional and international — programs and initiatives.

**Proposal 3-3.** The HGCA also should have specific responsibility for:

- identifying genetic tests that have particular concerns or sensitivities attached to them, and thus may require special treatment — such as through restricted clinical request pathways or through the assignment of a higher risk classification by the Therapeutic Goods Administration;
- approving specific genetic tests for use by the insurance industry for risk-rating purposes, or by employers for compelling occupational health and safety reasons; and

- performing any similar function or providing expert advice on any other matters relating to human genetics, upon the request of the responsible minister or ministers.

**Proposal 3-4.** The HGCA structure should involve at least two principal committees: (a) a Technical Committee, and (b) an Ethical, Legal and Social Implications Committee.

**Proposal 3-5.** Appointments to the HGCA should ensure a balanced and broad-based range of expertise, experiences and perspectives relevant to the use and protection of human genetic information. The appointments process should involve consultation with appropriate communities and stakeholders.

**Proposal 3-6.** As a general rule, meetings of the HGCA and its committees should be open to the public.

**Proposal 3-7.** The HGCA should liaise closely with other relevant governmental departments, authorities and entities (such as the NMHRC and its committees, state and territory departments of health, the TGA, the OGTR, and AHMAC) to promote a national approach to the protection of human genetic information.

## **5. Regulating Access to Genetic Testing**

**Question 5-1.** Should legislation be enacted to require laboratories that conduct genetic testing to be accredited by the National Association of Testing Authorities, Australia (NATA) and to comply with accreditation standards in respect of all genetic testing?

**Question 5-2.** Should genetic test results be admissible as evidence in court proceedings only where the testing is conducted by (a) an accredited Australian laboratory in accordance with the relevant accreditation standards, or (b) an overseas laboratory that complies with equivalent standards?

**Proposal 5-1.** The National Pathology Accreditation Advisory Council (NPAAC), in consultation with NATA and the Royal College of Pathologists of Australasia (RCPA), should consider whether accreditation standards should ensure that laboratories conduct genetic testing only on bodily samples collected with the appropriate consent of the individual to whom the sample relates or as approved by a Human Research Ethics Committee (HREC).

**Proposal 5–2.** The *Therapeutic Goods Act 1989* (Cth) and *Therapeutic Goods Regulations 1990* (Cth) should be amended to enable the Therapeutic Goods Administration (TGA) to regulate home use genetic in vitro diagnostic devices (IVDs) and home use DNA identification test kits, including for parentage testing.

**Proposal 5–3.** The proposed HGCA should be responsible for developing codes of practice and other advice on home use genetic testing, including advice to the TGA on the regulation of genetic home use IVDs under the *Therapeutic Goods Act 1989* (Cth).

**Question 5–3.** Should legislation be enacted to prohibit Internet advertising of home use genetic testing unless approved by the TGA?

**Proposal 5–4.** The Standing Committee of Attorneys-General should initiate the development of a model criminal offence relating to non-consensual genetic testing, for enactment into Commonwealth, state and territory law.

**Proposal 5–5.** Criminal liability should attach to any individual or corporation that, without lawful authority, submits a sample for genetic testing, or conducts genetic testing on a sample, knowing (or recklessly indifferent to the fact) that the individual from whom the sample has been taken did not consent to such testing.

## 7. Information and Health Privacy Law

**Proposal 7–1.** As a matter of high priority, Commonwealth, state and territory governments should pursue the harmonisation of information and health privacy legislation as it relates to human genetic information. This would be achieved most effectively by developing nationally consistent rules for handling all health information.

**Proposal 7–2.** The *Privacy Act 1988* (Cth) should be amended expressly to: (a) define personal information to include bodily samples from an individual whose identity is apparent or can reasonably be ascertained from the sample; and (b) define a ‘record’ to include a bodily sample.

**Question 7–1.** Does the *Privacy and Personal Information Protection Act 1998* (NSW) provide an appropriate model for amending the *Privacy Act* to include bodily samples within the definition of personal information?

**Question 7–2.** What are the implications of Proposal 7–2 for the operation of the existing audit, investigation, complaints handling and enforcement provisions of the *Privacy Act*?

**Question 7–3.** If the *Privacy Act* were amended to cover genetic samples, what problems, if any, might arise in the relationship between that Act and other laws relating to bodily samples, such as the Human Tissue Acts?

**Question 7–4.** Should genetic samples obtained in Australia be exported only to jurisdictions whose laws provide protections equivalent to that of the *Privacy Act* and the NHMRC’s National Statement on Ethical Conduct in Research Involving Humans?

**Question 7–5.** Is NPP 9 of the *Privacy Act* an appropriate model for regulating the export of genetic samples?

**Question 7–6.** Does the *Privacy Act* adequately deal with issues that may arise in relation to the genetic samples and information of deceased individuals?

**Proposal 7–3.** The *Privacy Act* should be amended to clarify that ‘health information’ includes genetic information, whether or not the information is collected in relation to the health of, or the provision of a health service to, an individual.

**Proposal 7–4.** The *Privacy Act* should be amended to ensure that all small business operators that hold genetic information are subject to the provisions of the Act.

## **8. Anti-Discrimination Law**

**Proposal 8–1.** Discrimination on the ground of genetic status should continue to be dealt with under the framework of existing federal, state and territory anti-discrimination laws, subject to the specific proposals for legislative amendments identified in this Discussion Paper.

**Question 8–1.** Should the name of the *Disability Discrimination Act 1992* (Cth) (DDA) be amended to the *Disability and Genetic Discrimination Act 1992* (Cth)? Should the objects of the DDA be amended to clarify that discrimination on the basis of genetic status falls within the Act?

**Proposal 8–2.** Federal anti-discrimination legislation should be amended to:

- define ‘disability’ in the DDA and define ‘impairment’ in the regulations made under the *Human Rights and Equal Opportunity Commission Act 1986* (Cth) (HREOC Act) to clarify the application of the legislation to discrimination based on genetic status;

- define ‘impairment’ in the regulations made under the HREOC Act to clarify the application of the legislation to a disability that may exist in the future;
- insert a definition of ‘disability’ in the *Workplace Relations Act 1996* (Cth) to conform with federal anti-discrimination legislation, as amended by these proposals.

**Proposal 8–3.** The States and Territories also should consider amending their anti-discrimination legislation to accord with the policies reflected in Proposal 8–2.

**Question 8–2.** What form of words should be used in federal anti-discrimination laws to ensure that they apply to discrimination based on genetic status?

**Question 8–3.** Should discrimination on the ground of a medical record be added to the DDA and other relevant legislation as a prohibited basis of discrimination?

**Proposal 8–4.** The regulations made under the HREOC Act should be amended expressly to include discrimination on the basis of association with a person who has an impairment or disability.

## **11. Enforcing Compliance with the National Statement**

**Proposal 11–1.** The *National Health and Medical Research Council Act 1992* (Cth) should be amended to prohibit the conduct of any human genetic research, other than in compliance with the NHMRC’s National Statement on Ethical Conduct in Research Involving Humans (the National Statement).

**Question 11–1.** How should ‘human genetic research’, or a similar term, be defined for the purposes of the NHMRC Act?

**Question 11–2.** What sanctions should apply to non-compliance with the National Statement and to whom should the sanctions be directed?

## **12. Human Genetic Research and Consent**

**Proposal 12–1.** HRECs should be required to report annually to AHEC with respect to human genetic research proposals for which waiver of consent has been granted under the National Statement.

**Question 12–1.** What sort of information should be contained in HREC reports to AHEC on waiver of consent?

**Question 12–2.** Are any changes needed to: (a) the National Statement; or (b) the s 95 or s 95A Guidelines under the *Privacy Act*, in relation to waiver of consent by HRECs to the collection, use or disclosure of genetic samples or information for research purposes?

**Proposal 12–2.** The proposed new chapter of the National Statement dealing with human genetic research databases (see Proposal 15–1) should provide guidelines dealing specifically with obtaining consent to unspecified future research.

### **13. Encouraging Best Practice in Human Genetic Research**

**Proposal 13–1.** AHEC should develop model research protocols for human genetic research to provide guidance to HRECs, researchers, and research participants about best practice in the conduct of human genetic research. These protocols should include guidance on:

- the mechanisms for coding or de-identifying genetic samples and information used in research, and the relative advantages and disadvantages of each approach in different research contexts;
- the use of independent intermediaries to hold codes linking genetic samples or information with the identifiers;
- the discharge of legal and ethical obligations to inform research participants about the health implications of testing of their genetic samples; and
- full disclosure by researchers to research participants of information about actual or anticipated commercial arrangements connected with human genetic research proposals.

**Proposal 13–2.** AHEC should develop guidelines for preparing consent forms for human genetic research, covering such matters as:

- graduated consent options;
- full disclosure by researchers about actual or anticipated commercial arrangements;
- ownership or property interests in genetic samples or information;
- methods of protecting privacy; and
- withdrawal of consent by participants.

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## **14. Strengthening Review by HRECs**

**Question 14–1.** Are any changes needed to the reporting obligations of HRECs under the National Statement in order to enhance the operation of the current system of ethical review?

**Question 14–2.** Should HRECs be required to report to AHEC specifically on commercial arrangements relating to human genetic research proposals?

**Question 14–3.** Are the current minimum monitoring requirements adequate for human genetic research projects? Are there certain categories of human genetic research that require more active scrutiny by HRECs? If so, what changes should be made to the National Statement?

**Question 14–4.** How else might the role of HRECs in ethical review be strengthened? For example, should HRECs be accredited or should there be changes to their structure, composition or resourcing?

## **15. Human Genetic Databases for Research**

**Proposal 15–1.** The National Statement should be amended to include a new chapter providing ethical guidance on the operation of human genetic research databases.

**Question 15–1.** Should human genetic research databases be subject to a licensing or registration scheme? If so:

- would a licensing or registration scheme be preferable?
- how should human genetic research databases be defined for the purposes of licensing or registration?
- what conditions should attach to licensing or registration?
- what form of independent scrutiny of database operations should be involved?

**Question 15–2.** Should the proposed HGCA have any role in the regulation of human genetic research databases?

**Question 15–3.** Should the use of a gene trustee or other independent intermediary be a condition of the licensing or registration of human genetic research databases?

**Question 15–4.** Do we need legislation governing the disclosure, for law enforcement purposes, of genetic samples and information held in human genetic research databases?

## **16. Human Tissue Collections**

**Question 16–1.** Do we need legislation governing the disclosure, for law enforcement purposes, of the genetic samples or information held on Guthrie cards?

**Proposal 16–1.** The Australian Health Ministers' Advisory Council, in collaboration with key professional bodies, should develop nationally consistent policies and practices in relation to the collection, storage, use of and access to pathology samples, banked tissue, Guthrie cards and other samples collected and stored as part of a population genetic screening program.

## **17. Ownership of Human Genetic Samples**

**Proposal 17–1.** The common law right to possession of preserved samples, which is currently enjoyed by hospitals and others, should continue to be upheld, but full property rights in genetic samples should not be granted.

**Proposal 17–2.** The Human Tissue Acts should not be used as the vehicle for regulating collection, storage, access to, or use of genetic samples, whether for the purposes of human genetic research or otherwise.

## **18. Health Professionals and Family Genetic Information**

**Proposal 18–1.** NPP 2.1(e)(i) of the *Privacy Act* should be amended so that disclosure of genetic information by a health professional to the genetic relatives of a patient is permitted where failure to disclose would place the health or life of a genetic relative at serious risk.

**Proposal 18–2.** State and territory governments should consider amending their privacy legislation in accordance with Proposal 18–1.

**Proposal 18–3.** The NHMRC should develop guidelines for health professionals pursuant to s 7 of the NHMRC Act dealing with disclosure of genetic information to the genetic relatives of their patients. These guidelines should address the circumstances in which disclosure to genetic relatives is ethically justified or required, and the need for patients to be counselled about the disclosure of information in these circumstances.

**Proposal 18–4.** The guidelines referred to in Proposal 18–3 also should assist health professionals in dealing with requests for access to genetic information by the genetic relatives of their patients.

## 19. Genetic Registers and Family Genetic Information

**Proposal 19–1.** An organisation operating a genetic register for public health purposes should seek a Public Interest Determination (PID) under the *Privacy Act* to ensure that it can continue to collect family medical history information without breaching the NPPs.

**Proposal 19–2.** State and territory governments should consider amending their privacy regulation in accordance with Proposal 19–1.

**Question 19–1.** Should the proposed PID referred to in Proposal 19–1 also apply to the collection of health information from other health professionals for the purpose of verifying information provided by the registrant?

**Question 19–2.** Do the requirements for the de-identification of information on genetic registers contained in the NHMRC Guidelines for Genetic Registers cause problems for the effective operation of genetic registers? If so, how should these Guidelines be modified?

**Question 19–3.** Should the proposed PID referred to in Proposal 19–1 also apply to the use or disclosure of health information recorded on genetic registers?

## 20. Genetic Counselling and Medical Education

**Proposal 20–1.** As a matter of priority, Commonwealth, state and territory governments should develop strategies to assess and respond to the need for more genetic counselling services throughout Australia.

**Proposal 20–2.** Commonwealth, state and territory governments should examine options for the further development of genetic counselling as a recognised health profession, including the possibility of a registration system for certified genetic counsellors.

**Proposal 20–3** The proposed HGCA should develop genetic testing and counselling practice guidelines, in consultation with the Human Genetics Society of Australasia, state clinical genetics services, and other interested organisations. These guidelines should identify genetic tests, or categories of genetic tests, that require special treatment in relation to procedures for ordering testing and ensuring access to genetic counselling. (See Proposal 3–3).

**Proposal 20–4.** The Australian Medical Council and the Committee of Deans of Australian Medical Schools should pursue measures to enhance medical school programs in clinical genetics, genetic counselling and related ethical issues.

**Proposal 20–5.** The Australian Medical Council and the Committee of Presidents of Medical Colleges should pursue measures to enhance postgraduate training and continuing professional development programs for medical practitioners, whether general practitioners or specialists.

**Proposal 20–6.** The proposed HGCA should play a role in working with the relevant groups to design and enhance education and training programs aimed at improving genetic health services provided by medical practitioners and other health professionals. (See Proposal 3–2).

## **21. Population Genetic Screening**

**Question 21–1.** Should tests used in population genetic screening programs be required to meet an agreed standard for reliability, sensitivity and utility? If so, should the proposed HGCA play a role in such regulation?

**Proposal 21–1.** The Australian Health Ministers' Advisory Council, in collaboration with the proposed HGCA and key professional bodies, should develop nationally consistent policies and practices in relation to the implementation and conduct of population genetic screening programs, covering such matters as informed consent, counselling and testing standards.

## **24. Genetic Discrimination in Insurance**

**Proposal 24–1.** Although there is no demonstrated justification for departing from the fundamental principle underlying the market in voluntary, mutually rated personal insurance (namely, equality of information between the applicant and the insurer), where the underwriting of such insurance involves the use of human genetic information, the process of underwriting should be subject to the qualifications identified in Proposals 24–3 to 24–9 below.

**Proposal 24–2.** The proposed HGCA should monitor the experience of the insurance industry in using genetic information in underwriting, both in Australia and overseas, with a view to reviewing Australian insurance practices at a later time.

**Question 24–1.** Should there be a fundamental change to the way in which genetic information is used to underwrite personal insurance, such as the introduction of a two-tier system; a prohibition on the use of genetic information; or a public subsidy for poorer risks?

**Question 24–2.** Should an adult applicant for insurance be obliged to disclose the result of a genetic test undertaken while that person was a child?

**Proposal 24–3.** No predictive genetic test should be used by insurers in underwriting mutually rated insurance unless the test has been approved for that purpose by the proposed HGCA.

**Question 24–3.** Would Proposal 24–3 be implemented most effectively through an industry code or legislation? If the latter, should this be through amendment to: (a) the insurance exemption in anti-discrimination legislation; (b) the duty of disclosure in the *Insurance Contracts Act 1984* (Cth); or (c) both?

**Proposal 24–4.** The insurance industry, through its peak bodies and in consultation with the proposed HGCA, should develop and publish policies on the use of family medical history for underwriting mutually rated insurance.

**Proposal 24–5.** The *Insurance Contracts Act 1984* (Cth) should be amended to clarify the nature of the obligation of an insurer to provide written reasons for an unfavourable underwriting decision. Where such a decision is based on genetic information, the insurer should give reasons that are clear and meaningful and that explain the actuarial or statistical basis for the decision.

**Proposal 24–6.** The *Disability Discrimination Act 1992* (Cth) and related legislation should be amended to clarify the nature of the information required to be disclosed by an insurer and to ensure that the complainant is entitled to access to the information so disclosed.

**Proposal 24–7.** The insurance industry, through its peak bodies, should develop a policy regarding the provision of reasons by an insurer to an applicant in response to an unfavourable underwriting decision based on family medical history. The policy should ensure that the reasons given are clear and meaningful and that they explain the actuarial or statistical basis for the decision.

**Proposal 24–8.** The insurance industry, through its peak bodies, should develop appropriate mechanisms for reviewing underwriting decisions involving the use of genetic information. Such reviews should be:

- conducted in a timely and efficient manner;
- undertaken by a panel of individuals, each of whom is independent of the insurer that made the decision;

- carried out by suitably qualified individuals with a demonstrated understanding of insurance law and anti-discrimination law, underwriting practice, and clinical genetics; and
- binding on the insurer but not on the complainant.

**Proposal 24–9.** The insurance industry, through its peak bodies, should review its policies and practices in relation to the training and education of industry members and their authorised representatives in relation to the nature, collection and use of genetic information in insurance.

## **25. Insurance and Genetic Privacy**

**Proposal 25–1.** Insurers should review their consent forms, including medical authority forms, to ensure that they contain sufficient information about the collection and use of genetic information to allow applicants to make an informed decision about whether to provide the information.

**Question 25–1.** Does the practice of ‘bundling consents’ by insurers undermine the ability of an applicant to make an informed decision about whether to provide genetic information to an insurer? If so, what measures should be taken to address this problem?

**Proposal 25–2.** Insurers should seek a Public Interest Determination under the *Privacy Act* in relation to the practice of collecting family medical history from applicants for use in underwriting insurance policies in relation to those applicants.

**Question 25–2.** Is there evidence that genetic information is shared between various arms of insurance organisations? If so, does this practice raise concerns about the protection of the privacy of genetic information? How might these concerns be addressed?

## **27. Genetic Discrimination in Employment**

**Proposal 27–1.** Employers should be able to collect and use genetic information in relation to their employees only where this is reasonable and relevant within the terms of anti-discrimination and occupational health and safety legislation, and subject to the limitations set out in the proposals in Chapters 28–30.

## 28. Inherent Requirements of the Job and Related Issues

**Proposal 28–1.** In assessing whether an applicant or employee is able to perform the inherent requirements of a job, only current ability to perform the inherent requirements should be relevant. The term ‘inherent requirements’ in the DDA, the HREOC Act and the *Workplace Relations Act 1996* (Cth) should be clarified accordingly. The States and Territories also should consider amending their legislation to similar effect.

**Proposal 28–2.** Peak employer associations should encourage members to produce clearly defined job descriptions that set out the inherent requirements of every position in the workplace.

**Proposal 28–3.** The DDA should be amended to prohibit an employer from requesting or requiring genetic information from a job applicant or employee unless the employer can demonstrate that the information is necessary for a purpose that does not involve unlawful discrimination, such as ensuring that a person is able to perform the inherent requirements of the job. The States and Territories should consider adopting a similar provision in their anti-discrimination legislation, where one does not already exist.

**Proposal 28–4.** HREOC should, in consultation with the proposed HGCA and other relevant stakeholders, develop Disability Standards dealing with the collection and use of genetic information in employment. As an interim measure, HREOC should issue guidelines in this area.

## 29. Occupational Health and Safety

**Proposal 29–1.** Genetic screening of applicants or employees for susceptibility to work-related conditions should be conducted only where:

- there is strong evidence of a clear connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of the applicant or employee; and
- the danger cannot be eliminated or significantly reduced by reasonable measures taken by the employer to reduce the environmental risks.

**Proposal 29–2.** The National Occupational Health and Safety Commission (NOHSC), in consultation with the proposed HGCA, should develop model regulations regarding genetic screening for susceptibility to work-related conditions. The model regulations should:

- specify the genetic tests that have been approved for use;
- provide guidelines for interpreting test results;
- indicate the circumstances in which family medical history may be collected and used;
- make provision for genetic counselling for those undergoing screening;
- provide for the confidentiality of test results; and
- indicate appropriate responses by employers where genetic screening reveals relevant susceptibilities.

**Proposal 29–3.** Genetic monitoring of employees should be conducted only where:

- there is strong evidence of a clear connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of the employee; and
- the danger cannot be eliminated or significantly reduced by reasonable measures taken by the employer to reduce the environmental risks.

**Proposal 29–4.** NOHSC, in consultation with the proposed HGCA, should develop model regulations for the conduct of genetic monitoring of employees exposed to hazardous substances in the workplace.

**Proposal 29–5.** Genetic information should be collected from an applicant or employee and used for the protection of third party safety only where:

- the applicant or employee’s condition poses a real risk of serious danger to the health or safety of third parties; and
- the danger cannot be eliminated or significantly reduced by other reasonable measures taken by the employer to eliminate or reduce the risks.

**Proposal 29–6.** NOHSC, in consultation with the proposed HGCA, should develop model regulations with respect to the collection and use of genetic information from applicants and employees for the protection of third party safety. (See also Proposal 29–2).

### 30. Employment and Genetic Privacy

**Proposal 30–1.** The definition of ‘employee record’ in the *Privacy Act* should be amended to exclude genetic information held by an employer in relation to a current or former employee.

**Proposal 30–2.** The pending inter-departmental review of the employee records exemption to the *Privacy Act* should consider whether health information generally should be excluded from the ambit of the exemption.

### 31. DNA Parentage Testing

**Proposal 31–1.** Legislation should be enacted to ensure that DNA parentage testing in Australia is conducted only by laboratories accredited by the National Association of Testing Authorities, Australia (NATA), and only in accordance with NATA accreditation requirements.

**Proposal 31–2.** NATA should review its accreditation requirements for DNA parentage testing to ensure that they meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing counselling. (See also Proposals 31–6, 31–9, 31–11 and 31–12).

**Proposal 31–3.** Part IIA of the *Family Law Regulations 1984* (Cth) should be reviewed to ensure that the legislative requirements for parentage testing meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing counselling. (See also Proposal 31–7).

**Proposal 31–4.** In accordance with Proposals 5–2 and 5–3, home use parentage test kits should be subject to regulation under the *Therapeutic Goods Act 1989* (Cth) and the *Therapeutic Goods Regulations 1990* (Cth).

**Question 31–1.** What steps, if any, should be taken to regulate Internet advertising of home use DNA parentage test kits and testing services?

**Proposal 31–5.** The *Family Law Act 1975* (Cth) should be amended to provide that parentage testing reports are admissible in proceedings under the Act only if made in accordance with the provisions of the *Family Law Regulations 1984* (Cth).

**Proposal 31–6.** NATA should develop accreditation requirements that require laboratories to be satisfied that the sample of each adult donor has been supplied for parentage testing with his or her consent.

**Proposal 31–7.** The *Family Law Regulations 1984* (Cth) should be amended to require that the prescribed affidavit and declaration submitted to a laboratory in relation to parentage testing include a signed consent form for each adult donor indicating that the sample has been supplied with his or her consent.

**Proposal 31–8.** Legislation should provide that a child who: (a) has attained 12 years of age; and (b) has sufficient maturity to make a free and informed decision, may decide on his or her own behalf whether to submit a genetic sample for parentage testing. The child's maturity should be assessed by two independent professionals, such as teachers, social workers, counsellors, medical practitioners, or ministers of religion, who have known the child for not less than two years.

**Proposal 31–9.** NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the required child consent in accordance with Proposal 31–8.

**Proposal 31–10.** Legislation should require that, where a child does not have sufficient maturity to make a free and informed decision whether to submit a genetic sample for parentage testing, such testing can be performed only with the written consent of all persons with parental responsibility for the child, or pursuant to other lawful authority. Where one person with parental responsibility withholds consent or cannot reasonably be contacted, a court should be authorised to make a decision on behalf of the child.

**Proposal 31–11.** NATA should develop accreditation requirements to ensure that laboratories conducting DNA parentage tests obtain the required parental consents in relation to samples of every child who is under the age of 12 years or who, being over that age, lacks sufficient maturity to consent on his or her own behalf.

**Proposal 31–12.** NATA should develop accreditation requirements that require laboratories performing DNA parentage tests to:

- inform all persons who provide genetic samples of the availability of counselling, both at the time the samples are submitted for testing and at the time the results are made available; and
- forward test results to an independent person who has the skills to counsel the tested individuals and other relevant family members. Such a person should be nominated by each individual who has provided a genetic sample, and might be a qualified counsellor, social worker, minister of religion, medical practitioner, lawyer or court officer.

**Question 31–2.** How should DNA kinship testing (other than parentage testing) be regulated? Should NATA accreditation standards be extended to cover this form of genetic testing?

## **32. Genetic Information and Aboriginality**

**Proposal 32–1.** The Aboriginal and Torres Strait Islander Commission (ATSIC) should consider the appropriate test or tests to be applied in determining Aboriginal or Torres Strait Islander identity. To the extent that any such test requires evidence of Aboriginal or Torres Strait Islander descent, ATSIC should consider the appropriateness or otherwise of using genetic testing and genetic information for this purpose.

**Question 32–1.** Are there circumstances in which genetic information may be relevant to a native title claim made under the *Native Title Act 1993* (Cth)? If so, how should genetic information be regulated to protect privacy and prevent unfair discrimination?

## **33. Immigration**

**Proposal 33–1.** The Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) should review its policies and procedures on the provision of information to applicants about kinship testing. Relevant officers should be required to advise applicants about the potential implications of kinship testing and the desirability of seeking counselling before or after testing.

**Proposal 33–2.** DIMIA should review the adequacy of its policies and procedures for dealing with identity fraud in relation to kinship testing.

**Question 33–1.** Should procedures for conducting genetic kinship testing for the purpose of migration decision making be given more formal status, for example in the *Migration Regulations 1994* (Cth)?

**Proposal 33–3.** The Department of Health and Ageing, in consultation with DIMIA and with the proposed HGCA, should develop policies on the use of predictive genetic testing and information for the purpose of assessing the health requirements under migration legislation.

## **35. Harmonisation of Forensic Procedures Legislation**

**Proposal 35–1.** The Commonwealth, States and Territories should work together to achieve harmonisation in Australian forensic procedures legislation, in particular in relation to the collection, use, storage, destruction and index matching of forensic material and the DNA profiles created from such material. Inter-

jurisdictional sharing of forensic material and DNA profiles, whether on a bilateral basis or via the national DNA database system, should be permitted only after such harmonisation has been achieved.

**Proposal 35–2.** In order to achieve greater transparency, ministerial agreements for the sharing of information and inter-jurisdictional matching protocols should be prescribed in regulations.

## **36. Criminal Investigations**

**Proposal 36–1.** Except in relation to volunteers, the consent provisions should be removed from forensic procedures legislation so that an order by the appropriate Australian Federal Police officer or judicial officer is required before a forensic procedure can be carried out on a suspect or serious offender.

**Proposal 36–2.** Notwithstanding Proposal 36–1, forensic procedures legislation should continue to provide that suspects and serious offenders must be given prescribed information about the nature and consequences of the forensic procedure prior to it being carried out.

**Proposal 36–3.** Forensic procedures legislation should provide that children and incapable persons who are volunteers should be given the prescribed information about the nature, purpose and consequences of a forensic procedure prior to it being carried out. (See also Proposal 36–2).

**Proposal 36–4.** Forensic procedures legislation should provide that a forensic procedure may be carried out on a child volunteer of 12 years or above only with the consent of a parent or guardian and the child.

**Proposal 36–5.** Forensic procedures legislation should be amended by:

- specifying that known victims of crime should be treated as volunteers;
- inserting a new index for ‘identified victims’ profiles’ into the DNA database system, with limited index matching rules that exclude comparisons between this index and the crime scene index; and
- providing that specified information should be given to victims regarding the storage of their profiles.

**Proposal 36–6.** Regulations or police guidelines should be developed in every jurisdiction on the conduct of mass screening programs, both in relation to the approval process for initiation as well as the manner in which such programs are conducted.

**Proposal 36–7.** Forensic procedures legislation should be amended to delete reference to the DNA profiles of blood relatives of missing persons from the definition of the ‘missing persons index’.

**Proposal 36–8.** Forensic procedures legislation should provide that samples (including crime scene samples) collected or otherwise obtained for use in the law enforcement context may be subject to genetic testing and analysis only with respect to the non-coding sections of the DNA, and only for the purposes of creating a DNA profile, quality assurance or equipment validation.

**Proposal 36–9.** Forensic procedures legislation should provide that forensic analysis of genetic samples must be conducted only by laboratories accredited by NATA in the field of forensic science.

**Proposal 36–10.** Forensic procedures legislation should require the permanent retention of forensic material found at crime scenes to ensure the preservation of crime scene material for post-conviction analysis.

**Proposal 36–11.** Forensic procedures legislation should provide that forensic material taken from a suspect, and any information obtained from its analysis, must be destroyed as soon as practicable after the person has been eliminated from suspicion, or police investigators have decided not to proceed with a prosecution in relation to that investigation.

**Proposal 36–12.** Forensic procedures legislation should be amended to prohibit the establishment or maintenance of any DNA database that does not fit within the legislative definition of a DNA database system.

**Proposal 36–13.** Forensic procedures legislation should be amended to provide for independent, co-ordinated and nationally consistent monitoring of the operation of the entire national DNA database, and in particular the interaction of the forensic procedures regimes operating in each jurisdiction that participates in the national DNA database system.

**Proposal 36–14.** Forensic procedures legislation should be amended to:

- specify the person responsible for notifying the forensic laboratory, and CrimTrac, of the destruction date of forensic material and any information obtained from it;
- establish a process for persons to obtain confirmation that their forensic material, and any information obtained from it, has been destroyed; and

- provide (in regulations) a standard consent form for use at the time the forensic procedure is carried out to enable a volunteer (or parent or guardian) to specify the retention period for both the forensic material and any information obtained from it.

**Question 36–1.** Should the definition of ‘destruction’ in Part 1D be changed to provide for physical destruction of forensic material and information obtained from its analysis? Do the practical difficulties in tracing and physically destroying all remnants of a sample, and all records of the profile, justify confining privacy protection to de-identification rather than physical destruction?

### **37. Criminal Proceedings**

**Proposal 37–1** The National Judicial College of Australia and the Law Council of Australia (through its constituent professional associations) should ensure the availability of continuing legal education programs for judges and legal practitioners, respectively, in relation to DNA evidence.

**Proposal 37–2.** A standard jury direction should be inserted into the *Evidence Act 1995* (Cth) for use where DNA evidence has been admitted in criminal proceedings. The direction should outline the warning that trial judge should give the jury regarding the need for caution in evaluating DNA evidence and the statistical calculations relating to that evidence.

**Proposal 37–3.** The National Institute of Forensic Science should provide ongoing guidance to forensic scientists and legal practitioners regarding reliable methods of DNA analysis, statistical calculation, and presentation of evidence in criminal proceedings.

**Proposal 37–4.** Forensic procedures legislation should be amended to provide that the prosecution has a duty to provide defendants with reasonable pre-trial notice of all DNA samples collected at a crime scene in order to give defendants an opportunity to have this evidence independently analysed.

### **38. Post Conviction Use of Genetic Information**

**Proposal 38–1.** The Commonwealth should legislate to establish an independent body to consider applications for post-conviction review based on DNA evidence where the person provides prima facie evidence that there has been a miscarriage of justice.

**Proposal 38–2.** The Standing Committee of Attorneys-General should consider developing equivalent legislation and processes in the States and Territories.

### **39. Civil Proceedings**

**Proposal 39–1.** The National Judicial College of Australia and the Law Council of Australia should ensure the availability of continuing legal education programs for judges and legal practitioners, respectively, in relation to the use in civil proceedings of evidence based on genetic information.

**Question 39–1.** Should employers or insurers have access to an employee’s genetic information to determine the liability, or to assess compensation or damages, in relation to a workers’ compensation claim or a common law claim for work-related injury?

