TALKING ABOUT
GENETIC TESTING

Information for participants

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The following people contributed to its production:

These research team members facilitated group discussions and/or contributed to the design of material used in these focus groups:
Anne Scott, Bevan Tipene-Matua, Rosemary Hipkins, Lesley MacGibbon, Rosemary Du Plessis, Joanna Goven, Jane Gilbert, Rachel Bolstad, Andrew Moore, Hazel Phillips, Murray Parsons, Trina Taupo and Fiona Cram.

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What did focus groups say about genetic testing and the storage of genetic information?

This document is a summary of discussions about genetic testing and the storage of genetic information in 25 focus groups facilitated in 8 different locations by members of the FRST funded Constructive Conversations/Korero Whakaaetanga research team in Aotearoa/New Zealand between October 2003 and May 2004. Discussion in these groups was prompted by three scenarios relating to genetic profiling, direct to consumer genetic testing and biobanking. In some of the groups all three scenarios were used, in others one or two were used to prompt discussion.

A hypothetical story, a mock advertisement and a fictional pamphlet were used to prompt discussion. The story explored the genetic profiling of newborn babies, the advertisement promoted commercial direct to consumer genetic testing, and the pamphlet was designed to recruit volunteers for a future ‘biobank’ that would involve collaboration between public good science and pharmaceutical companies. These materials elicited talk about the ‘mapping’ of human genes, testing for specific disorders or predispositions, and the storage of genetic material. (See Appendix One for more information about the resources used when developing these materials)

This summary has been prepared specifically for those who participated in the study and for distribution to the organisations or informal groups to which they belong. It illustrates how research participants used their knowledge and life experience to pose questions, to assert ethical principles, and to consider the impacts of genetic testing and the storage of genetic information.

What you had to say has been organised around sets of questions. These questions were not directly asked in the focus group discussions, but they were the issues that engaged the attention of diverse participants. The focus is on the words you used and the answers you offered to these questions. Attempts have also been made to capture differences in positions adopted by individuals and groups. All participants are anonymous – identified only by a general description of the group in which they participated. This summary of responses will provide the basis for further discussion when contact groups meet again in early 2005.
What did you say?

These were the questions that emerged during researchers’ analysis of discussion in the first round of contact groups on genetic profiling, direct to consumer genetic testing and biobanking.

1. Why do genetic tests?
   What sort of tests should be done?
   What will genetic tests tell us?

2. What are the consequences of testing?
   What does it mean for whakapapa?
   What are the costs of knowing?
   Will it affect what people do? Do we want to know?

3. How will genetic information be used and stored?
   Will it remain confidential?
   Who benefits from genetic testing and biobanking?
   Who decides?
   How can we act responsibly?
   Where do we draw the line?

4. What will genetic testing cost?
   Who will have access to genetic testing?
   What impact will it have on other health services?
   What role does private enterprise have in genetic testing and biobanking?
   What about the patenting of genes?

5. What about science and scientists?
   Who determines what is studied?
   How are scientists affected by the commercialization of science?
   What is the relationship between scientists and non-scientists?
   Are they human just ‘like us’?

6. What can we do?
   Can ‘ordinary people’ have an impact on how genetic technologies are used and their consequences?
   What can governments do?
   Can we trust people in government to act on our behalf?
Groups that participated in the first round of contact groups

**Health focused groups – 6**
- Health support group 1
- Health support group 2
- Health support group 3 (Maori)
- Iwi community health service
- Rongoa health providers
- Primary care/Public health group

**Professional/job focused groups – 5**
- Business and professional group 1
- Business and professional group 2
- Scientists group 1
- Scientists group 2
- Lawyers group (Maori)

**Religious/spiritual groups – 3**
- Religious organisation 1
- Religious organisation 2
- Religious organisation 3 (Maori)

**Community organisations – 7**
- Community group 1
- Community group 2
- Community group 3
- Adult education group 1 (older adults)
- Adult education group 2 (young adults – Maori)
- Maori community organisation
- Iwi community organisation

**Personal/family networks/identities – 4**
- Friendship network 1 (young adults)
- Friendship network 2 (mid career adults)
- High school students group
- Rural whanau

**Focus groups were conducted in the following locations:**
- Dunedin, Christchurch, Kaikoura, Wellington, Hamilton, Auckland,
- East Coast, Taranaki
1. Why do genetic tests?

In all the contact groups participants were cautious about genetic testing and the storage of genetic information. Several people referred to history and Hitler’s use of eugenics in an attempt to create the master race. Many participants associated genetic testing with a drive for ‘perfection’ and attempts to ‘fix up’ people, rather than support for diversity and creating environments in which all people could flourish.

And what will they do to people who have unattractive [genetic] maps? …the mind boggles really, as to the way that the situation could be abused. (Friendship network 2 (mid career adults))

As we gain more perfection in who we are and where we are going, something else pops up that we could fix. Where does it stop? Because once again it’s that aspiration to whakama i te uri (to clean the lineage) that keeps [us] thinking about what if, what could be? (Health support group 3 (Maori))

If something isn’t right, if this individual will have a problem or a health problem, do we then try to manipulate to actually change it, or do we just try and help them live with it or make the best of it and so on? And it’s this area of having control or manipulating and so on … people are so much more than their genotypes… (Religious organisation 1)

A number of participants thought that it was not appropriate to interfere with ‘the laws of nature’. For this reason, they rejected, at least for themselves, the use of genetic testing for diagnosis or potential ‘treatment’.

My whanau is predisposed to heart attacks, so it’s only natural that that’s going to be my fate at the end of the day…I don’t believe in finding out other ways that I can live until a hundred. It doesn’t seem natural to me… Why play with your genes? (Rongoa health providers)

This crazy kind of fear of death and living forever, we need to extend our life span to 120 years, or whatever they’re trying to do, because they are afraid of that natural cycle of life and death. It’s a fear. (Maori community organisation)

In terms of the spiritual implications, nature had an integrated system of letting go of what is not healthy and supporting healthy organisms. What man has done is come along and said, ‘I don’t accept I’m an organism. I am better than everything else on this planet and because I have the ability to think, I will interfere with all those other systems and that inter-connectiveness across the world’. (Maori community organisation)

Others said that they were open to consideration of testing if their children or grandchildren were involved. They saw this use of genetic testing as linked to their responsibilities to ensure the well-being of future generations.
My heart says definitely, 'No, no, no!', but that’s for me, but my head says, ‘Yes’, for my mokopuna. I’ve had my life, so I’m pulled both directions if it’s doing to help my children and the future generations. (Rural whanau)

Some participants talked about the positive benefits of genetic testing. They were interested in tests for specific conditions and predispositions, especially when treatment options were available and when knowing more about their DNA would improve their quality of life. Those who saw the benefits of genetic testing also emphasized the importance of confidentiality and control over that information.

I would be very keen to know if I had the gene, simply because there is good stuff that can happen for bowel cancer if you know early enough. And the same for breast cancer. (Health support group 2)

If you knew you had the gene, maybe you would have mammograms or start them earlier. (Scientists group 2)

The reality is it is here. It is not going to go away and there are positive points in terms of genetic testing and we should embrace the positive points. But there is access and privacy and those issues…I don’t mind a professional that I authorize knowing everything about my genetic makeup, but I don’t want you to know. (Business and professional group 2)

I feel that it is better to know because then you can do something about it…People have always wanted to know their fate, and so why not have a scientific way of knowing your fate, rather than something that is not so scientific? (Adult Education group 1 (older adults))

What sort of tests should be done?

Most people questioned the need for genetic profiling of new born babies. If testing was to be done, it should focus on tests for specific treatable conditions. Why identify conditions or diseases which have no cure? It was different if “something could be done”.

If there was a cure for Huntington’s disease, I would be quite keen for my daughter to be tested and told she had a defective gene… (Health support group 1)

So what would be the point of testing if there is no treatment? … Maybe psychologically you kind of advance the disease, because of knowing about it? (Friendship network 1 (young adults))

Do I want to know what’s going to happen to my granddaughter and if there’s something that I can help prevent her, would I want to do that to prevent something happening? And the obvious answer is – yes. (Business and professional group 2)
Other people thought that, even if “nothing could be done”, knowing that someone had a genetically transmitted disease or a genetic abnormality was better than not knowing and could enhance their lives.

I think it would optimize knowing I was going to die at 60 as distinct from 90, or 55 instead of 90 … [it] would alter the way I lived and would be a valuable piece of information to me. (Religious organisation 1)

They know they are only going to be a limited time on this earth, so they go out and achieve a lot more than … they thought… You have got terminally ill people who have done some absolutely wonderful things, and had they not been told they might have just sat back and they mightn’t have done it. (Community group 3)

A small number of people said that genetic profiling of newborn babies could help people to be better parents, as they could avoid or reduce the factors contributing to certain genetically transmitted diseases. A few people felt very strongly about this and said that it was irresponsible to not access this information for the benefit of your child, if testing was available.

If it was me, I would want to know it. I would want to start planning for how we might deal with it as a family and what those children might need to know. (Health support group 2)

So there is always risk, there’s always doubt, and always uncertainty, but I do want as much information as I can get. (Religious organisation 1)

What will genetic tests tell us?

People were often concerned that genetic testing could be seen as verifiable ‘facts’ about what would happen, whereas for many conditions it only indicates a predisposition or a probability.

And you have to understand that if you have got the gene, it doesn’t necessarily guarantee that you are going to get the condition. (Health support group 2)

Such knowledge appears to be so rock solid, verifiable fact … it’s really just a hypothesis, isn’t it? (Friendship network 2 (mid career adults))

The word that sticks out most to me is ‘predictive’ because they are not going to be completely sure. They might say, ‘Oh, you have got this chance of getting heart disease, so change your diet and your lifestyle, and then you will be fine.’ …but you might never get the chance to do anything that you would otherwise have wanted to, so that changes your quality of life. (High school students group)

A number of participants questioned the significance of genes as a source of health or illness relative to the experiences of poverty, colonialism and environmental factors
that determine health. They also speculated about discrimination that might follow a ‘bad’ test result.

I mean genetics aren’t everything. There are no clear cut answers to the fact that if someone has a predisposition, they are going to get a disease. We can do lots of other things… we can work towards not getting diseases. (Community group 2)

All they know is your genetics and it is just taking one variable into account. …They don’t know about your family background… (Scientists group 2)

As a parent I want my child to have the best, and I’d want to know that, if my child was at risk of things, I’d want to do things so that my child wouldn’t have to experience any harm later on. But then you’re taking that risk. You may do it in the child’s best interest, but then down the track, if there’s other things happening you can put the child at risk as well. (Iwi community health service)

I am quite ‘pro’ to a point, because I would certainly like them to DNA my whanau because we have got some pretty strong traits in our whanau. To be straight up – one of them is alcoholism and depression and [what] I would really like to know is … is it truly genetic in my whanau or is it just crap that happened? Or is it acquired? (Health support group 3 (Maori))

2. What are the consequences of knowing?

What does this mean for whakapapa?

Many participants were concerned about the effect on whakapapa (descent lines) of the use of genetic tests and the storage of genetic information. They were particularly worried about how their genetic material, and that of their tamariki (children) and mokopuna (grandchildren), could be used and the implications for them and their descendants.

How will I know if cloning does come through, that somebody is not going to go into my mokopunas’ database, take their DNA and then add it to somebody else’s and mix it up? That is my biggest concern – the policing. (Adult education group 2 (young adults – Maori))

I’m sure it could happen, the misuse of information. It would be misused into changing whakapapa and we have no power over that... You know I want my mokopuna to know their whakapapa. I don’t want them to find out a hundred years from now that there was a cow involved in our whakapapa. (Rongoa health providers)

And it is certainly going to change whakapapa and I don’t want that happening to my children. I want them to have their whakapapa clear from Te Po, Te Kore to where we are now. (Rongoa health providers)
What are the costs of knowing?

In almost every group, someone reflected on the impact of knowing about a genetic condition.

I lost faith in that kind of science when they diagnosed me. When they tell you that you’re going to die, they give you 5 years, you actually believe it… You will actually believe what these people say to you, even if it’s not true. But at the time it’s true, at the time you believe it… but I am a very positive person. That is probably the reason why I am living. (Lawyers group (Maori))

And then we decided to go ahead and have a child … and I had to see an obstetrician and he just turned round and said to me, ‘You should not get pregnant because of HD.’ (Health support group 1)

One of the costs really is giving up that right of confidentiality of your own stuff. The abuse as well, because you could be quite marginalised from society, and then carrying this label – I mean your whole whanau will be carrying that label because they are related to your siblings. (Health support group 3 (Maori))

A number of people thought that genetic profiling could lead to people being primarily defined in terms of their DNA. They were concerned about discrimination against those who were identified as having ‘defective’ or problematic genes.

The analogy of the bar code is slightly worrying as it assumes a code that encapsulates the person, which is a bizarre reduction of a human being to DNA. (Friendship network 2 (mid career adults))

M… was a taxpayer for about 35 years before he had to stop work, but if he was born say 50 years later and some of these systems were up and running, would he have the opportunity to be a taxpayer? (Health support group 1)

We all know quite well that if you tell a child that they are an idiot sufficient times, that is what they will believe… So I mean what we’re doing is creating a situation for people. We’re putting them in a box before they’ve actually got there. (Business and professional group 1)

On the other hand, some Maori participants recognised that traditionally parents mapped out their children’s lives.

From womb to tomb we said: ‘Right, here is a healer, that person is going to be nurtured and we did that traditionally and we want to go back to that traditionally, so there are some mappings that are part of our society and for the betterment of the society… (Rongoa health providers)
**Will it affect what people do?**

Some people said that people already know a lot about preventable health risks and that genetic testing would not add much to our knowledge about what we need to do if we want to avoid heart disease, lung cancer and diabetes.

*At my medical they told me I should lose 3 kilos… but do I actually do anything? No, I don’t.* (Health support group 2)

*It is pretty much common knowledge what the medical community considers the appropriate response for avoiding these things [like heart disease, lung cancer, diabetes] and things that we’re encouraged to do anyway.* (Religious organisation 1)

The political implications of knowing about ‘what is wrong’ were raised in one of the health focused groups:

*The thing is it is really deficit based. It is saying that if the test showed that you were susceptible to obesity or diabetes, then we would put you on this healthy kind of programme… We know what leads to diabetes; we know how to diet and that. We know how to die from being obese, but what a lot of people don’t know is how to be healthy, or if they do know, they are choosing not to follow it. Why is it that people do choose to follow it [a healthy diet] and not get diabetes?* (Exchange of ideas in Health support group 3 (Maori))

**Do we want to know?**

Participants talked about whether they would want to know about their children’s genetic make-up. Some people tended towards the view that it was better to know, especially if something could be done about the condition.

*If my baby was there and they took DNA and told me something serious was going to happen to it, then I definitely would do something about it straight away. I’m totally against GE, but if it was my baby there, I would do that.* (Adult education group 2 (young adults – Maori))

*I’d like to know if my kids or my grandkids had anything that could be fixed.* (Community group 3)

A number of participants spoke about why they or members of their family would not want to have a genetic test or know about a genetic disorder.

*I got [asked] in the hospital if they could do a genetic test on my son who is nearly 14 and I actually turned around and said no. If he is to grow up, he is going to grow up like a normal child, as an individual. They told me to abort him at 26 weeks because I couldn’t keep him… And I said, ‘No, we’ve got to save this one because I lost two others before him…’ And he’s fine… And I wouldn’t trade him or lose him for anyone.* (Community group 1)
I thought, well, when he is 18 I’m sure he will want to know … but as he got used to the idea of Huntington’s and his dad having it, and as his own life progressed… he has decided he is not going to be tested. He wants to enjoy his life, and I think that is the important thing …and I think that it is the fear of all this interference from agencies and government and insurance companies and prospective employers that’s going to happen and just smack – like hitting a brick wall at 22 because you may have this condition that just removes all that freedom and that joy of living. (Health support group 1)

As far as my daughter is concerned, I would want to know if they could fix something, but if they couldn’t fix it, I don’t want to know. Because I wouldn’t want to be sitting at home thinking in five year’s time my daughter is going to die, because it puts extra stress on your life. (Community group 2)

Other people spoke about the possible impact of genetic profiling on a child’s life. Would a parent love a child more/less because they knew the child might have a limited life span? Would children expect less of themselves?

I also think that if parents have that information they treat their children differently. They have to. And I’ve seen that once where some parents [had] a child dying of a heart condition … but they tried to let him live a life as well as he could. But I’ve seen other parents – they are wrapping up these children in bubbles. (Community group 3)

If it was my daughter and that was my moko, I would say ‘no’ because as mothers we are already over protective of our children, and if somebody told me that my son was having a certain condition by the time he was 15, then I would be doubly over-protective. He would have this over-protective mother that was going to wrap him up in cotton wool and try to protect him from everything in the world. (Adult education group 2 (young adults – Maori))

Many Maori participants thought that you could not separate issues relating to genetic testing and the storage of genetic information from the historical experience of colonisation and its consequences. The impact of gene technologies and whether you wanted to use this knowledge had to be considered against the background of other things that undermined Maori health.

It’s very difficult for us to actually preserve the integrity of our tikanga that was left to us by our matua tipuna [grandparents] because it’s been compromised daily. It’s the things that we should practice that we can’t because of their laws and their acts … that are put in place to prevent us from doing this. So how can we be a well people when the very things that kept us well, like the environment, the whenua, is no longer there? (Maori community organisation)
3. How will genetic information be used and stored?

Will it remain confidential?

All participants thought that it was vital that people had control over information about their own bodies or those of their children. Whether or not they thought genetic tests provided useful or problematic information, they were convinced that individuals and whanau/families should decide whether tests were done, who heard about the results, and how the information was used.

_I would want to have the ability to take the test and all those results are given back to me and I can have the decision whether to burn it, to destroy it so that information isn’t kept in the public record. So the ownership rests either with the individual, or perhaps with the whanau group, not with the state. …Then that empowers people to deal with it how they want to deal with it._ (Lawyers group (Maori))

People talked critically about the possibility of pre-implantation genetic diagnosis (PGD) being used to create ‘designer babies’, where specific genetic characteristics, like blue eyes, are desirable. In most of these discussions ‘designer babies’ was used as a negative term. People drew parallels with the trend in China to produce male babies, and the social imbalance that has resulted in millions of men unable to find women partners.

While most research participants considered PGD negatively, those with direct experience of new reproductive technologies were much more positive about it. They considered PGD more desirable than terminating a pregnancy of a severely disabled child.

_And that’s the irony of the present New Zealand situation in that you can terminate a pregnancy up to 20 weeks for a whole lot of reasons, some of them might be genetic…And that’s funded at present in New Zealand where there is no PGD available…We will pay for that and put you through that but we won’t pay for genetic testing._ (Health support group 2)

A number of participants spoke about their mistrust of the medical profession, scientists, commercial companies and governments, and why they were distrustful. They were often skeptical of guarantees about ‘confidentiality’ and reflected critically on who would benefit from advances in human genetics.

_We just can’t trust them (the medical profession), they always put good intentions in front of us, that it is for our own good and for health and etc., and our people buy it, but then they do all sorts of other things that aren’t good for us._ (Maori community organisation)

_I can see the point of view of saying, ‘Hey, we can have this information earlier’ [through genetic profiling of newborns], But my concern is as long as it can be kept confidential… It_
has to be kept confidential and it’s not to be given out to a third party for extra research and whatever. (Community group 1)

Well, that just seems like you can’t guarantee that — ‘no employers will ever be able to find out anything about you from these records’ — ever. I think that is not true. (Scientists group 1)

Everything is run by computers these days and if it’s on a computer, anybody can get into it. It doesn’t matter about the Privacy Act. (Community group 2)

Without being too paranoid, we live in a corrupt society and we are seeing more and more in the media these days about tissue banks, illegal tissue banks, illegal organ buying… How will the information be stored and protected? (Iwi community health service)

Other participants highlighted the extent to which genetic diagnosis and the storage of genetic information entailed trust in the medical profession.

You totally have to trust the establishment to tell you what it means and who you are. And it is the essence of who you are, surely? …there’s nothing left if you’ve got all your genetic information on a computer somewhere and someone’s able to say, ‘Well, you’re predisposed to this.’ And ten years later say, ‘Oh, I was looking at the wrong file.’ (Business and professional group 1)

Who benefits from genetic testing and biobanking?

Some people thought that there was a need for more debate before these new technologies could be used effectively and before we could assess their benefits.

I guess my feeling is that the technology has outstripped our ethics at this point in terms of debate and discussion. I am not fazed by the technology of genetic testing, or genetic engineering. I can see that there is a hell of a lot of good could come out of it, both for individuals and the community as a whole, but I think that we haven’t really done enough in-depth discussion and debate… What happens inside the person? What happens inside me if I know this information? Who is going to know it? All of those issues around the intellectual property rights. Who owns my DNA? … Those debates have to happen before these sorts of things come on-stream in a big way. We may be trying to shut the gate after they have gone, I don’t know. (Scientists group 2)

Many people were concerned about control over the tissue samples provided for genetic tests, especially if commercial companies were involved. They raised questions about who would benefit from the collection and storage of DNA.

One dishonest person and some company out there hold your DNA and decide, right, we will randomly pick this person and use it for our cloning project… I mean, it is bits of you out there after all. (High school students group)
In my opinion… who has that right to even look at processing such a thought? I saw that DNA and I thought my DNA, my whanau, my tipuna DNA, and I thought: ‘Who are the people to lay claim to a DNA strand when they don’t even know who it is?’ (Iwi community health service)

I look at it as another form of exploitation. Commercial companies having access to information that you don’t, so they can develop a drug that will fix whatever, that you can pay hundreds of thousands of dollars, and somewhere down the line you provided the material for them to actually do this. (Lawyers group (Maori))

Where are the benefits going to go ultimately – research? Again and there’s that question, what is the purpose of their research? When is their research complete and when do they start another [project] with the same information? If they are not going to share it back with you, what other purpose is it for? (Iwi community health service)

Some people thought that genetic testing could be important for some families if there was a family history of genetic disease. But they were only positive about this if employers and insurers could not access the information.

You don’t have to tell your insurers or anything about that… but if you knew that your parents or something bad had this… it could put a lot of people’s minds at ease… but if you don’t have to take it … and it’s not written down in stone or anything, it could help you. (High school students group)

There are ways in which you could make sure that access to the information doesn’t have to be universal, like insurance companies, does it? (Friendship network 2 (mid career adults))

A few participants thought we should not get too “paranoid” about the use of information arising out of the use of genetic technologies. They focused on the usefulness of information available through genetic testing and biobanking of genetic and medical information.

It’s a very complicated subject… But I feel positive about it. I want to see it [genetic testing] continue to develop and we shouldn’t be too paranoid about the role of the bad and try and focus on the good… If I thought I was going to be susceptible to something – that is the first thing I would want to know. (Business and professional group 2)

**Who decides? How can we act responsibly?**

For many participants, decisions about genetic testing and storing DNA were seen as not just decisions for individuals, but collective matters.

I was thinking here, who stops my brother who has got serious diabetes, from donating his genes, which at the end of the day I regard as my family genes? … I’m over here saying: ‘Hang on bro, those are my genes as well as yours – you can’t do that.’ He goes, ‘I don’t want
to do that, I want to fix up the whanau line. ’I’m going: ’The whanau line is fixed; you just need to keep fixing yourself rather than rely on externals.’” (Health support group 3 (Maori))

We should be able to scrutinize, because that is our role, being kaitiaki of our people. You have got to ask, to ensure that it’s got nothing that’s going to cut across tikanga Maori and things that we believe in. (Lawyers group (Maori))

Some people thought that decisions about genetic testing affected a much wider set of people.

It is not just your decision to make alone. This stuff affects the whole human race. So how can one person, two people, or ten people make their decision about themselves that affects hundreds and thousands and millions of people? (Health support group 3 (Maori))

There was strong resistance to any mandatory genetic profiling of babies or prenatal testing. Many people thought that parents should decide.

I’m not happy about babies being tested mandatory when they are born. But this way is fine, if people want to do it. (Community group 3)

Parents could be seen as surrogates who held information about their child’s genetic profile “in trust”.

The parents might hold it … in trust or something, but only until the child gets its majority or whatever, when it is handed over. They don’t need to have opened it, or known it in detail after that. (Religious organisation 2)

One participant suggested that people might not want ‘a genetic profile’ of their child, but would want to test for specific things.

I’ve got a friend who’s got two children with cystic fibrosis. She didn’t realize until the second one was born. You could actually then go and have a test and say, ’I don’t want to know about alcoholism or depression or attention deficit disorder, I just want to know about cystic fibrosis because it is in the family. (Community group 3)

For some people it might be in their own best interests and that of the child to terminate the pregnancy and I don’t feel I have the right to tell that person that they can’t make that choice. (Religious organisation 1)

But several people were concerned about parents making such decisions. In the case of genetic profiling, the decision to be tested affected children’s lives, but they were not in a position to give their consent.

By doing that when the baby is a couple of days old, you’re taking away from the baby because it is not in a position to make a decision as to whether it wants the genetics stored in the first place. (Business and professional group 1)
I believe that it should be the person himself or herself who is the owner of that information, and it has to be his or her consent. So if it is a baby, I don’t think that the parents can actually claim consent, or ownership of the information. Neither can the doctors. (Religious organisation 2)

But when you get to that age you can have the test then; you don’t need to have it done when you are a baby. (Friendship network 1 (young adults))

My daughter is now six years old, but when my wife was pregnant, obviously a test was available and we chose to go through fetal testing with a view to terminate the pregnancy if the fetus had the defective HD … and somewhere in that period my wife went into labour and this little baby popped out and my rights as a parent changed. I could find out the genetics from the placenta, but I couldn’t take blood from my daughter. [Now] I don’t want to know my daughter’s genetic make-up. I want her when she is eighteen to make her decision whether she wants to know … and it comes back to that ownership thing. (Health support group 1)

Sometimes participants thought that you had to balance issues of consent against the value of knowing when there was a family history of genetically transmitted disease. They spoke about the importance of “putting parents’ minds at rest”. This was often based on experiences within their families or friendship networks.

There are times when things are so awful that you would prefer to know that they didn’t have them [genetic predispositions or genes associated with inherited disorders]. (Business and professional group 1)

Participants often talked about how difficult it was to make decisions about genetic testing. How was informed consent possible when you didn’t know what the consequences would be for you, your child or your family?

I’m quite worried about this whole idea of informed consent. This is a nice idea, but I think that something like genetic testing is just so – the ramifications are so vast and complex. (Religious organisation 1)

I think it would help going into those decisions with your eyes open … one hopes that when that disease, if it does sort of come to the fore, there may well be a cure for it. (Business and professional group 2)
Some people thought that marginalised and vulnerable people might be pressured into agreeing to participation in health research, or to providing samples of genetic material. They won’t get very many Maori, ’cos Maori do not operate with pieces of paper… [like the biobank pamphlet used in the contact groups] Maori do not operate like this. Only very very colonised Maori do. (Religious organisation 3 (Maori))

…and that’s the reality for Maori in the lower class that wants that drink, that wants that drug. All the poor areas are usually the guinea pigs …They are never going to pick on the elite. (Religious organisation 3 (Maori))

Where do we draw the line?

People recognised that genetic testing could be used to eliminate genetic disorders by testing in vitro and terminating the life of any fetus that was less than perfect. Some people thought that this gave parents who had genetic disorders greater choice whether to continue with a pregnancy. Other people were concerned about some people deciding characteristics are ‘undesirable’. People talked about how difficult it was to “draw the line” on these difficult moral issues.

[Testing unborn babies] would be the ultimate sort of use for it. We have a family friend where two of them will probably never have kids because they have a major genetic problem which they will pass on. They were tested and they haven’t got it themselves, but you know if you have DNA testing, and it’s at J… says, where do you draw the line? (Business and professional group 2)

You know, the minute you bring in that kind of genetic testing you are bringing in the whole euthanasia thing. Exactly. And, why not kill off depressives? I mean, God knows, we don’t need them, any more than we need people who have intellectual disability or physical disability. There is a whole stream of argument around there that nobody has even dared to start a conversation about really. (Friendship network 2 (mid career adults))

One of the younger participants commented on the effects of genetic testing on the aging population.

Money is going into all this, extending people’s lives, and making them better, because everyone is focusing on that, no-one is focusing on, what we are going to do with all these people that are living nowadays. Was it four billion people they reckon the world has now? What are they going to do when people just don’t die of disorders, like at an early age because they have already been tested for them? They will be on special drugs and they’ll be all fixed and you won’t die. (High school students group)

In one contact group many participants had watched a TV documentary where a family had a child with spinal muscular-atrophy (SMA), a particularly devastating condition
where the child died at the age of three. Participants supported genetic testing and the termination of pregnancy if the child born would suffer and die at a very young age. They supported the parents’ choice to terminate a pregnancy when they knew that the fetus had the same disorder.

They didn’t want to bring another child into the world that was going to die, and they knew it was going to die. (Health support group 2)

She said she thought it was much better to have [a termination]. The point she was making was she wasn’t having a designer baby. (Health support group 2)

4. What will genetic testing cost?

Who will have access to genetic testing?

Participants were concerned that access to genetic testing could be restricted to those who could afford to pay. If genetic testing was available, they wanted everyone to have access to it regardless of income. Many people talked about what a society would be like if some, but not all, of its members had access to genetic testing.

I think it should be something free for everyone, because it is about health. It should be optimal for anyone, if they are doing exactly what they say they are... I definitely would not do it (direct to consumer genetic testing), but if other people think it is a good idea and want to, you can’t really stop that. (Friendship network 1 (young adults))

But is there going to be a change in society where those people that could afford the tests, the preventative treatment, take out the bad gene and pass on everything ok to their children. They can do it and they can afford to do it, whereas other people can’t. Do you have a ‘have’ and ‘have not’ society, where the rich get richer and fitter and healthier, whereas the poor die off through not having this ability? (Business and professional group 2)

Another person stated that we could not begin to assess the costs of new biotechnologies until, as a society, we had made some of the fundamental decisions about what kind of society we wanted. How important is universal provision of healthcare? And where does genetic testing fit if you consider that health services should be provided regardless of income?

Doesn’t that also come down to what kind of society do we want? Like if we go back thirty years most New Zealanders seemed to be very, very happy and on board with the idea that we have a free health system, free education and full employment and these sorts of things even though we had to pay very high taxes... but now we’ve moved through the whole privatisation, corporatisation sort of philosophy and we’ve moved a long, long away from that, so to me... these questions about ethics and genetic testing also come back to what kind of society do we want? Do we want a hierarchical society where only certain people can get these expensive
medical type things done because they can afford to pay? Or do we want a society where we can have the maximum good health for the maximum number of citizens? (Religious organisation 1)

One person suggested that, if genetic testing was very expensive, the people who utilised it would be more likely to act on the findings. They suggested that we value what we pay for.

Well, if genetic[testing] is really expensive, just say it was really expensive, you really had to save up to have it done, you have to be wealthy. I think that if it required some effort on your part, you might be motivated to do something with the results mightn’t you? (Health support group 2)

What impact will genetic testing have on other health services?

Many people questioned spending huge sums of money on new biotechnologies when they felt that basic health services were not adequate. Sometimes they reflected on the lack of public input into decisions about investment in scientific research and new technologies. For some participants these were the fundamental decisions.

I think unfortunately one of the decisions that we have absolutely no influence over is probably the fundamental decision. I mean who decided to spend all these billions of dollars on the human genome project? When you think of all the other positive health options that people could have decided to do with that money if there hadn’t been the scientific and entrepreneurial steam behind this project and if it had just been decided in terms of benefits for human health. I mean no one in their right mind would have put money into the human genome [project]. They would have funded health services and health education to actually help some people instead of actually employing more scientists. (Religious organisation 1)

Everyone has to ask themselves, ‘What is the intention?’ All those scientists have to ask themselves, if they come back to the start because they are so focused on what they are doing …that maybe they don’t actually remember what the true intention for what they are doing is now any more. (Friendship network 1 (young adults))

While participants thought that access to genetic testing should be free, they were concerned about the escalating costs of providing such a service.

And I mean, that is what’s happening in the health services at the moment – it’s the expensive technologies that are funded. So apparently our local Health Board’s already kind of millions in deficit, one-third into its year. It’s partly the profit motive which is making the fancy technology expensive unnecessarily and the drugs unnecessarily expensive, but, it’s also kind of being in love with the technology isn’t it? If it’s there, you’ve got to use it and it means that the money goes into those fancy areas, like this, instead of into good, public health, you know, health promotion areas. (Friendship network 2 (mid career adults))
A participant in the primary care/public health group stated:

I know at the moment that 65% of the primary health goes into pharmaceutical and laboratory testing. It leaves 45% for actual interventions. Now this [genetic testing] is a new site, the taxes are going to go up for sure; it's going to be costly. (Primary care/Public health group)

Many people talked about the way that people are already being excluded from receiving the health care they need because of limited public funding. They questioned who would benefit from genetic testing and drew on aspects of their life experience to highlight why they were concerned about these issues.

I remember sitting in a private hospital and watching this old man bargaining for a pair of knees. He was saying, ‘How much would it cost to get my left knee done?’ … And the woman said whatever the price was, and he said, ‘I can’t afford to get both knees done, so which knee shall I have?’ It was just, I thought, ‘My God, what a sick situation!’ It was so sick that this person would bargain to try and get at least half his knee done and it’s just obscene, because there is nothing more pointless than the profit motive, and there’s nothing more that drives so much of what we are talking about. (Friendship network 2 (mid career adults))

Is there any evidence to show that by having the genetic test we as ordinary people are going to benefit in some ways? What good comes from having a genetic test? Does science give us that information yet? Does anybody have an answer to that? (Community group 2)

Some people said that the introduction of new technologies created demand, and that people now expected results from the technologies, and were dissatisfied with their lives in a way that they would not have been if expectations had not been raised. They used infertility as an example of how technological advances raised expectations that conceiving a child is possible if you persist with the technologies.

It is expectations, isn’t it? If you think about reproductive technology and fertility treatment, when they weren’t available, then people, maybe, were not happy that they were infertile, but they accepted it. But now there is an expectation that you will get fertility services, and you will achieve. (Friendship network 2 (mid career adults))

A number of people were concerned that genetic testing would lead to a focus on finding genetic solutions to certain diseases, when lifestyle changes such as diet might be as effective, and a whole lot cheaper.

I believe that for the majority of problems we face the environment is far more important. A very close friend of mine has Celiac disease and he almost died. When he found out and he was in his mid twenties, he changed his diet and he is fine now. When they had a child, both learned all they could about it as there was a chance of the child inheriting his problem. She breastfed the child as long as she could and did not introduce him to gluten until he was much
older. I think I would much rather have a situation where everybody was encouraged to
breastfeed and eat healthy food, rather than where children can be genetically tested, and then
treated. (Adult education group 1 (older adults))

**What role does private enterprise have in genetic testing
and the storage of genetic information?**

It is not just a conversation about the nature of science, but it’s a conversation around the
nature of profit and the whole way in which it is all commodified, and we don’t talk about
that. (Friendship network 2 (mid career adults))

The relationship between science and private enterprise was discussed in several contact
groups. People recognised that increasingly business and commercial interests provided
the context for the work of scientists.

It is not just basically up to the scientists any more, a lot of the time, what they are going to
study, because it all comes down to funding. A lot of the funding is controlled by multi-
national corporations, pharmaceutical companies. It is often where they can see there’s a lot of
money to be made, where they are going to put the funding. (Religious organisation 1)

I get very frustrated with what I see as the demise of the scientific community, where everything
is so intellectually stamped now. That in fact everything is bought and sold, whereas for myself
anyway, I have come from a far more open community where if information is there that has
been paid for by the public, you know [it is] everyone’s. It is there, it is open and anyone can
pick it up. (Scientists group 2)

It’s not the science that restricting us, it’s the other companies that are grabbing that information
and giving it to agencies. So the scientific community is actually giving us a very valuable tool;
valuable information. It’s the other factions. (Business and professional group 1)

Lots of people talked about the role of private enterprise in the development of genetic
testing. People were concerned that the drug companies, with their vested interests in
illness, rather than health, could become a driving factor behind the availability of genetic
testing.

To choose the profit motive, there is an industry built on profit and finding out about this stuff,
but they don’t make any money out of people necessarily being healthy, so it becomes about
people being ill. So it [the direct to consumer genetic testing advertisement] talks about health,
but it actually wants people to be ill because then it can sell you more drugs or whatever. There
will be other industries that will benefit by people being healthy, but they are not as strong.
(Friendship network 2 (mid career adults))

Even the name ‘bio-bank’ – a bank has connotations of money and profit and that sort of thing. (Lawyers group (Maori))
I am happy to have it [genetic information] shared, but I would be a bit cheesed off if they took the blood off me for free, and then sold it to somebody else. (Scientists group 2)

Many people also had concerns about the trustworthiness of a private enterprise organisation in partnership with a government to set up genetic testing or a biobank. Major concerns were that the information could be on-sold to other organisations, for example other drug companies, or the police.

I guess I can see why pharmaceutical companies would be interested in this sort of information. If they could see that there was a big chunk of the population that were pre-disposed to a particular illness that hadn’t yet manifested itself, I guess that might be useful information. And I guess if you’re sending back results to people that you’ve got a pre-disposition to this, it would be real interesting if you received the next day in the mail something that said ‘have we got the drug for you’. [sounds of general assent in the background] (Health support group 2)

Do we really want to help pharmaceutical companies? … Are they going about things in a way that doesn’t actually fix the problem? … Is it actually fixing the problem or is it just making money? (Friendship network 1 (young adults))

Another participant questioned the ethics of some pharmaceutical companies:

But they are making such huge profits with the drugs they use. And they do some fairly unethical things too about supplying them because of the profits they are going to make from them, when they are sometimes not fully tested, and have caused huge damage. (Scientists group 2)

Some people said that they wouldn’t trust a commercial company to do genetic testing. They were concerned that there might not be any quality controls on the testing, that their sample might get mixed up with or contaminated by another person’s sample. Others said that, if they needed a genetic test, they would want it done by a doctor they could rely on, rather than people who “don’t care about you personally.” (High school students group)

A few participants saw commercial involvement in genetic testing and the use of information stored by genebanks as a potential contribution to human well-being.

Well, you know if they are selling the products, like it says here, to companies who are … researching to make better medicines, it is like it is all benefit here. I don’t have a problem with people getting rewarded with money for doing something good. (Friendship network 1 (young adults))

What about the patenting of genes?

Integral to the discussion of private enterprise and multi-nationals developing genetic testing (and other health and biotechnologies) was the issue of patenting. People were
generally appalled that discoveries around genes and DNA could be patented. As one participant expressed it:

Oh, my God, this is getting really awful. I mean that in itself it is immoral that people can patent that sort information. (Religious organisation 1)

In another group a participant expressed concern that use of patents was being stretched away from its original application.

I read about patenting. It was only meant to be for inventions or stuff like that, so they have twisted it slightly. The application is the invention, not the actual length of gene. But it is like all these big companies own little bits of us, and if we want anything treated in the hospitals we have to pay all these royalties. (High school students group)

However, some people talked about patenting as a way of protecting research and development that is extremely costly.

There are arguments for and against because the technology is expensive to unfold. One can go either way, whether pharmaceutical progress or technical progress will evolve if they can’t cover their development costs. (Adult education group 1 (older adults))

5. What about science and scientists?

Some participants distinguished between genetic science and issues surrounding how it was used. They focused less on the uncertainty associated with genetic testing and more on the risks associated with commercial interests, government economic strategies and unscrupulous use of information.

Seems to be that genetic testing … is a fairly neutral testing mechanism, it’s what you do with those tests that… is where the engineering comes in. (Adult education group 1 (older adults))

A few people were concerned that geneticists were being presented negatively as determinist or unethical. They said that good geneticists recognise that environmental factors interact with genetic factors and they are interested in producing useful knowledge. They recognised that lack of knowledge among non-scientists often produced uncertainty and anxiety and embraced the need for conversation and ‘give and take’.

We need to allow people to continue to develop those kinds of things, but without all the negative side effects … in terms of insurance industries and people being disempowered or whatever… decision-making around those social issues has to somehow come up with those balancing factors, and that is not an easy thing to do, is it? (Religious organisation 1)

Scientists have got some good stuff, cures for diseases, really awesome stuff. I suppose if you had been in the 1940s and they talked about airplanes, everyone would be like: ‘It’s not natural to go flying across the sky in a plane. You just don’t do that. It’s not God’s way. If God
wanted us to fly, he would give us wings.' It's the same kind of thing. Here we are sitting in this day and age talking about something that we don't really know what's going to happen and just saying: 'No, no, no, it can't happen', really closed minded about it because we don't know. It is scary what's in the future, we don't know… (Adult education group 2 (young adults – Maori))

Some people spoke about the need for ongoing conversations among scientists and members of the community – with accommodation on both sides.

So, they believe what they are doing is the right thing for their subject and it's the same thing with us. We think we got it right from the start. We don't want you interfering with us, we got it right. But never mind, we've got to learn to live with one another today. (Rural whanau)

Scientists are just tutus; they are just human, like us. (Adult education group 2 (young adults – Maori))

6. What can we do?

Can ‘ordinary people’ have an impact on how genetic technologies are used and their consequences?

Participants often said that human genetic research was inevitably going to have an impact on their lives, but they could exercise agency by being knowledgeable – by considering the consequences before it happened. Some people talked about this as a way of exercising mana motuhake or self-determination.

I'm here because I don't really know much about this kaupapa at all, but I'm here for the benefit of my mokopuna because I am an older person now and I'm really interested in what's going on… the only thing about this is, I wish I knew about it ten years ago and then we'd all know what's going on for the future of our tamariki. (Rural whanau)

But we have to have control over it and I think that's where the Treaty partnership really comes into play in terms of that protection afforded to Maori under the Act. Hopefully, where the government is going is not just in genetics, but will be pushed over into the area of social/cultural issues. Maori need to be actively participating at the decision-making level, because that is how it should be. (Lawyers group (Maori))

Assertions about agency relating to genetic testing and the storage of information were particularly important for Maori because colonialism had undermined control over wellness and the knowledge and other resources that produced it.

What they have done is taken away our ability to know ourselves and to trust our own knowing and to do what would support our health. They've taken that ability away from us. They're always telling us what's good for us and yet they've taken away our own ability to know
what is good for us. Not taken, we let them do this too, by thinking that it’s the best thing for us…

And our tohunga, they understood energy was the first primal energy, and form came later as secondary energy so they were able to heal… But, of course, Pakeha are discovering this. It’s like we have been forced through laws and rules to put down things that gave us well-being and now we are at the bottom of the pile of unwellness in the statistics. (Maori community organisation)

Many participants had a sense that scientific knowledge was developing rapidly and it was difficult to ensure that members of the public had any control over what new technologies were developed and how they would be used.

We’re opening … ‘a Pandora’s Box’. Unfortunately, the scientists have already opened it. And we’re not going to be able to stop. It is like stopping the sea, the tide, but what are we going to do about it? And I think that we need to get some strong kind of controlling body and ethics committee to which the community can refer, and that will report back… We are not often listened to in the community. (Adult education group 1 (older adults))

We end up as a society being tossed by decisions that are made without ethical and value discussion occurring before they are made. (Religious organisation 1)

What can governments do? Can we trust people in government to act on our behalf?

Most participants thought that developments in genetic testing required effective state regulation with respect to who would access genetic data and protection against discrimination on the grounds of genetic information. Even those convinced of the benefits of genetic testing considered that there must be legislation that protected citizens. However, some participants wondered whether you could rely on such regulation and current political processes. Was trust in politicians, the government and officials appropriate at the moment?

I was just thinking myself that I suppose what happened in the 80s and 90s really broke a kind of covenant in a way. The fact that they sold public assets was the first sort of shock, horror; these were the people’s things, and they sold them. So how far does politics go? (Friendship network 2 (mid career adults))

I honestly don’t trust… if you have the dollar, you have access to everything and anything and I just don’t believe government… There is no point in being silly and staying in the dark ages, but I just don’t trust them with the information… Ten minutes and they can alter whatever’s in your file. (Health support group 1)
It's about the perception that people have of government, or people in power. And what is it that I want to know from that? I want to know what their intentions are. I want to know that they are in a space which honours the sacredness of life, as we were talking about. That honours something higher than material gain, and knowing how to be really clever with words and documents. (Religious organisation 2)

A critical approach to politics and politicians affected people’s confidence in guarantees relating to privacy of information provided by state actors.

At the point in time when the test is taken, you don’t know whether or not the legislation might change later, which would mean that it could be used for other purposes…(Health support group 2)

Some people were particularly concerned about the possible use of tissue samples for forensic purposes.

“You say, ‘Oh, I wasn’t there’. And they say, ‘Oh, but your genes say you were…’ (High school students group)
Appendix One

Information about genetic testing and biobanking

Gene profiling and genetic testing:
The hypothetical story about genetic profiling and the mock advertisement for direct to consumer genetic testing advertisement were primarily informed by analysis of the following documents:


Biobanking and the storage of genetic material:
The fictional biobank pamphlet utilized knowledge available about UK Biobank Ltd, a charitable company funded by the UK Medical Research Council, the Wellcome Trust, the Department of Health and the Scottish Executive. UK Biobank will collect genetic material, medical records and life-style and diet details from 500,000 volunteers aged 45-69. This information will be available to pharmaceutical companies as well as public sector researchers. Information about UK Biobank Ltd, is available on the following website: www.ukbiobank.ac.uk.

Papers about genetic testing and gene banking:
Research team members are currently writing papers that consider specific issues in more depth. They will be available on the research website over the next 3-6 months. Visit this website to find out more about the research strategies used in this study, the materials that prompted discussion in the groups and why these research processes were used: www.conversations.canterbury.ac.nz.
Information about how the research materials were used in the first set of contact groups and the research process:

Visit the contact group meeting page on the Constructive Conversations/Korero Whakaaetanga research website to access the materials used to prompt talk about genetic profiling, direct to consumer genetic testing and biobanking as well as the kit used by those facilitating the focus group interviews. www.conversations.canterbury.ac.nz/overview/meetings.htm