



# Informing about genetics – a submission to the Australian Law Reform Commission Inquiry into the protection of human genetic information

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*This submission has been prepared by  
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## **Introduction**

This paper is a contribution to the debate on genetic information and its use. It signals the types of matters that UnitingCare NSW.ACT would take into account in assessing future detailed policy proposals from the ALRC. It is a preliminary comment, not a position paper.

The ALRC Issues Paper is an excellent paper. It provides good background information and appropriate case studies to illuminate the sort of situations that need to be taken into account in developing this area of policy.

The Issues Paper recognizes that there are pitfalls if the law either underestimates or overestimates the significance of genetic information. It exposes a number of competing concerns that must be taken into account in developing the law in this area. It exposes a number of ethical dilemmas.

The view of this submission is that some of these ethical dilemmas can only be resolved by ethical argument to clarify the relevant human rights and concepts, and empirical research to ensure that proposed solutions actually meet the needs of particular groups who experience genetic related illness or disability.

Since different genetic conditions have quite different effects on people's lives and relationships, it is crucial that people with different genetic disabilities and illnesses be consulted. There are a number of places in the Issues Paper where dilemmas arise that really cannot be solved by theoretical concepts alone. They involve judgements that can only be made by the people with particular genetic conditions and the judgement may well vary from one condition to another. The discussion below, for

example, differentiates between information about breast cancer and information about Huntington's disease.

All comments within this submission assume the current privacy legislation and the confidentiality provisions in health and other professions. The discussion is not about this basic principle, but about what it means, and what are the legitimate exceptions to it, given the particular significance of genetic information.

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## ***A methodological issue – what are the underlying principles?***

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It is clear from the Issues Paper that there are a number of overlapping issues in considering genetic information and privacy. To resolve these, there is need to define a number of concepts, their origins and warrant. For example, it is somewhat confusing to talk about "the right to know" or "the right not to know" since these are not in themselves human rights and the ethical implications vary depending on what knowledge is involved. There is no "right to privacy", but rather a right to freedom from arbitrary interference with privacy. This leads to the question of what is "arbitrary" interference, and what is appropriate action in the light of various other rights and responsibilities.

The human rights instruments recognize as valid only those limitations on human rights that are determined by law, are compatible with the nature of the rights, and are for promoting the general welfare in a democratic society. In some matters raised in the Issues Paper, there is a danger that some arbitrary principle such as the so-called "right not to know" is substituted for an analysis of which rights are at stake in the various options that are possible. Principles need to be understood in a

context-sensitive way – is only one right or principle at stake, or are there several rights that need to be weighed against one another. While some human rights are about limiting government action, other human rights require government action.

Some of the human rights relevant to matters raised in the issue paper are as follows.

#### **UNUDHR**

Article 3 – the right to life, liberty and security of person.

Article 7 – the right to equal protection before the law.

Article 12 – “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation.”

Article 16 – marriage requires the free and full consent of both intending spouses.

#### **ICCPR**

Article 6 (1) “Every human being has the inherent right to life”.

Article 17 – about privacy

Article 23 – right to marry and found a family

#### **ICESCR**

Article 7 (b) the right to safe and healthy working conditions

Article 10 Right of children and families to protection

Article 12 – the right to “the highest attainable standard of physical and mental health”

The implication of the above rights taken together would seem to be that the law should ensure that genetic information is used only for the benefit, and not for the detriment, of those persons to whom it pertains. In determining benefit, there is a need to seriously how genetic information can be used to protect and enhance their health, and the health of their family.

The international human rights instruments recognize that people do not exist in isolation, but as part of families and communities to whom they have responsibilities. Since genetic material is, by its very nature, familial, it would seem to be consistent with the concept of human rights

to take seriously the health implications that genetic information has for other family members. The human rights instruments are about limiting government’s arbitrary interference in the lives of individuals and families, not about promoting one individual’s interests at the expense of the rights of other members of that individual’s family. In particular, it would seem to be reasonable to expect genetic information to be used for the purposes of protecting the health of the members of the family.

Informing people of information that has the potential to improve or protect health is not “arbitrary interference”, but purposeful and consistent with the nature of human rights. Failure to provide such information would seem to be “arbitrary” interference, since it denies people access to information that can affect their health. Failing to give people access to relevant information limits their choices and their ability to act.

This argument requires that there be differentiation between information that has some potential to be used to improve health, and information that indicates health status but which cannot be used to improve that status. Information has potential to improve health if it can lead to preventative measures being put in place, or lead to monitoring and early diagnosis so that curative treatment is possible. Neither prevention nor cure needs to be 100% effective to be taken into account under this argument – if it improves health prospects significantly, then that probably is sufficient.

#### ***Applying these principles to case studies in chapter 3***

To take two of the examples in Chapter 3. In the case of breast cancer, genetic information might lead to more careful monitoring and therefore early detection of the disease and a higher likelihood of treatment curing the illness. The right to health would imply that it is appropriate to share the relevant information with other family members. With Huntington’s Disease, on the other hand, knowing the information about oneself does not, at the present time, have any positive potential for health. For some people, it is burdensome knowledge and may damage their mental health. If they prefer not to know their exact status, it would seem inappropriate to tell them. Also, the

fact that someone will develop Huntington's Disease in later life does not outweigh the fact that the person is a unique individual who may enjoy life and make a unique contribution to society before the onset of the disease. The disease does not eliminate past life achievements, and does not negate their human worth.

However, in the case study regarding Huntington's Disease in Chapter 3, there is a further issue – one parent wanting to know the status of her unborn child, and the other parent not wanting to know, because of its implications for himself rather than the child. This changes the whole situation. Best practice in genetic counseling requires that parents be encouraged to consider the implications of acquiring particular information about their unborn child, and have some idea of what they would do if particular results emerge, before they embark on testing. Some mothers, for example, prefer not to have certain tests during pregnancy because the only choice would be to abort or not to abort. Having already decided not to abort, they quite legitimately see no point in having some tests. It would be inappropriate to force them to acquire genetic information in this case.

An important point needs to be made here. The Uniting Church recognize the right of parents to decide whether or not to have a child with a diagnosable disability, but we encourage parents to recognize that the human worth of the child is not determined by whether or not the child has a disability. The church questions the view that because a person has a genetic makeup that will result in a disability or illness, there should be an abortion. In our experience, people with disabilities and genetic diseases value their own lives and very few of them question their own birth or their life after acquiring a disability. The idea that a genetic problem negates all other aspects of a human life is immoral, discriminatory, and unrealistic. Law about genetic testing and the use of genetic information should NOT be based on a view that discovery of certain genetic conditions will "normally" lead to an abortion.

We would be strongly opposed to the use of genetic information to force or strongly encourage a mother to abort a fetus.

In Case Study 3-2 the problem is that the parents are unclear about how they see the implications of the information. Or, to be more precise, the mother is unclear and the father does not want to know. At the very least, they need to be offered family counseling to help them deal with the situation and make a shared decision about what decisions need to be made and what should be left unknown. Public policy cannot resolve the tensions in this family, but it can ensure that the appropriate resources are made available so the family has real choices about how they relate to one another and to the family's genetic information.

This is not about the right to know or not know, but rather about the need to have access to appropriate services if one is to fulfil one's responsibilities in relation to genetic information about one's family.

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#### ***Are professional codes of ethics enough?***

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It is obvious that around the world, genetic material has been collected and analysed by a wide range of individual researchers and organizations with a diversity of medical, scientific and commercial aims. Many of these people do not seem to be required to adhere to any particular code of ethics. This is evident in the fact that genetic material, that is, naturally occurring DNA sequences, has been patented, as if it was an invention rather than a discovery. In some cases, unusual genetic material from Indigenous peoples has been patented and in other cases stem cell material, without regard to the rights and interests of the individuals and communities from whom the original material was taken.

As the ALRC Issues Paper points out on pages 126-7, there are a number of reasons why genetic information is particularly sensitive, including the fact that it conveys information not only about the individual, but also, by implication, about relatives, and the predictive nature of some genetic information.

There are a number of reasons why professional codes of ethics can be inadequate in dealing with issues of privacy related to genetic information.

- (a) Codes of ethics tend to focus on the individual relationship of professional with patient or client. Genetic information may involve other people with similar or competing interests to the client or patient.
- (b) Many people with access to genetic information are not adequately covered by codes of ethics.
- (c) Codes of ethics were not formulated with genetic information in mind.
- (d) The increasing involvement of commercial corporations in health care means that interpretation of codes of ethics maybe skewed by commercial considerations.

### **Questions 4.1-4.3**

It appears from chapter 4 (4.74 – 4.79) that not all genetic information will be considered “health information”, although health information is subject to greater safeguards than some other types of information. It seems inappropriate and dangerous that genetic information be treated differently depending on who collects it and for what purpose. If some genetic information should be treated with a high level of confidentiality, then all genetic information should be so treated. The onus should be on those want some genetic information to be less protected to show why this is appropriate.

Chapter 4 has some interesting implications regarding people who are adopted, and people who are the result of Artificial Insemination by Donor. If it is recognized that family genetic information belongs to the family rather than the individual, and that health purposes are served by sharing such information, then society will need to reconsider matters such as anonymous sperm donations and the priority given to maintaining the confidentiality of biological parents whose children have been adopted. In many cases, mothers, having been told at the time of the adoption to forget the incident and the child and get on with their lives, 40 or 50 years later when approached by the offspring cannot remember who the

father was. This is problematic on both sides – the father and his known relatives are excluded from information about one of their genetic relatives, and the adopted child is excluded from half their genetic information.

There is an urgent need to require that any records identifying sperm donations or the biological parents of adopted children be preserved, whether or not that material can currently be disclosed. Once records are destroyed, as they often have been by adoption agencies, they cannot be recovered.

That is, if it is accepted as a principle of legislation that people have right to family genetic information, this will have implications for other legislation and public policy.

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### ***Ownership of genetic material***

The problem with question 7-5 is that it deals with one aspect of ownership of genetic material in isolation from other aspects. The question needs to be set in a broader context.

It is of some concern that corporations seem to be able to acquire tissue samples and use them for purposes not intended by the individuals from whom those samples were taken, or the communities to whom the individuals belong.

Particularly worrying is the evidence that some corporations have patented human genetic material, such as particular DNA sequences which are associated with particular diseases or produce particular proteins. Naturally occurring genetic sequences and their biological function constitute scientific discoveries, not inventions. The law seems to have erred in allowing such patents. The laboratory synthesis of the same sequence, or its incorporation into a treatment is of course a different matter, and can appropriately be patented. The patenting of naturally occurring genetic sequences gives corporations property rights that are inappropriate. It allows them to control and limit scientific research, and to override the rights and needs of the individuals and communities from which the original material came. They have not given informed

consent to use these samples, because they did not know at the time the commercial purposes to which the material would be put, or the restrictions that would accompany such use.

However, it can be argued that this is not a matter of privacy, but of commercial exploitation of human beings as if they are a crop or a herd. This is inconsistent with respect for human dignity, and inconsistent with the right of peoples to sovereignty over their own natural resources.

Where the samples come from research, this is an abuse of the gift relationship. People cooperate in a research project, to contribute to knowledge, only to find that their genetic material is used to make large profits for corporations, many of whom acknowledge no responsibility to share their profits with the community.

The human genome, the naturally occurring sequences of DNA material that constitute genes and generate protein belong, from a Christian viewpoint, to God. They are not human inventions. Human beings may discover the sequence, but human beings did not invent them, any more than the British invented Australia. Legal decisions that allow corporations to patent and thus own such information are the equivalent of those that supported *terra nullius*.

The human genome should not be controlled by commercial corporations. It is not their invention. They do not have to make their research results known publicly, but they should not be able to prevent or limit academic, publicly available research on such material.

These lines of argument suggest that there may also be limits to an individual's ownership of their own genetic material. We share in the genetic inheritance of humankind; it is not anyone's exclusive possession.

It is not clear in what sense the human right to freedom from arbitrary interference is violated by allowing research on unidentifiable tissue samples. If the sample cannot be identified, what is the privacy issue? If the research is for academic medical research that will be publicly available, it is hard to see what exactly is the problem. Indeed, it could be argued that we

each have a responsibility to contribute to such research, provided it is for the public interest rather than private commercial interests.

There is need to avoid the human rights fundamentalism that absolutises the rights of the individual at the expense of the rights of people as collectives. In the end, the individual right to health depends on adequate knowledge of how the human body, including human genetics, functions. Medicine would still be in the dark ages if doctors had not shared information about patients in the interests of expanding knowledge. It can be argued that anyone who accepts medical treatment gives tacit approval to all the information sharing that has allowed treatment to be created. It is would appear to be immoral to want the benefits of research without contributing at the minimal level of unidentifiable samples and information to the research.

That is, while it may be appropriate to allow individuals a form of ownership over tissue samples and genetic information to prevent commercial exploitation, it would appear to be ethically inappropriate to allow individuals to prevent the sharing of unidentifiable information that is the *sine qua non* of public research, provided that that information is not gathered on a discriminatory basis (whether on the grounds recognized in antidiscrimination law, or other grounds such as class), ie provided it is not gathered from groups defined by characteristics irrelevant to the purpose of the research. ***Disclosure of information to employers, insurers, and researchers***

- One problem with privacy legislation is that a wide range of things can be done with information provided that the individual gives their consent to a company to disclose the information. This assumes that individuals are aware of the implications, for themselves and others, of information being disclosed. This is likely to be untrue in many situations. People lack the information necessary to give informed consent. This makes legislative requirements hollow.

- Reliance on individual consent also ignores the difference in power in the relationship of individuals with organizations. Employers and insurance companies have considerable power compared to individuals, based on their economic power, knowledge power, and coercive power. Individuals can feel powerless to say “no” to insurance companies or employers. They need the law to protect them from unnecessary invasion of their privacy and erosion of their interests.
- It is therefore important that the matter of *informed* consent be adequately covered in legislation which allows companies and researchers to ask people to consent to use of their genetic information.
- The issues paper mentions the dilemma between individuals wanting privacy and employers wanting to avoid employing individuals with a genetic makeup that makes a particular work context hazardous. The international human rights require that workplaces be safe and healthy. This appears the articles about work and about health. It would appear to be a valid interference to require that people be tested for a genetic condition that would mean a particular workplace was hazardous. This is not about discrimination but about fulfilling employer responsibilities. This argument only works, however, if the genetic information requested is about a specific characteristic related to the workplace – a genuine occupational qualification and if the conditions set out in 10-81 are met. Where genetic information does not fulfil these conditions, then it should not be available to employers, since there is a human right to work. To base assessment on a genetic characteristic rather than work qualifications, experience and performance is a clear case of discrimination on irrelevant characteristics and should not be allowed.
- At the seminar UnitingCare NSW.ACT held last year on genetic screening, concern was expressed about the level of discrimination people with disabilities experience from insurance companies. Insurance is about spreading of risk. It is inappropriate for either the company to exclude all risk or an individual customer to expect insurance for an inevitable outcome. We have no simple solution to this, but suggest that rather than extending the general exemption or right of insurance companies to information they should have to demonstrate the appropriateness of the information they seek and the purposes to which it is put.

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