Genetic Privacy:
Issues in Aotearoa/New Zealand

Jennifer Molina
JRM116@student.canterbury.ac.nz

June 2005

This project was completed as part of a summer studentship at the Social Science Research Centre, University of Canterbury, Christchurch, New Zealand between Nov 2004 and Feb 2005.

Supervised by:
Rosemary Du Plessis
School of Sociology and Anthropology, University of Canterbury
Rosemary.duplessis@canterbury.ac.nz

The work reported in this document is part of a larger interdisciplinary research programme: Constructive Conversations/Kōrero Whakaaetanga: Biotechnologies, dialogue and informed decision-making. This programme is funded by the Foundation for Research Science and Technology and is based at the University of Canterbury. The programme has been running for two years, and has many different facets, but one component focuses on facilitating the participation by members of the community in discussion and policy making in the field of new health biotechnologies. The focus in the first two years of this programme has been on social, cultural, ethical and spiritual issues relating to genetic testing. Visit the website for this project: www.conversations.canterbury.ac.nz
ABSTRACT

This paper examines various privacy issues relating to genetic testing that arose in the context of 16 predominantly Pākeha focus groups in Aotearoa/New Zealand. Participants were given three fictional scenarios about a potential genetic future and asked to discuss the implications of such a future for themselves as individuals and for others. Privacy emerged as an important issue within a largely ‘genetic exceptionalism’ discourse, where ambivalence arose between participants’ commitment to ‘the common good’ of increased knowledge about human health and the potential risks new genetic health technologies could pose to their individual privacy. The central issues discussed in the focus groups were: the potential for discrimination in insurance and employment based on genetic test results; the pros and cons of criminal DNA databases; the merits of both commercial and government control of genetic information, and security issues related to the electronic storage of DNA. All of these issues will be analysed in relation to international policy documents on genetic testing from Canada, Australia and the United Kingdom, and recent academic literature on ‘genetic privacy’. This is followed by a brief overview of the current regulatory framework in New Zealand and a discussion of the challenges for policy makers in Aotearoa/ New Zealand of ensuring the privacy of people’s genetic information.
## CONTENTS

1. Introduction ........................................ p.4
2. Methodology ........................................ p.6
3. ‘The Common Good’ versus Risks to Individual Privacy p.7
7. Control & Storage of DNA ............................. p.15
8. The New Zealand Regulatory Framework ................ p.19
9. Conclusion ........................................... p.21
10. References .......................................... p.23
1. INTRODUCTION

This paper examines various privacy issues around genetic testing that arose in the context of 16 predominantly Pākeha focus groups in Aotearoa/New Zealand. Participants were given three fictional scenarios about a potential genetic future and asked to discuss the implications of such a future for themselves as individuals and for others in Aotearoa/New Zealand. Privacy emerged as an important issue within a largely ‘genetic exceptionalism’ discourse, where ambivalence arose between participants’ sense of responsibility to ‘the common good’ and the potential risks new genetic health technologies could pose to their individual privacy.

From my initial overview of the transcripts, I discerned a general discourse of fear that the opportunity for misuse of new genetic health technologies may be too great and could therefore “jeopardise my generation’s future.” As illustrated by the following quote, issues around genetic privacy are vast and often contradictory, leading to very challenging decisions for people:

“Finding out the information that’s held in your blood is very personal and individual and I don’t think it should be used by companies to dictate whether you get a job, or what job; that you can’t be a pilot because in 20 years time you’ve got a dodgy ticker like the old man. I don’t think that kind of information should be allowed to be used by companies, by government. It’s really personal information. ...I’m shocked really that we’re this far down. We’ve got this big wide open gate haven’t we, and we don’t have any views on policy, it’s amazing.”

I was interested in the discourses people used to make sense of potential genetic futures. Ambivalence was a key issue; most participants struggled to come to terms with the lack of easy solutions to the contradictions between ‘progress’ in human health and maintaining privacy for themselves as individuals. This is consistent with a recent report from the OECD (2004: 1) which stated that: “Both the indigenous Māori and European populations in New Zealand agree that the collection of genetic information may threaten individual autonomy, dignity and privacy and raise concerns of discrimination.”

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1 Constructive Conversations: Biotechnologies, Dialogue and Informed Decision-Making is a five year interdisciplinary, multi-sited research project. In the first phase of the project, twelve researchers conducted 25 focus groups that addressed issues relating to genetic profiling, direct to consumer genetic testing and biobanking in seven different locations between 2003 and 2004. Nine of the focus groups consisted solely of Māori participants, usually facilitated by Māori research team members. The other sixteen groups were composed of members of the general population, recruited through community organisations and informal social networks. Participants in these groups were mainly Pākeha (European New Zealanders), but also included some Māori and people of other ethnicities. This paper draws on the transcripts of these sixteen focus groups. The analysis of material from the Māori specific groups is being conducted by Māori researchers on this project and will be reported in future papers. See Hipkins (2004) ‘Methodological Overview – Phase 1’, available on the Constructive Conversations/Kōrero Whakatanga website: http://www.conversations.canterbury.ac.nz for an overview of the aims, objectives, methodology, research strategies and stimulus materials associated with the first phase of this research project which involved conducting 25 focus group interviews in different parts of Aotearoa/New Zealand.

2 Abigail in Primary care/Public health group.

3 Male in Patient Support Group 1.
DeCew, who describes herself as a ‘moral philosopher,’ sheds light on why privacy is important:

Privacy acts as a shield to protect us in various ways...its value lies in the freedom and independence it provides for us, nurturing our creativity and allowing us to become better people. ...Protection of privacy enhances and ensures the freedom from...pressure to conform, and exploitation...so that as self-conscious beings we can maintain our self-respect, develop our self-esteem, and increase our ability to form a coherent identity and set of values, as well as our ability to form varied and complex relationships with others. Loss of privacy leaves us vulnerable and threatened. We are likely to be more conformist, less individualistic, and less creative....the potential harms from disclosure range from embarrassment, loss of self-esteem, social stigma, isolation, and psychological distress to economic loss and discrimination in such areas as employment, child custody, insurance, housing, and immigration status (2004:5).

Participants in this study reflected such philosophical discourses around privacy:

“First of all it seems to me that genetic information is personal; it belongs to the person. It’s a big factor in the whole of the person’s potential personality, and in my ethical book...insistence on the rights of the person to development of their full personality is the most fundamental human right of all. ...I applied those principles to this sort of situation now, and I say that a person has the right and only the person has the right, to the information of their genetic code.”

In looking at the issue of genetic privacy in the context of Aotearoa/New Zealand, several questions need to be addressed: Is genetic information different from other forms of personal information? How can policy protect people and ensure the privacy of their genetic information? What are the central issues arising in the genetic privacy debate? How is New Zealand different from other countries? In examining the ways people talked about these issues in the focus group I wanted to know: What are the discourses people are using? How can these be placed, explained, examined and put into context? There are particular sets of assumptions about science that underpin the discussions; where do these come from and how do they shape people’s talk? People were asking questions such as: What proof is there that genetic testing will improve the quality of life? Who should have control of genetic information and how can people be empowered to make informed decisions? It has often been a feature of recent policy documents on genetic testing that discussions of regulation do not go into discussions of any depth about privacy issues. There is a general awareness of the issues, but consensus has not been reached leaving people uncertain about their rights and the protection available. Combined with a level of sensationalism in the media, it is no wonder that the discourses people are using are sometimes fatalistic, cynical and sceptical.

The central issues discussed in the focus groups were: the potential for discrimination in insurance and employment based on genetic test results; the pros and cons of criminal DNA databases; the merits of both commercial and government control of genetic information, and security issues related to the electronic storage of DNA. All of these issues will be analysed in relation to international policy documents on genetic testing from Canada, Australia and the United Kingdom, and recent academic literature on

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4 Ken in Religious organisation 1. The issue of property rights is also discussed in section 8.
‘genetic privacy,’ followed by an overview of the current regulatory framework in New Zealand and a discussion of the challenges for policy makers in Aotearoa/ New Zealand of ensuring the privacy of people’s genetic information.

2. METHODOLOGY6

Participants were given three stimuli to encourage discussion around the social, ethical, cultural and spiritual implications of genetic testing. The first was a story set ten years in the future where new parents must decide whether to allow their baby’s genes to be ‘mapped’. The second was a fictional advertisement for a private company called ‘Gene Futures’ which offers genetic testing services over the internet for susceptibility to common diseases. Lastly was a pamphlet about ‘Biobank’, an imaginary project seeking volunteers between the ages of 45 and 65 to donate their genetic, medical and lifestyle information to a research project aimed at better understanding the role of genes in disease. Sixteen focus groups were held with predominantly Pakeha participants and the interviews transcribed.7 Each of the transcripts was coded using NVivo,8 and participants’ responses were categorised according to the various questions and issues arising during the discussion. One of the aims of the Constructive Conversations/Kōrero Whakaaetanga project is to explore how personal narratives are used as a basis for understandings about risk, protection and regulation with respect to genetic testing.9

I began this project by using NVivo to search the focus group transcripts using relevant key words10 to find discussions related to privacy. I explored the relationship between the issues raised by focus group participants and discourses on genetic privacy articulated in policy documents from New Zealand, Australia, Canada and the United Kingdom, as well as recent academic discourses on genetic privacy issues. I have employed the “triangulation” approach used by Cilla, Reisigl and Wodak (1999: 157) which explores the interconnectedness of discursive practices by combining various interdisciplinary, methodological and source-specific approaches to investigate a particular discourse phenomenon (in this case the way participants in 16 focus groups talk about genetic privacy issues). Cilla, Reisigl and Wodak (1999: 157) argue that:

Critical Discourse Analysis perceives both written and spoken ‘discourse’ as a form of social practice. …It assumes a dialectical relationship between particular discursive events and the situations, institutions and social structures in which they are embedded: on the one hand, the situational, institutional and social contexts shape and affect discourses; on the other hand,

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6 For more information about the methodology and project goals of Constructive Conversations/Kōrero Whakaaetanga please visit the project website: [www.conversations.canterbury.ac.nz](http://www.conversations.canterbury.ac.nz)

7 The groups interviewed included: health focused, professional/job focused, religious/spiritual groups, community organisations and personal/family networks/friendship groups/identities. Nine Māori specific groups were also facilitated using the same stimuli materials. Discussion in these groups is being separately analysed by Māori team members.

8 NVivo is a software program used for the electronic analysis of qualitative research data.

9 For an article on the benefits of public partnership and inclusion in scientific processes and policy decisions see Michael J. Garland 1999, ‘Experts and the public: a needed partnership for genetic policy’ in Public Understanding of Science, 8: 241-254. He also makes reference to genetic privacy as an issue that needs this sort of public participation to ensure effective legislation and policy decisions.

10 Key words used included: privacy, security, discrimination, misuse, legal, regulation, policy.
discourses influence social and political reality. In other words, discourse constitutes social practice and is at the same time constituted by it.

The resources that people have to think about genetics are a mix of emotional and intellectual, private-world and public. These are socially available ways of talking about the issue of genetic testing that are distributed unevenly and linked to different groups’ ideological investments in the issue. The participants in this project were given three different ways of reflecting on futures that involve public and private provision of genetic testing and the storage of genetic information. Using these stimulus materials Constructive Conversations/Kōrero Whakaaetanga researchers were able to explore how different groups drew on different discursive resources to make sense of the issues presented in the story, the advertisement and the biobank pamphlet. My interest is in looking at the relationship between the discursive resources used by focus group participants as they responded to these materials and the ‘official’ discourses represented in national and international policy documents.

3. ‘THE COMMON GOOD’ versus RISKS TO INDIVIDUAL PRIVACY

The overarching theme in relation to the genetic privacy discussions in the focus groups is a tension between the possible benefits of genetic testing for ‘society as a whole’ and scepticism about the potential risks on a personal level. Genetic testing to some participants seems excellent on a macro, societal level, in terms of its potential to ‘make society better,’ but on an individual level participants found decisions about testing and the use of genetic information much more problematic. This is illustrated by the following quotes from focus group discussions:

“I mean there is all sorts of wonderful science in there, which could be so useful, it is once you get to the personal level isn’t it that it becomes objectionable.”¹¹

“When I think about genetic engineering and all the issues that go with that I am really positive. But when it comes down to asking things that are actually so personal, it makes me bring out the mother and the individual side of things.”¹²

“The reality is that it is here. It’s not going to go away and there are positive points in terms of genetic testing and we should embrace those positive points. But there is that access and that privacy and those issues. As I was saying I don’t mind a professional that I authorise, knowing everything about my genetic map, but I don’t want you to know.”¹³

“I think it’s an amazing opportunity to move the medical and health people forward because I think one of the best things is to be able to prevent things from happening... Although on the other side is the question of once this information is out there who has access to it, when do they have access to it, is it controlled by legislation?”¹⁴

¹¹ Julie in Scientists’ group 2.
¹² Sue in Scientists’ group 2.
¹³ Jessica in Business and professional group 2.
¹⁴ Jason in Business and professional group 2.
“With our group I think it’s a real question of balancing the potential benefits say for fixing medical problems at an early stage before they’ve developed too far against the real fear that once you’ve put this information into a database, no matter how careful you are about proscribing boundaries, information spreads and the potential for misuse of such information is very high indeed.”

The statements of academics mirror this ambivalence over the benefits of genetic testing and the storage of genetic information. As argued by Callan and Gillespie (2003: 3) “building biobanks is a balancing act between enabling research, protecting information and winning public support.”

There is a huge paradox created between a privatised and individualised western society and information that by its very nature is shared. As outlined by Weisbrot (2004: 10), “most of our laws, ethical principles and regulatory models in Western societies…are built around our powerful preference for focusing on the individual, and the primacy of the individual doctor-patient relationship. Yet…genetic information is by definition shared information.” Weisbrot’s study revealed that:

In response to questions about whether it would be proper to reveal to genetic relatives the fact that a patient tested positive…health professionals in Northern Europe, Western Europe and most especially the English-speaking countries (including Australia, the United States, the United Kingdom, Canada and New Zealand) placed their focus squarely on the individual doctor-patient relationship and were reluctant to breach this confidence, whatever the consequences for other family members. By way of contrast, health professionals in African, Asian, Latin American, Middle Eastern, Eastern European and Southern European societies were much more likely to value familial and communal interest over individual autonomy (2004: 11).

Within multi-ethnic New Zealand it is not surprising that participants in the sixteen focus groups analysed for this study drew on various and often contradictory discourses in weighing up the potential positive society-wide benefits of accumulating genetic information and the potential challenges of ensuring privacy protection for individuals.

Spinello (2004:33) argues that examples thus far show that the ‘common good’ usually takes precedence over individual privacy concerns. This was exemplified by the statements of participants who did not object to contributing their genetic material for the betterment of society:

“I have no objection to my children’s blood or my blood being kept on Guthrie cards. Because I see in terms of contributing to research and scientific research that gets us further. I mean people are living longer because of good science in this country I mean in the world.”

“We have moved forward in science by people taking a leap over a cliff. …if we don’t stretch what we don’t know we would still be going around with skins on and bashing people over the head…and living in a cave.”

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15 Hannah in Business and professional group 1.
16 Rose in Scientists’ group 1.
17 Jennifer in Business and professional group 1.
In contrast to this, a study by DeCew (2004: 6) concluded that, “Eighty-five percent of those questioned...put a far higher priority on confidentiality of medical data than on providing universal coverage, reducing paperwork, and gaining better data for medical research on disease and treatments.” In analysing the focus group participants’ discourse around this issue it is apparent that individual privacy concerns trump ‘the common good’ because people tended to argue that collective benefits could only be pursued if privacy protections for individuals were in place. In most cases people wanted to ensure that individual privacy was not at risk before the altruistic benefits afforded by new genetic health technologies were pursued.

A further dimension to this that has been discussed by DeCew (2004: 12) is that if an unwillingness to share genetic data for medical research becomes common, “research samples may be skewed and less useful than data collected without the restraint of patient consent. This may well lead to inadequate or statistically invalid research databases and declines in other public health activities.” DeCew (2004: 12) argues it is “preferable to endorse a public policy allowing individuals to decide for themselves whether it is worthwhile to relinquish some of their privacy for higher-quality medical care, for the potential for future cures, for public health, and for genetic research.” All of these discussions over ‘the common good’ versus risks to individual privacy are underpinned by what is called ‘genetic exceptionalism’ – the argument that genetic information is in some ways different than other types of health information.

4. GENETIC EXCEPTIONALISM: How valid is it?

O’Neill (cited in Tavani 2004: 19) defines genetic exceptionalism as, “the view that genetic data are intrinsically unlike other personal, including medical, data because they provide information not only about an individual from whom a sample is taken, but also about related individuals.” The tendency to treat genetic information as deterministic is what makes privacy such an issue. Because of the common belief in the determinism of genetic information, the threat of discrimination and misuse is paramount, as illustrated by the following two quotes from participants:

“I think it’s really scary...for authorities to know that you genetically have the potential to be something or someone. It takes away the human element of being able to climb obstacles in life, to change your life track.”18

“So you’ve got knowledge that purports to be real, rock solid, forever, truth...in the hands of people who are not very wise, and maybe really badly motivated and it’s not a very good scenario, so I think that’s a worry.”19

Spinello (2004: 30) is one of several academics who draw upon the ‘genetic exceptionalism’ argument in talking about the issue of genetic privacy: “one’s genetic code is fixed and unchangeable. It creates an indelible mark on a person’s history, and that ‘mark’ might work against a person’s legitimate interests if it becomes known by others….unlike other forms of data, it is subject to broad and subjective interpretation,

18 Deidre in Business and professional group 1.
19 Samantha in Friendship network 2 (mid-career adults).
opening up considerable room for bias and manipulation.” Similarly Weiss (2004: 59) argues that, “because genes are usually considered immutable and central to the determination of who a person is, information about genetic mutations may cause a person to change his or her self-image and may alter the way others treat that person.”

Those who reject genetic exceptionalism are often referred to as “anti-exceptionalists” and both positions have their disadvantages. As argued by Tavani (2004: 21) “genetic exceptionalists tend to over emphasize the differences between genetic and non-genetic personal information. Anti-exceptionalists, on the other hand, arguably underestimate some critical differences.” Most countries agree that genetic information is different because of its familial and predictive nature, and therefore argue that to ensure the privacy of people’s genetic information it is necessary to have special regulation above and beyond the standard privacy act, or the disability and employment relations and insurance acts. Alone these are not enough to ensure people do not slip through the loopholes. The NZ Ministry of Health (2004: 47-48) has summarised the major reasons why the United Kingdom Human Genetics Commission has identified genetic information as different from other sources of health related information.20 Even the policy documents themselves exhibit an underlying genetic exceptionalist discourse. For instance, Henaghan et al. (2003: 9) state:

None of this legislation [currently available in NZ] is specific to the genetic information context. The question is whether the existing framework represents adequate regulation of the area. Can genetic information be lumped together with and dealt alongside general health information or does it have special characteristics that mean it warrants special treatment? Possible distinguishing characteristics include the fact that genetic information is familial, predictive, often lacks predictive power due to environmental interaction, permanent…and incompletely understood at the present time.

The unique features of genetic information have also been identified by Diana Sarfati, a public health physician in a report for the National Health Committee. She suggests that informed choice for genetic testing is more complex than for most other forms of health related information because of the potential effects of access to that information on the whole family, not just individuals (Sarfati 2002: 16).

What is covered in the news also reflects the participants’ anxieties and the discourses they use to articulate their concerns about what is different about genetic information. For instance Bingham (2003: 1) stated: “Could elections of the future feature DNA screening of political candidates to see whether they are worthy of power?” Mr. Pulpick (cited in Bingham 2003: 1) said, “Any new technology seems to carry within it the seeds of inevitable function creep. The dangers clearly exist that DNA taken for one purpose or in one set of circumstances may end up being used in a quite different, and perhaps

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20 “Genetic information is uniquely identifying information; genetic information can be obtained from a very small amount of material and does not require lengthy observation; genetic information may be used to predict some rare inherited disorders; the predictive possibilities may be of interest to people other than the owner of the tissue sample tested (i.e. employers, insurance companies, family members); genetic information has a potential commercial value and methods of obtaining it may be subject to patents; drug treatments may be targeted to sub-sets of the population identified, in part, by genetic information; once this information is collected, it can be used for a quite different purpose from that for which the provider of the information originally gave consent.” (NZ Ministry of Health 2004: 47-48).
inappropriate, fashion.” Underlying the dominant public discourses around genetics is an overall assumption that genetic information is different and it is this distinction which should be the focus of the genetic privacy discussion. Tavani, however, moves away from the focus on exceptionalism in genetic privacy discourse and believes that “the key privacy issue at stake has to do with the way in which the privacy of research subjects is threatened by certain uses of ICT in manipulating one’s genetic information once it has been acquired. In particular, a special kind of privacy threat arises for research subjects because of the use of data-mining technology” (2004: 21). These issues will be discussed in the following sections.

5. EMPLOYMENT & INSURANCE: Issues of Discrimination

There was an overarching cynicism in the focus group discussions about the potential for discrimination in employment and insurance if genetic testing became widespread, which reflects an enduring societal discourse circulating about the potential for discrimination in these areas based on genetic health information. A typical comment was: “Yes this nice little quote in this thing [Gene Futures ad] about: ‘No employers or insurance companies will ever be able to find out anything about you from these records.’ You know pigs will fly.”21 Participants also used the mass media as a frame of reference for making sense of a potentially dangerous genetic future, as in this example: “There’s this film called Gattaca which...as soon as this came up it just stuck into my mind. I’ve seen the film and it’s just amazing how people who seem to be genetically inferior got the lower jobs and those who were deemed to be genetically superior got the higher paying...and the whole thing smacks of employers and insurance.”22

Use of real life experience with insurance and discrimination were also drawn upon in focus group conversations to imagine the disadvantages a genetic future could bring: “I mean there are some ethical issues around at the moment. For example my brother-in-law cannot now go back to his GP to get his blood pressure tested because his insurance company has already demanded access to it and set his premiums on the basis of his existing medical record and if he goes back he can only go back if he’s confident he will have a better record that he has currently got or his premiums will go up.”23 It is not only in fictional accounts that such discrimination has occurred but real-life situations have also been documented. Shorett (2004: 1) states that, “in as many as 200...cases, genetic information has been used to deny employment and health, life, and disability insurance to otherwise healthy Americans.”

Internationally the issue of genetic testing in insurance has garnered cautious responses, as illustrated by Henaghan et al. (2003: 12-13) who found “the majority of countries that have considered this issue, including the US, UK, Canada and Germany, have decided

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21 Hannah in Business and professional group 1.
22 Unknown in Patient support group 1.
23 Joshua in Religious organisation 1.
that insurers should not be allowed to require genetic testing. …the UK insurance industry has accepted that the limited scope of genetic tests at the present time means that excluding their use would have little economic impact.”24 In New Zealand it would seem that we have less to worry about in regards to potential discrimination in insurance based on genetic test results because we have a reasonable level of public health care (Henaghan et al. 2003: 15). Isac (2004a: 1) states, “the obvious risk is that individuals might be declined insurance on the basis of a deeply intimate and unchangeable personal quality over which they have no control. …On the face of it, there is little to distinguish genetic discrimination from discrimination on the basis of disability or race.” Isac (2004a: 2) also argues, “as knowledge of the implications of genetic testing on insurance spreads, it is likely that individuals will decline to take tests and suffer the risk of adverse health consequences rather than place their personal and family financial security in jeopardy.” Isac (2004b: 1) points out that there is currently no specific legislative response to the issue of genetics in insurance in New Zealand so, “in the meantime the ability of insurers to require applicants to undertake tests and the use which can be made of test results is governed by a self-imposed moratorium promulgated by the Investment Savings and Insurance Association of New Zealand (ISI).” Isac (2004b: 1) suggests that “the Human Rights Act 1993, which is New Zealand’s principal anti-discrimination legislation, does not prevent insurers requiring testing, or from relying upon the results in making decisions about the provision of insurance.”

With regard to employment: “In New Zealand, the situation is influenced both by occupational health and safety and accident compensation legislation. Under s6 of the Health and Safety in Employment Act 1992, employers are responsible for providing a safe work environment for their employees. It is conceivable that this responsibility could be held to extend to doing genetic tests to identify those susceptible to workplace hazards or who pose dangers to others” (Henaghan et al. 2003: 17). Sample (2004: 1) discusses legislation proposed by the Human Genetics Commission25 which “is designed to prevent the emergence of a genetic underclass, where people find themselves rejected by employers and unable to get life insurance, as a result of having genetic tests for medical conditions.” It is also interesting to look at the voices predominating in the news discourse around genetic privacy issues. The Human Genetics Commission proposal discussed by Sample (2004: 1) was put forward by a Nobel scientist and submitted with the backing of a Law School professor and advisor to the British Medical Association, and a bioethicist stating: “We affirm that humans are born equal, that they are entitled to equality of opportunity, and that neither genetic constitution nor genetic knowledge should be used to limit that equality…this principle should be incorporated into UK legislation and practice.” Genewatch UK also supported the proposal,26 whereas the British Insurance industry, represented by Malcolm Tarling (cited in Sample 2004: 1), did not welcome a new law stating:

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24 For a full overview of other countries’ stance on genetic testing for insurance see Henagahn et al. 2003, pp. 14-15.
25 The Human Genetics Commission is an advisory group based in the United Kingdom and supported by the Crown which publishes research regularly on the implications of new genetic health technologies. Its reports can be downloaded here: http://www.hgc.gov.uk/Client/library.asp.
26 Genewatch UK is an independent advisory group with a focus on the ethical and social issues related to new biotechnologies. For more information visit their website: http://www.genewatch.org.
It is contrary to the way insurance operates to the benefit of everybody. What we’re trying to do is have a debate so we can establish a situation whereby insurers can continue to have access to medical information, including any relevant genetic tests. Insurers have to tread a fine line between a position that doesn’t put people off having genetic tests because they think they’ll have problems getting insurance, and at the same time being able to assess risk on the basis of all relevant medical information. It’s a very tricky issue to get right.

Both sides of the story were represented but the emphasis was placed on the side of the rights of the individual over ‘the common good’.

Weiss (2004: 60) draws attention to the situation in the United States where the Senate passed The Genetic Information Nondiscrimination Act on October 14, 2003, “banning the use of genetic information by insurance companies or employers to restrict coverage or make hiring decisions.” Tavani (2004: 19) points out that thus far in the United States “41 states have enacted legislation on genetic discrimination, and 31 states have passed laws affecting genetic discrimination in the workplace….The Health Insurance Portability and Accountability Act (HIPAA)…provides no special privacy protection for personal genetic information.” Judging by this, then, the countries leading the way in privacy protection are not following a genetic exceptionalist argument.

This ‘fear of discrimination’ discourse was also reflected in academic literature which examined issues beyond the insurance and employment context; for instance Weiss (2004: 55) argues, “DNA databanks are not uniformly regulated, and it is possible that DNA samples contained in them may be used for purposes unintended by donors of the samples….They cannot be assured that these tiny specimens will not be taken or used against their will or without their knowledge for activities such as profiling to measure tendencies such as thrill-seeking, aggressiveness, or crimes with threatening behaviour.” It was also considered by Yeh, Morley & Hall (2004: 16) that “the unnecessary disclosure of genetic information may lead to harmful labelling in the classroom.” More recent discussion has focused on the potential benefits of criminal DNA databases, which was also discussed by those participating in the Constructive Conversations/Kōrero Whakaaetanga focus groups.

6. CRIMINAL DNA DATABASES: Friend or Foe?

The focus group participants in this small study often reflected on the more social issue of the potential benefits and dangers associated with human genetics and criminal databases. These discussions were underpinned by the genetic exceptionalism argument where participants expressed fears and anxieties that, while criminal databases could be a great tool for society in catching guilty criminals, there is also the danger that these databases could be a detriment to the ‘presumption of innocence’ in the criminal justice system and create an unfair intrusion, because of the familial nature of DNA, into the privacy of the families of suspects in criminal investigations:

“You imagine from a police point of view if that information was on there and that particular child came from a criminal background or family or something like that, that child may be treated quite differently by the police or something like that because...
of what their parents or grandparents or uncles or aunts or something so it could have huge implications."  

“And who’s going to have access to your files, because anything can be stolen. There is not really anything that is safe, unless you, like lock it in a safe, and anchor it 30,000 miles out in space. It is not really safe anymore, what if the wrong person got hold of it, because we all talk about how criminals, finger prints and stuff, ever since finger print testing came up, and now they are finding hairs and using them for DNA testing and stuff. What if they start finding more? They found this person’s profile and they try and frame him up for it.”

Academic discourse mirrors these participants’ anxieties. Weiss (2004: 56) for instance, states “The fear has been expressed that if people are included in the database, they have a greater chance of being erroneously accused of a crime. The risk of false accusations from database searches is a reason to have strict quality control and assurance measures, and to educate police that a ‘hit’ is not the end of the investigation.” These comments by focus group participants also illustrate a ‘moral responsibility’ discourse. Many people feel that we have a ‘moral responsibility’ to use this technology for ‘the common good’ and for future generations.

Similarly, discourses in the news reflect the combination of genetic exceptionalism, and moral responsibility versus ‘potential for misuse’ binaries. Bingham (2003: 2) wrote “the main DNA problem was that people saw it as a silver bullet for criminal cases.” In another news article, Moody (2004: 2) explored the potential (mis)uses of criminal databases:

Another group that is likely to be deeply interested in googling your genome are the law enforcement agencies. Currently, DNA is used to match often microscopic samples found at the scene of a crime, for example, with those taken from suspects, by comparing special, short regions of it – DNA ‘fingerprints’. …Last September, the police called for the UK national database of DNA samples to be extended to include everyone. …the perfect trail for Government surveillance.

In New Zealand we have a DNA Databank which, according to Henaghan et al. (2003: 31) “has been established and is run by the Institute of Environmental Science and Research (ESR). It currently holds 18,000 individual profiles and this is increasing at a rate of 400 profiles a month. Police powers to take blood samples for DNA identification and possible entry into the Databank, is governed by the Criminal Investigations (Blood Samples) Act 1996. …If the suspect is not convicted of the charge and only gave the sample by compulsion then it must be removed within 6 months.” In contrast to this, samples in Australian DNA Databanks are stored permanently (Henaghan et al. 2003: 33). An article in the *New Zealand Herald* used discourses that reflect common anxieties about the potential for misuse:

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27 Female in Patient support group 1.
28 Sierra in high school students group.
29 For more detailed information on the laws and regulations surrounding the use of the New Zealand criminal database and others in Australia, UK/Ireland, Canada and the USA see Henaghan et. Al. 2003, pages 31-41.
Dr. Keith Bedford, forensic manager for the Institute of Environmental Science Research (ESR), said legislation protected New Zealand’s DNA database from misuse. It stated the database was only to be used for law enforcement reasons and it set out penalties, including prison terms, for anyone misusing it. And the DNA database was physically protected from tampering – it was in a secure area and, to thwart hackers, was not connected to any other computers (Bingham 2003: 2).

Despite the focus on legislation and its role in protecting the privacy of our genetic data, a large amount of discussion in the focus groups examined the merits of government versus commercial control of DNA, and explored issues related to the security of data in a digital age.

7. CONTROL & STORAGE of DNA

An area of high ambivalence that arises in the participants’ discussions relates to who should control the storage of, and access to, genetic test results. The merits of both government and commercial control were discussed and debated and participants said some very relevant and illuminating things that connect to wider policy and academic discussions on this issue. One participant stated: “If a government did this then in fact it would probably take away the need for private places to do it. If you felt that the government would be any better at looking after the information then that’s probably questionable.”30 The main problem participants pinpointed with Government control is that public policy, privacy protection, laws and regulations can change with political change, therefore do not necessarily offer a permanent or secure solution:

“That depends on the political climate and social climate, that could change [with a change] in government. That’s a concern. You can’t necessarily predict it.”31

“I think it’s all about trusting the political process again.”32

Participants also drew on past experiences with Government control to express their scepticism about the ability of political processes to adequately protect citizens:

“Once that knowledge is there how do the scientists maintain control? ...we’ve got heaps of examples...where the government just changes the law to get what they want. I mean the foreshore and seabed’s a really good example so what’s to say that the government’s not going to say that all genetic information that has been collected by the state is going to become the property of the state for the use of these things? The government will change the rules for its purposes and we don’t know who’s going to be in the government in 2 years time or 50 years time.”33

Participants expressed anxieties about both commercial and government storage of genetic information, highlighting that neither situation is ideal, and therefore the issue of control needs considerably more attention in the New Zealand context. This quote illustrates how the issue of control and storage of genetic information is tied in with

30 Unknown in Business and professional group 2.
31 Lucy in Friendship network 2 (mid-career adults).
32 Caterina in Friendship network 2 (mid-career adults).
33 SusAnne in Business and professional group 1.
participants’ ambivalence about making the choice between personal privacy risks and ‘the common good’:

“The majority of the world just get used for multinational and big companies and if you have the dollar you have access to everything and anything, and I just don’t believe Government. I just hear so many lies. But anything that can help then yes – we’ve got to do it. There’s no point being silly and just staying in the Dark Ages but I just don’t trust them with the information. They don’t tell you the truth as much as we’ve got the Privacy Act when you go somewhere you don’t have access. Ten minutes and they can alter whatever’s in your file and I just don’t believe they give you all the information but anything we do has got to help.”

DeCew (2004: 9) argued that the reaction of Americans to a proposed ‘unique health identifier,’ “demonstrates that many Americans are distrustful of giving governments more power, and more access to their data, through centralized databases and the federal regulation model, but studies show the public is also becoming more and more sceptical about the self-regulation model.” With commercial control and self-regulation there is a potential risk of misuse and exploitation for profit motives, but government control is just as insecure because of the potential for political change.

The commodification of genetic information is a problem noted by Jeremy Rifkin, the President of the Foundation on Economic Trends, in the documentary film The Corporation, where he argues that human beings will end up being ‘owned’ by corporations (Achbar, Abbott, & Bakan 2004). For instance in Iceland, “charges involving ‘commodification’ have been made by critics who fear that Iceland’s health care and genetic information has been commercialized and that as a result, this information has been reduced to a marketable commodity” (Tavani 2004:18). Similarly, DeCew (2004: 12) argued that “pharmacies may sell data on patient prescriptions to drug manufacturers, allowing commercialization of sensitive medical information.” She came to the conclusion that corporate interest was at odds with patients’ interests hence, “from the patient’s point of view, the disadvantages of a corporate self-regulation system for medical data far outweigh the advantages” (DeCew 2004: 9).

The possibility of data going overseas for testing was also raised, which hinted at the importance of international regulation, and what the responsibilities should be of each country to have similar international standards. One participant stated:

“Control regulations are definitely better in NZ. And I guess if the regulations were there in the overseas country that was doing the tests, and then those regulations changed, as we obviously don’t have any control over that, I guess the option becomes then – well do you continue to use that particular research provider or do you go somewhere else? I think the bigger risk is that you have some unscrupulous organisation using the information for something else.”

34 Male in Patient support group 1.
35 The issue of where the ‘public interest’ factors in is also discussed, in relation to both government and commercial control, by Spinello (2004: 32).
36 Peter in Patient support group 2.
This also raises issues about the security of data in the digital age. Participants showed an awareness of the vulnerability of data in an ‘electronic era’. The real question people were asking is “how water tight is it?” Participants said some interesting things about the security of information in response to the three stimuli:

“There’s the huge thing about corruption. …people can hack into the Pentagon like they did the other year, a 17 year old hacked into the Pentagon. You know, who is to say they can’t hack into this?”

“If it was on a web-site, it wouldn’t be of concern. But if you got hacked into and you were onto a government database of DNA – the kind of information that’s there – particularly if you knew how to read it. It could be open to all sorts of abuse.”

Academics seem to share these anxieties, such as DeCew (2004: 6) who argues, “computerized records introduce new risks and new opportunities for abuse. At every stage of the process of collection and storage, dangers can arise, including entry errors, improper access, exploitation, and unauthorized disclosure.”

There are, however, advantages to computerized storage: “The options for protecting privacy need no longer be total denial or total access to a medical record or database. Well-designed computer systems can incorporate and differentiate customized access controls such as layering or partial restriction of very sensitive data items such as genetic test results, enhancing security for medical information” (DeCew 2004: 10). The issue goes beyond simply storage, however. Tavani (2004: 15) draws attention to the issue of ‘data-mining’ and how individuals’ data is grouped and the potential problems this creates for privacy, property and control. He argues, “this technology has significantly threatened the privacy of research subjects participating in population genomics studies, who may, unwittingly, contribute to the construction of new groups (based on arbitrary and non-obvious patterns and statistical correlations) that put those subjects at risk for discrimination and stigmatization” (Tavani 2004: 15). Privacy laws only exist for already existing and labelled ‘groups’ not new groupings that may arise through the use of data-mining technology (Tavani 2004: 22). It can be argued, therefore, that our current privacy laws are inadequate because,

They are based on too narrow a conception of ‘personal data.’….once an individual’s data has become aggregated and generalized, the individual has no say in how that data is further processed because the rights and requirements for protecting personal data apply only to that data qua individual persons. Whereas an individual has a legal right to access and rectify one’s personal data as it applies strictly to that individual, one does not enjoy the same rights with respect to the kind of personal information about oneself that is derived from that data (Tavani 2004: 22).

Many academics have suggested that the solution to the government-commercial control conundrum is ‘property rights’. Participants in the Constructive Conversations/Kōrero Whakaaetanga study were certainly concerned about who owned DNA, as in the quote below:

37 Anne in Patient support group 2.
38 Molly in Business and professional group 2.
39 John in Scientists’ group 2.
“And who does that information belong to? It should belong to the individual but it never does, it belongs to the institution. And you know it’s like the DNA in the human genome project. The DNA belongs to the pharmaceutical company or who ever else buys your DNA. It’s no longer mine. So all those kinds of things are a concern really.”

Henaghan et al. (2003: 50) have explored the issue of ownership and control in New Zealand and concluded:

The current approach to ownership and control of genetic samples and information is based on the idea of the altruistic gift and consent. Samples taken for research are considered to be gifted to the recipient, giving them ownership and control over the sample. These rights are limited by the requirement that the recipient has consented to the intended use of the sample from the source of the sample. The Health Information Privacy Code provides protection against the non-consensual disclosure of genetic information about a subject.

Because genetic samples and information can potentially garner researchers and developers huge financial rewards, a debate has arisen over whether the current system of consent should be replaced with a property-based system, whereby property rights over genetic samples would be retained by those they are taken from. This has been discussed thoroughly outside New Zealand “without any firm consensus emerging.” The issue that emerges, then, is “if we leave bits of DNA behind as we move through our day…[have] these bits of DNA actually been abandoned? …The threshold question becomes, therefore, whether an individual can actually own her body?” (Weiss 2004: 57).

Spinello (2004: 32) argues that, “one’s personal information may at times need to be relinquished for the common good.” He believes that individuals should not have proprietary rights to their genetic material because, “the recognition of such ownership rights would lead to inefficiency along with the disutility of genetic discoveries. Biomedical research will be hampered if property rights in genes and genetic material are too extensive” (Spinello 2004: 29). He also points out, however, that we need to avoid the contradiction that would occur if individuals cannot claim property rights of their own genetic material yet others are able to patent the results of its use. The rub then becomes that without the incentive of patents, “the genome will not be adequately exploited by researchers” (Spinello 2004: 36). Spinello therefore supports ‘informed consent’, stating “the enhancement of biomedical research and the protection of privacy are not mutually incompatible goals” (Spinello 2004: 38). The next section will look in more depth at the current New Zealand regulatory framework as it relates to genetic privacy and the participants’ discussions, focusing on the challenges faced by policy makers in Aotearoa/New Zealand.

40 Sophia in Business and professional group 1.
41 For a brief overview of how the approaches to the property-rights debate have been favoured in other countries see Henagahn et al. 2003: 51-52.
8. THE NEW ZEALAND REGULATORY FRAMEWORK

Tavani (2004: 16) suggests that looking at the local context will enable us to explore these arguments about privacy further. New Zealanders had varying opinions and degrees of knowledge about the regulatory framework relevant to the issues around privacy discussed throughout this paper:

“You’d hope that they’d have, like, laws or regulations in place to deal with that, though, because otherwise there would be like cowboy doctors out there, like practicing tests on bits of you.”

“Wasn’t there such a thing as a privacy law though? What’s happened to that?”

“There are lots of mechanisms already for ensuring privacy of information to your doctor and that sort of thing.”

“Well my babies had that little prick in the heel but I never thought that that information was still stored somewhere.”

“They don’t make laws and rules and regulations about things until after they have had a bad example of it.”

One of the most in-depth reports on genetic testing was the National Health Advisory Committee on Health and Disability’s (2003) Molecular Genetic Testing in New Zealand. It stated, “the committee acknowledges the importance of these issues, along with intellectual property and social and ethical issues in genetic testing, and the implications for insurance and employment, but has not attempted to explore them in any depth in this document.” These issues need to be dealt with in an individual document because the public obviously see privacy as an area of particular concern.

The NZ Ministry of Health (2004: 22) document, Review of the regulation of human tissue and tissue-based therapies, discussed the relevance of the Health Information Privacy Code 1994 to the genetic context, again drawing on exceptionalist discourses:

The Health Information Privacy Code is established under the Privacy Act 1993 and governs the collection, storage, security, access, correction and retention of health information. It is concerned with protecting the privacy of individuals and the highly personal information that is required for health care. In terms of the review of human tissue, the question arising more frequently is whether genetic information, obtainable from human tissue, requires more protection than that currently provided by the Health Information Privacy Code.

The central concern is that New Zealand lacks an overall framework for dealing with genetic information, and the legislation we do have only provides a patchwork of

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43 Nicole in High school students group.
44 Angela in Patient support group 1.
45 Daniel in Adult education group 1.
46 Andrea in Business and professional group 2.
47 Sierra in High school students group.
coverage that “is not comprehensive, consistent, or organised in an easily understandable way” (NZ Ministry of Health 2004: 22).

As outlined in Henaghan et al. (2003: 64-69), the relevant legislation, policy statements and professional guidelines addressing human genetic issues are:

- Insurance Law Reform Act s4 1997
- Criminal Investigations (Blood Samples) Act 1996
- Code of Health and Disability Consumers’ Rights 1996
- Health Information Privacy Code 1994
- Human Rights Act 1993
- Privacy Act 1993
- Health and Safety in Employment Act s6 1992
- New Zealand Bill of Rights Act 1990.

Regarding Ownership and Storage we have the HGSA’s “Guidelines for Human DNA Banking, July 1990” and a “Policy Statement on the Retention, Storage and Use of Sample Cards from Newborn Screening Programmes.” As stated in OECD (2004: 2)

In New Zealand, privacy of individual information is primarily governed by the Privacy Act 1993. …The Privacy Commissioner has stated that genetic information should be considered ‘health information’ until more is known about the context in which genetic information is held, obtained, used and disclosed. There is general agreement that many of the basic provisions of the Act and Code will control collection, storage and use of genetic information.

It goes on to say that the Human Rights Act 1993 may protect “against the use of genetic information by third parties to discriminate against an individual” (OECD 2004: 2). News coverage, such as Bingham (2003: 2) featured quotes from people such chief Human Rights Commissioner Rosslyn Noonan stating, “One of the issues…is the question of whether human rights legislation in New Zealand adequately covers the immediate and longer-term implications of human genetic testing.” The focus of the debate internationally has been that, despite the relevance of each of these pieces of legislation, genetic information requires a more comprehensive and complete oversight to ensure privacy is protected. In regard to the situation in the United States, Shorett (2003: 2) wrote, “Despite legislative activity for more than a decade, the U.S. continues to lack a nationwide minimum standard or protection for genetic privacy. Instead, individuals must rely on a mixture of state and federal statutes that regulate access to genetic and other health information by specific entities…and for specific purposes.”

The Human Rights Commission (NZ) (2005) has produced a very important document titled Human Rights in New Zealand Today. In Chapter Three of that document it was argued that “a State’s obligation to respect, protect, promote and fulfil the right to freedom from discrimination is not limited to avoiding negative measures but includes taking positive measures as well” (2005: 2). Apart from a brief statement found in Article 3 of the Treaty of Waitangi, “in which the Crown extended to Maori the Queen’s protection and imparted to them ‘all the rights and privileges of British subjects’, there is no specific reference in New Zealand law to the right to equality, a fact that the United Nations Committee on Human Rights has consistently criticised in assessing New
Zealand’s compliance with international standards on equality and freedom from discrimination” (The Human Rights Commission (NZ) 2005: 2-3).

Chapter Nineteen of Human Rights in New Zealand Today discusses how human rights standards can be applied to biotechnology and the developments of the human genome. It is argued that a human-rights-based approach to the biotechnology question should:

- Emphasise the participation of individuals and groups in decision–making;
- Introduce accountability for actions and decisions, so that individuals and groups can complain about decisions that affect them adversely;
- Seek non-discrimination of all individuals through the equal application of rights and obligations to all;
- Empower individuals and groups by allowing them to use rights as leverage for action and legitimise their voice in decision-making;
- Link decision-making at every level to the internationally agreed human rights norms, as set out in the various human rights covenants and treaties (Human Rights Commission (NZ) 2005: 2).

Chapter Nineteen also looks at the issue of biotechnology internationally, outlining that in 1998 the UN General Assembly endorsed the Universal Declaration on the Human Genome and Human Rights. The Declaration, “provides that any research, treatment, or diagnosis affecting an individual’s genome shall be undertaken only after the risks and benefits have been assessed and the persons concerned have given informed consent” (Human Rights Commission (NZ) 2005: 2). It is also mentioned that UNESCO adopted the Universal Declaration on Human Genetic Data (UDHGD) in 2003 which, “complements the Declaration and is based on the principle that genetic data have a special status because of their complexity. Given the predictive nature of genetic data, it is important that confidentiality is balanced against the public good (Human Rights Commission (NZ) 2005: 3).

The multicultural nature of New Zealand inevitably influences policy decisions regarding privacy because the various cultural values and beliefs must be taken into account, as illustrated by this participant “I mean any system of policy that gets made in ten years or fifteen years has to be flexible can’t be like, this is right and this is wrong....I mean New Zealand is becoming more multicultural isn’t it. I mean we’re having lots and lots of immigrants and all the rest of it – I mean they’ll never be a basis to accommodate them.” What the role of the government should be in protecting citizens from discrimination based on genetic information is beyond the scope of this paper, but the contributions of participants in these focus groups has shed light on some significant areas of concern to the New Zealand public, and those views deserve consideration in future policy discussion.

9. CONCLUSION

This paper has examined various issues relating to genetic privacy that arose in the context of discussion about genetic testing and the storage of genetic information in 16 focus groups with predominantly Pakeha participants in Aotearoa/New Zealand. When asked to consider three fictional scenarios of a potential genetic future, privacy emerged as a key area of concern. Participants drew upon discourses of genetic exceptionalism –

48 Male in Patient support group 1.
the belief that genetic information is somehow different from other forms of health information because of its predictive and familial nature – to explore both the potential benefits of new genetic health technologies for ‘the common good’ and the potential risks posed by genetic science to individual privacy.

Particular areas of contention included anxiety that genetic test results could be used in the employment, insurance and education contexts to discriminate against individuals, possibly leading to the development of a ‘genetic underclass’ like those imagined in films such as Gattaca. These fears are echoed throughout international policy documents and academic literature, where solutions to the ‘genetic discrimination’ problem are discursively produced predominantly through the ‘exceptionalist’ lens, focusing on the rights of the individual to privacy and freedom from discrimination based on inherited, uncontrollable and often misunderstood health information. The pros and cons of criminal DNA Databanks were also disputed, where the discourse of an individual’s right to privacy was at odds with participants’ perceived ‘moral responsibility’ to utilize new genetic health technologies to make law enforcement more effective.

Participants had much to say about how DNA should be controlled and stored and by whom. Cynicism and scepticism were common in discussions around the Government’s ability to protect sensitive data. Likewise, commercial interests in human genetics were expounded and critiqued within the overall framework of ‘common good’ versus ‘individual’ where commercial interests were seen to be both an advantage, in their ability to push the boundaries of science, and yet also a threat to privacy. Electronic storage of data is another area that prompts ambivalent responses because its potential for misuse is considered alongside the advantages of the potential knowledge generated through the analysis of this information.

Some of the issues raised by these focus group participants have been the focus of attention in international and local policy documents, in academic literature and in the news and popular media. The concerns of citizens have shaped policy documents, whilst the ‘official’ discourses represented in policy documents also shape available ways of talking about these issues. While New Zealand has a variety of legislation designed to protect privacy, human rights and prevent discrimination, our nation, like most others, lacks an overall framework for privacy protection in the area of human genetics. The comments of those who participated in the focus groups facilitated by the Constructive Conversations/Kōrero Whakaaetanga team indicates that there are a variety of different concerns that have not been adequately addressed in the academic literature nor in New Zealand policy. The reflections of these members of community groups, friendship and family networks provide a stimulus for more detailed decision making on how human genetic technologies can best be utilized in Aotearoa/New Zealand and, in particular, how the privacy of genetic information about individuals and families can be protected.
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