Who gets born? Pre-birth testing

toi te taiao
the BIOETHICS
COUNCIL

Tēnā koutou Welcome!

If you ask people who are about to have a baby what they want for their child, they will often say “a healthy baby”. While this wish is not a new one, the fact that we can now test embryos and foetuses for a variety of factors, ranging from the baby’s sex to his or her risk of contracting specific illnesses or disorders, is relatively new. With this capability come certain moral, ethical and social questions that might have profound implications for the way we think about reproduction and the family.

Martin Wilkinson

Chair, Toi te Taiao:
the Bioethics Council

Toi te Taiao: The Bioethics Council has produced this online deliberation to stimulate discussion on these important issues. The public input we receive will be reflected in a report to Government and it is expected that policy and decision makers will take these recommendations seriously when they address issues about pre-birth testing.

There are no easy answers to the “who gets born?” question, so every perspective matters – we thank you for adding your voice to the deliberation.

Martin Wilkinson,
Chair, Toi te Taiao: the Bioethics Council

Tena koutou katoa i runga i nga ahuatanga o te ao hurihuri nei. He panui tenei hei whakamohio atu ma te Kaunihera o Toi te Taiao e whakahaere ngā hui huri noa o te motu, hei āta kōrero i ngā kaupapa whakahirahira ara te whakamatau hapu.

He hui mo tātou katoa ahakoa ko wai, ahakoa no hea, nau mai haere mai.

Toi te Taiao: the Bioethics Council is engaging the public on an issue which touches the lives of many men, women and children: pre-birth testing.

This is a hui (meeting/discussion) for all people regardless of who you are or where you come from. Welcome, please join us.

Complete the choicebook online!

This choicebook is easily accessible on the internet and we encourage you to complete it online. You can access the online survey from any computer, at any time while it is in the field by going to **nzbioethics.dialoguecircles.com**. If you choose to respond to the choicebook online and can’t complete it in one session (or if you encounter technical difficulties), your answers will be automatically saved and you may return to complete it at another time.

How to use this choicebook

This choicebook will allow you to learn about pre-birth testing, and to reflect on how we, as a society, should deal with this issue.

It is *not* meant to advocate one policy option at the expense of others. Rather, it encourages you, as a citizen, to reflect on what you value and the tradeoffs you would be willing to make with respect to pre-birth testing.

To this end, the choicebook is divided into three sections:

- Part 1 offers some background information on pre-birth testing;
- Part 2 invites you to review and react to various approaches to pre-birth testing;
- Part 3 asks you to identify what you see as the best way for moving forward.

Did you know?

As you will see, some areas of this choicebook provide additional facts in highlighted text boxes such as this one. These are provided for your information.

Please remember there are no right or wrong answers here. What matters is asking yourself the tough questions and making the tough choices to determine what direction we should take when it comes to pre-birth testing.

On the last page of this choicebook, you will also find a submission form that you may use to share your stories and ideas relating to pre-birth testing.

Returning your completed choicebook

Once you've completed your choicebook, please return it to us by mail or fax for compilation and analysis.

Our mailing address is:
Toi te Taiao: the Bioethics Council
PO Box 10362
Wellington
New Zealand

Programme leader: John Pennington
Telephone: (04) 439 7673
Fax: (04) 439 7704
Email: prebirth@bioethics.org.nz

Take your seat at the table!

The Council will be hosting an **online deliberation** (using friendly chat technology) on the issues presented in this choicebook, starting **15 November.**

You may sign-up at the end of this choicebook to participate in the online deliberation. Completing the choicebook is required if you wish to participate in the online deliberation.

This will be an easy – and fun! – way to engage with others in a dialogue on the issue, to further explore, refine and prioritise possible courses of action, and perhaps identify new ones!

Please tell us about yourself

Knowing a little bit about you will help us better understand the information we receive during this deliberation.
This information is strictly confidential and will only be reported in ways that cannot identify you personally.

1. I am:

☐ Male
☐ Female

2. My **age** is:

☐ Under 20
☐ 20-25
☐ 26-35
☐ 36-45
☐ 46-55
☐ 56-65
☐ 66-75
☐ Over 75

3. My **ethnicity** is *(Please check only ONE)*:

☐ Asian
☐ Māori
☐ NZ European/ Pakeha
☐ Pacific Island

☐ Other *(please specify)*: ____

4. My **home** is in *(Please check only ONE)*:

☐ Northland
☐ Auckland
☐ Coromandel
☐ Waikato
☐ Bay of Plenty
☐ East Coast
☐ Central Plateau
☐ Hawkes Bay
☐ Taranaki
☐ Manawatu-Wanganui
☐ Wairarapa
☐ Wellington
☐ Nelson
☐ Marlborough
☐ West Coast
☐ Canterbury
☐ Otago
☐ Fiordland
☐ Southland
☐ Stewart Island
☐ Chatham Islands

5. I would describe the **community** I live in as *(Please check only ONE)*:

☐ Rural
☐ Urban

6. The highest level of **schooling** that I have completed is *(Please check only ONE)*:

☐ I am currently in secondary school
☐ Secondary school
☐ Polytechnic
☐ Other tertiary
☐ Wānanga
☐ Undergraduate degree
☐ Postgraduate degree

Part 1: About pre-birth testing

As illustrated in our short history of pre-birth testing *(below)*, the desire to know more about a baby before he or she is born is not a new one. However, as we understand more about genetics and as technology progresses, more testing becomes possible: while some tests relate to medical conditions (e.g., pre-birth testing for Down syndrome), others could test for characteristics such as height or eye colour.

Pre-birth testing can include 2 types of tests:

- **Screening:** A positive result from screening shows there is an increased *chance* of a particular condition being present.
- **Diagnostic tests:** These can show more reliably whether or not the condition *is* present.

A short history of pre-birth testing (PBT)

Pre-birth testing… 1350 BCE!

An ancient Egyptian papyrus describes a test in which a woman who might be pregnant could urinate on wheat and barley seeds over the course of several days: "If the barley grows, it means a male child. If the wheat grows, it means a female child. If both do not grow, she will not bear at all."

Testing of this theory in 1963 found that 70 percent of the time, the urine of pregnant women did promote growth, while the urine of non-pregnant women (and men) did not!

Testing during pregnancy

Pre-birth testing technology has evolved greatly since 1350 BCE! For example, in 1959, it was discovered that people with Down syndrome have an extra chromosome 21. This was the first time that a disability and a **chromosome disorder** had been linked.

Amniocentesis was invented in 1968. In the 1980s, **ultrasound tests** became available to monitor whether a foetus appears to be developing well or if certain foetal abnormalities are present.

Testing IVF embryos

In 1978, Louise Brown was born, the first baby from an embryo created outside the mother using **in vitro fertilisation (IVF)**.

IVF technology then allowed embryos to be tested before the woman became pregnant.

Pre-birth testing *during* pregnancy

The first pre-birth test typically encountered by pregnant women is… the pregnancy test!

A number of other pre-birth tests are regularly conducted **during pregnancy** to monitor the health of both mother and baby. These include:

- Maternal blood pressure, urine and blood tests;
- Monitoring of foetal heartbeat; and
- Ultrasounds at various stages of a pregnancy.

A variety of more sophisticated tests, such as NT screening and the triple screening test *(explained below)*, can be conducted during pregnancy to test for various conditions, diseases or disorders.

Pre-birth tests may require only simple interventions (e.g., a maternal blood test) or may require more invasive – and therefore riskier – procedures such as amniocentesis *(explained below)*.

If a test shows there is a problem, the mother / parents will have to decide whether or not to continue the pregnancy *(see below to learn about New Zealand abortion laws).*

Amniocentesis

A sample of the amniotic fluid surrounding the foetus is extracted. The cells from this fluid are then tested to detect some genetic disorders like Down syndrome.

Because amniocentesis is an invasive process, it has some risks for the pregnancy. Nonetheless, from the 1970s, this test has been frequently offered to older women because it was known that Down syndrome is more common if the mother is older.

NT screening

Using ultrasound imaging, it is possible to measure the fluid-filled area at the back of the foetus' neck. An increase in this fluid between 11 and 14 weeks into the pregnancy is associated with Down syndrome. This can be detected by a nuchal translucency measurement (NT screening).

Triple screening test

NT screening is more reliable if combined with testing blood from the mother, and taking her age into account (hence the name "triple screening"). If the screening indicates a possible problem, the pregnant woman is offered a more invasive diagnostic test (usually amniocentesis or chorionic villus sampling), which can identify a number of other conditions in addition to Down syndrome.

New Zealand abortion laws

In New Zealand today, abortion is:

- legal up to 20 weeks gestation, if there is a serious danger to the mental or physical health of the mother or a substantial risk that the child would be seriously handicapped;

- only permitted beyond 20 weeks gestation if it is necessary to save the life of the woman or prevent serious permanent injury to her physical or mental health.

What do YOU think?

We'd like to know more about your experience with and thoughts about testing during pregnancy.

7. Did **your mother** have any form of pre-birth testing when she was pregnant with you?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

8. Imagine **you** were pregnant. Would you agree to pre-birth testing?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

9. Have you, or your spouse/partner, ever been **pregnant**?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

10. Do you have **children**, or plan to have children?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

11. Have you/your spouse/your partner, or someone close to you:

a) Been asked to undergo tests during a pregnancy **without fully understanding what these tests were for**?
Please check only ONE.

☐ Yes ☐ No ☐ Not applicable

What do YOU think?

11. Have you/your spouse/your partner, or someone close to you *(continued)***:**

b) **Felt torn** between the medical reason for undergoing a specific test during pregnancy and a personal fear of what the results of that test might be?
Please check only ONE.

☐ Yes ☐ No ☐ Not applicable

c) Asked your health care provider to conduct a specific test during a pregnancy and been **refused**?
Please check only ONE.

☐ Yes ☐ No ☐ Not applicable

d) **In response to the results of test(s)** conducted during the pregnancy,
Please check only ONE.

☐ Continued the pregnancy ☐ Terminated the pregnancy ☐ Not applicable

e) Ever made decisions about a pregnancy that turned out to be based on **incorrect test results**?
Please check only ONE.

☐ Yes ☐ No ☐ Not applicable

If you've responded "yes" to any of the preceding questions (questions 11a-e), you may use the comment box below (or attach an additional sheet of paper) to provide additional comments about your experience:

Pre-birth testing *before* pregnancy

Perhaps less obvious is the fact that pre-birth tests can be conducted on an embryo *before* an actual pregnancy begins. This is referred to as **preimplantation genetic diagnosis (PGD)**.

In vitro fertilisation (IVF), or the creation of an embryo outside the mother, has enabled PGD: a form of testing that involves removing one or two cells from a number of IVF embryos and testing these cells for a genetic condition. Embryos free of the condition are then transferred to the mother, while the others are destroyed.

Before PGD, people who knew there was a genetic condition in their families which they did not want to pass on to their children had only two choices: not to have children or the woman could become pregnant, *then* test for the condition. In the event of positive results, the woman or couple would choose whether or not to continue the pregnancy.

When no genetically matched donors are available to treat a child with a serious medical condition, parents might also choose to use PGD for tissue typing to ensure that their next baby will be a genetic match to the sick child. In such cases, the umbilical cord blood from the baby is usually used to treat the sick child *(more on "saviour siblings" at right).*

"Saviour siblings"

At present, using PGD to have a "saviour sibling" in New Zealand must be approved by an ethics committee on a case-by-case basis. This is only allowed if the sick child has a condition that the new baby might also inherit; therefore ensuring the new baby will not inherit the condition.

PGD **cannot** be used to produce a "saviour sibling" for a child with a condition that is **not inherited**, such as leukaemia.

New Zealand guidelines for the use of PGD

The guidelines state that:

- The sick child must suffer from a single-gene disorder or familial sex-linked disorder.
- The parents must only intend to use the cord blood of the saviour sibling.
- There must be no other treatment available.
- The embryo must be a sibling of the affected child.

These guidelines are currently being reviewed by the Advisory Committee on Assisted Reproductive Technology (ACART). *To find out more about ACART, please visit www.acart.health.govt.nz.*

When can PGD be used?

PGD may be used without ethics committee oversight if one of the following types of disorders would cause the child to be "seriously impaired":

- A single gene disorder has been identified in the family and there is a 25% or greater risk of an affected pregnancy;
- For sex determination if familial sex-linked disorders have been identified in the family and no test is available for the specific mutation;
- For familial chromosomal disorders if the disorder has been identified in the family;
- For non-familial chromosomal disorders if the woman is of advanced reproductive age, or has had recurrent implantation failure or miscarriage;

The fertility clinic and a clinical geneticist must decide whether the disorder is likely to be serious.

Any other uses of PGD (e.g using PGD to create a "saviour sibling") must have the approval of ECART, the government-appointed Ethics Committee on Assisted Reproductive Technology. *To find out more about ECART, please visit www.ecart.health.govt.nz.*

What do YOU think?

We’d like to know more about your experience with and thoughts on PGD.

12. Had you ever heard of **PGD** before completing this choicebook?

☐ Yes ☐ No

13. What is your general reaction to the idea of **PGD**?
Please select the statement that most closely reflects your views.

☐ PGD should be permitted.
☐ PGD should not be permitted.
☐ I’m not sure, I would need more information to decide.

14. Please indicate to what extent you would agree or disagree with the **use of PGD in the following circumstances**:

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**I don’t know**
If the condition being tested for would not develop until **after childhood**.						
If the condition being tested for was **treatable with no guarantee of a cure** (e.g. breast cancer).						

15. Had you ever heard of **“saviour siblings”** before completing this choicebook?

☐ Yes ☐ No

What do YOU think?

16. What is your general reaction to the idea of **"saviour siblings"**?
Please select the statement that most closely reflects your views.

- ☐ "Saviour siblings" should be permitted.
- ☐ "Saviour siblings" should not be permitted.
- ☐ I'm not sure, I would need more information to decide.

17. Please indicate to what extent you agree or disagree with each of the following statements regarding the **use of PGD to create "saviour siblings"**:

Using PGD to create "saviour siblings" should:

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**I don't know**
…. be permitted, **whether or not the condition of the sick child is inherited,** because a child's life may be saved.						
… be permitted **only if** the testing would prevent the new baby from inheriting a genetic disorder – otherwise there is no benefit for the "saviour sibling".						
…**NOT** be permitted because the "saviour sibling" may be used in the future as a tissue or organ donor for their sibling.						
…be permitted, because **mothers/parents** are in the best position to make decisions for their families.						

18. Have you/your spouse/your partner, or someone close to you, undergone **in vitro fertilisation**?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

What do YOU think?

19. Have you/your spouse/your partner, or someone close to you, undergone **PGD**?
Please check only ONE.

☐ Yes ☐ No ☐ Uncertain

20. **If yes**, what was the main motivation for undergoing PGD?
Please check only ONE.

☐ NOT APPLICABLE
☐ Because of a serious genetic condition that had been identified in the family
☐ Because the woman was older, or has had recurrent implantation failure or miscarriages
☐ Because a sibling was seriously ill and umbilical cord blood from a “saviour sibling” was required to treat him/her
☐ Other *(please specify):*

What do YOU think?

21. Please indicate to what extent you agree or disagree with the following provisions of New Zealand's <u>current legal position</u> on pre-birth testing:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	I don't know
PGD may **<u>not</u>** be used for non-medical sex selection (e.g., parents who want to balance their families, by having boy/s and girl/s).						
PGD may **<u>not</u>** be used to alter the genetic constitution of an embryo (e.g., in the future it may be possible to fix genes that cause disorders).						
PGD may **<u>not</u>** be used to select embryos with a genetic impairment seen in a parent (e.g., deaf parents wanting a deaf child).						
The **fertility clinic** and the **geneticist** (rather than the mother/parents) must decide whether the disorder is serious.						

Part 2: Let's deliberate!

Pre-birth testing has become a routine part of a woman's pregnancy, while the use of PGD (although much less common) is increasing. Depending on where developments lead to, PGD could, in the future, be as much in demand and as routine as scans, blood tests and amniocentesis are today.

To help you reflect, this choicebook considers pre-birth testing from four different perspectives, and suggests approaches by which the issues might be resolved.

These approaches reflect the interests, concerns and values that the Council heard from 56 members of the public at preliminary workshops. While other approaches might still be added to this list, these four do represent a variety of perspectives and we offer them as a starting point for discussion.

Each approach offers a different diagnosis of what's important. Each provides a direction for public action. We will invite you to consider each approach individually, before asking you to give us a sense of what you think to be the best way forward. Using insights from a range of perspectives is what deliberation is all about!

Approach 1: My choice, my right

Some people say that mothers/parents should be able to make their own decisions about reproduction.

This approach promotes personal responsibility and the freedom to make our own choices.

According to this view:

- Decisions whether to begin or continue a pregnancy involve the woman's right to control her own body, the father's interests, and the rights of the whānau/family.
- Mothers/parents are in the best position to know whether a decision is right for them, their whānau/family and their child.
- Pre-birth testing is a very personal and private issue. Allowing the government to regulate reproductive decisions will lead to erosion of our personal freedoms and will allow the government to increase its control over individuals.
- If you are free to make any choice you want, you may have to pay for it yourself.

In New-Zealand today…

Barriers to accessing pre-birth testing

No data is collected about how many women are offered pre-birth testing. However, research has found that some people cannot access pre-birth testing because:

- not all tests are available everywhere;
- only 50% of practitioners offer screening to all women;
- some women don't know to ask for tests;
- some women cannot afford tests.

How pre-birth testing is funded in New Zealand

Depending on circumstances, pre-birth tests are:

- fully government funded;
- subsidised by the government;
- paid for by the user.

For more details about the cost of tests, see Table 1 (p. 21) of the "Antenatal Down Syndrome Screening in New Zealand 2007" report provided in the Reading Room of the online deliberation website.

Approach 1: My choice, my right

Ma te tika te pono me te aroha - *Correctness, truth and love will carry the issue/day.*

Those who support this approach say that it:

- Places decision-making where it belongs: in the hands of mothers/parents.
- Allows parents to engage in collective decision making with whānau/family if they wish.
- Acknowledges that parents are in the best position to decide whether they can cope with a child (or further children) with a disability.
- Ensures that no one set of values is dominant.
- Reduces state involvement in people's personal lives.
- Allows people to make their own personal and financial decisions.

What do the critics say?

- Parents' reproductive autonomy and right to use PGD should not be unrestricted.
- Every embryo and foetus has a right to life.
- The sum of many individual choices, however personal, can have an effect on society that might not be positive.
- People should not be able to select against embryos or terminate pregnancies if it is likely that the condition can be successfully treated.
- Individuals don't always have the wisdom to make good decisions.
- If people have to pay for testing themselves, this approach is not fair or equitable, as many families do not have the resources to meet the full costs of testing.

What do YOU think?

22. The “my choice, my right” approach suggests actions such as those listed below.

Please indicate your level of agreement or disagreement with each of the following actions:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	I don’t know
Remove all restrictions on PGD.						
Let mothers/parents decide whether or not to use IVF with PGD in order to choose a particular embryo.						
Let mothers/parents select any embryo they wish to transfer to become pregnant.						
Let mothers/parents decide whether or not to have screening and testing during pregnancy.						
Let mothers/parents decide whether to **continue** a pregnancy.						
Let mothers/parents decide whether to **terminate** a pregnancy.						
Require that people pay for any pre-birth testing themselves.						

23. If asked to choose, which of these proposed actions you would prioritise:
Please check only ONE.

☐ Remove all restrictions on PGD.
☐ Let mothers/parents decide whether or not to use IVF with PGD in order to choose a particular embryo.
☐ Let mothers/parents select any embryo they wish to transfer to become pregnant.
☐ Let mothers/parents decide whether or not to have screening and testing during pregnancy.
☐ Let mothers/parents decide whether to continue a pregnancy.
☐ Let mothers/parents decide whether to terminate a pregnancy.
☐ Require that people pay for any pre-birth testing themselves.
☐ None of the above

Approach 2: Life is a gift

Some people would not allow any decision to destroy an embryo or terminate a pregnancy, because they believe every embryo or foetus has a right to life.

This approach suggests that when it comes to unborn children, we should interfere as little as possible.

According to this view:

- People should not have the right to discard embryos created by IVF or abort foetuses on the basis of pre-birth tests.
- We should focus on ways to make sure all children have the best chance to reach their potential. Doing this would mean paying serious attention to our most important values: love, respect for all human life and care of our most vulnerable people.
- Trying to control our babies' characteristics interferes with what is natural and could have unintended and unwanted consequences.

In New-Zealand today…

Some believe that embryos and foetuses have a right to life.

This might be based on the belief that:

- Embryos and foetuses have souls;
- God made us and the world around us – pre-birth testing therefore goes against what is God-given;
- It is a "biological fact" that at conception, when the two halves of the human genetic material combine, a new individual is formed with its own unique DNA, and organised development begins.

He tapu te tangata ahakoa ko wai

Humans are sacred, regardless of who they are or where they come from (this links with Māori thinking that sanctions or certain ramifications will follow should one risk tampering with the sacredness of the human being).

Those who support this approach say that it:

- Recognises that embryos and foetuses have a right to life.
- Prevents pre-birth testing being used to get rid of certain types of people from our community.
- Would maintain the diversity of our community.
- Recognises that diversity is more important than financial considerations.
- Recognises the worth of people with disabilities.

What do the critics say?

- Why wouldn't we try to prevent children being born if they are going to suffer or die young?
- Caring for disabled children can be stressful for parents and has caused relationships to break up.
- If more severely disabled people are born, more care will be needed – we can't ignore the financial cost of caring for more disabled people.
- Pre-birth testing is routinely available overseas: why shouldn't New Zealand parents be able to make the same choices?
- More restrictive grounds for abortion may increase the number of "back-street" abortions.

What do YOU think?

24. The "life is a gift" approach suggests actions such as those listed below.

Please indicate your level of agreement or disagreement with each of the following actions:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	I don't know
Allow testing that benefits the mother or helps parents prepare for a child, as long as embryos are not discarded and foetuses are not aborted.						
Require that every IVF embryo be transferred into a woman – none must be destroyed.						
Ensure there are sufficient support services for people with illnesses, diseases and physical disorders.						
Provide adequate government support and funding to family members who choose to care for disabled relatives.						
Provide adequate levels of government-funded respite care to family members who choose to care for disabled relatives.						
Provide the infrastructure so that disabled people can participate fully in our society.						
Provide opportunities for people to develop the ability to make moral judgments about complex issues.						

25. If asked to choose, which of these proposed actions would you prioritise:
Please check only ONE.

☐ Allow testing that benefits the mother or helps parents prepare for a child, as long as embryos are not discarded and foetuses are not aborted.
☐ Require that every IVF embryo be transferred into a woman – none must be destroyed.
☐ Ensure there are sufficient support services for people with illnesses, diseases and physical disorders.
☐ Provide adequate government support and funding to family members who choose to care for disabled relatives.
☐ Provide adequate levels of government-funded respite care to family members who choose to care for disabled relatives.
☐ Provide the infrastructure so that disabled people can participate fully in our society.
☐ Provide opportunities for people to develop the ability to make moral judgments about complex issues.
☐ None of the above

Approach 3: Tāngata whenua perspective

Some people feel that efforts are needed to inform and empower Māori, to enable them to develop tikanga (custom, rules) about pre-birth testing and have these tikanga respected by health providers and researchers.

This approach holds that it is important that Māori values and the Treaty of Waitangi are taken into account appropriately. Māori and non-Māori alike may sympathise with the tāngata whenua ("people of the land") perspective.

According to this view:

- It is crucial that when it comes to pre-birth testing, the needs of Māori are met and Māori values are taken into account.
- The government must work with Māori to ensure that the Treaty of Waitangi principles of partnership, protection and participation are applied to pre-birth testing.
- Māori must have access to adequate resources to inform and empower them, so they can develop tikanga and matauranga (knowledge) about infertility and pre-birth testing.

In New-Zealand today…

Core values for Māori are:

- **Whānaungatanga:** family, familial relationship.
- **Hapūtanga:** it in its literal sense, pregnancy; but also the sub-tribe or a large tribe.
- **Iwitanga:** tribal-ness, history, family and sub-tribal links to the larger tribe.
- **Whakapapa:** genealogy, the link back to the family, sub-tribe and tribe; to a geographical place (land) and time, which links the present to the past and the perceived future.
- **Mauri:** the life force of animated and non-animated things.
- **Whenua:** land – the most important treasure humans have.
- **Tino rangitiratanga:** independence, self/collective empowerment.

Antenatal care for Māori

Many Māori women miss out on the first trimester screening tests because they begin their antenatal care after the 14th week of pregnancy.

The value of human tissue for Māori

In traditional Māori culture, body parts separated from the body were accorded a ceremony similar to a tangi (funeral). It is therefore important that Māori tissue/blood is stored or used for research only with appropriate consent.

Ethics committee approval of research on humans

Researchers based in universities or being funded by the Health Research Council must obtain the approval of an ethics committee before starting research on humans.

To find more about ethics committees, please visit the Reading Room section of the online deliberation website.

Māori as subjects of genetic research

A lot of genetic research is carried out on Māori. However, some Māori question whether the research adequately benefits Māori and whether Māori values and customs are adequately taken into account.

Others worry that the results of some this research (e.g., on the so called "Warrior gene") could be used to reinforce stereotypes and prejudices.

Approach 3: Tāngata whenua perspective

Naku te rourou nou te rourou ka ora ai te iwi

Literally, with my basket and your basket we will feed the people (this relates to health and wellbeing - meaning that with your help, your research, your knowledge and the strengths that I bring, we will serve the people).

Those who support this approach say that it:

- Means the Crown will comply with its obligations under the Treaty of Waitangi to actively protect the social, economic and cultural well being of Māori.
- Māori women/whānau (family) will be able to make more informed choices.
- Access to all antenatal care by Māori women would be improved.
- Whānau with genetic diseases will have choices and be supported, whatever choice is made.
- There will be less chance that Māori will be the subjects of research and yet be denied the benefits of that research.

What do the critics say?

- Māori may benefit from more than a fair share of the limited resources available.
- Who speaks for the unborn child or foetus?
- If the government pays for pre-birth testing such as PGD, these funds may be diverted from more common healthcare needs that particularly affect Māori, such as the treatment of diabetes.
- Māori should be treated the same as everyone else.
- It's up to Māori to take responsibility for finding out about testing for themselves, as the information is widely available.

What do YOU think?

26. The "tāngata whenua perspective" approach suggests actions such as those listed below.

Please indicate your level of agreement or disagreement with each of the following actions:

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**I don't know**
Involve iwi (tribe), hapū (subtribe) and Māori organisations when developing policy and setting priorities with respect to pre-birth testing.						
Ensure that decisions about whether to have pre-birth testing – and what to do about test results – are made collectively by the whānau (family).						
Produce culturally-appropriate information about pre-birth testing, genetic counselling and care during pregnancy.						

What do YOU think?

27. The “tāngata whenua perspective” approach suggests actions such as those listed below *(continued)*.

Please indicate your level of agreement or disagreement with each of the following actions:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	I don’t know
Ensure that Māori women know the importance of getting antenatal care early in pregnancy, including screening and testing.						
Ensure that Māori genetic material is not retained or used for research without the informed consent of the appropriate **collective**.						
Ensure that Māori genetic material is not retained or used for research without the informed consent of the **individuals** who provided the material.						
Require that ethics committees make sure that iwi, hapū and individuals are fully aware of the purposes, harms and benefits of a research proposal to use Māori genetic materials before approving research proposals.						

28. If asked to choose, which of these proposed actions would you prioritise:
Please check only ONE.

- ☐ Involve iwi (tribe), hapū (subtribe) and Māori organisations when developing policy and setting priorities with respect to pre-birth testing.
- ☐ Ensure that decisions about whether to have pre-birth testing – and what to do about test results – are made collectively by the whānau (family).
- ☐ Produce culturally-appropriate information about pre-birth testing, genetic counselling and care during pregnancy.
- ☐ Ensure that Māori women know the importance of getting antenatal care early in pregnancy, including screening and testing.
- ☐ Ensure that Māori genetic material is not retained or used for research without the informed consent of the appropriate **collective.**
- ☐ Ensure that Māori genetic material is not retained or used for research without the informed consent of the **individuals** who provided the material.
- ☐ Require that ethics committees ensure that iwi, hapū and individuals are fully aware of the purposes, harms and benefits of a research proposal to use Māori genetic materials before approving research proposals.
- ☐ None of the above

Approach 4: Knowledge is power

Some people believe that better information about pre-birth testing must be more widely available and in more accessible forms.

This approach implies that "knowledge is power" and emphasises the importance of public involvement.

According to this view:

- For most mothers/parents pre-birth testing is just a routine part of pregnancy. However, if issues arise, parents must be able to make informed decisions – free of any pressure, intended or not, to follow a particular course of action.
- Government must provide people with relevant information and access to knowledgeable people for further advice on pre-birth testing. These resources need to reflect not only "medical facts", but also the cultural, ethical and spiritual issues which might help people come to terms with such potentially difficult decisions.
- Public involvement in the development of pre-birth tests and information resources is required if we are to put the needs and interests of families first (and not those of the medical profession, fertility clinics and drug companies).

In New-Zealand today…

Practitioners say they lack the resources to do screening properly.

Parents and health practitioners say they lack high quality information about screening and chromosomal abnormalities.

Many women do not get sufficient information to make an informed choice.

Not all women have access to screening.

"Designer babies"

"Designer babies", the idea that we might be able to "dial-up" whatever kind of child we want, isn't scientifically or technically possible: you are stuck with the genes you inherit from your parents.

However, in the future, we might be able to modify embryos to choose certain features or characteristics e.g. a child with blue eyes and dark hair who would be a world-class high jumper.

The question is: who decides how far we can, or should, go?

Approach 4: Knowledge is power

Te manu i kai te matauranga nona to ao

Literally, the bird that eats of knowledge is the bird that will have the world at its feet. In other words, if you are educated and have knowledge, the world is your oyster – you can fly in all senses of the word.

Those who support this approach say that:

- You can only make informed decisions if you have access to the right information.
- Decisions about whether to test and what to do about the results involve more than just medical matters. Consideration of the emotional, cultural, spiritual, ethical and moral issues are just as important.
- The implication of these technologies affect us all – members of the public should be involved in developing the necessary information resources on pre-birth testing to ensure that the information reflects the needs, interests and values of communities.
- In light of future possibilities, such as “designer babies”, citizens must be involved in decisions about how far these developments should go.

What do the critics say?

- Plenty of information on pre-birth testing is already available, so there is no need to use resources which could be better spent in other parts of the health system.
- There aren’t enough interested people available who would be willing to get involved in developing the necessary information – and who would decide which members of the public would be involved?
- More information would not necessarily make it easier to make decisions.
- If pre-birth testing is more widely discussed, this could lead to conflict within some cultural and ethnic groups.

What do YOU think?

29. The “knowledge is power” approach suggests actions such as those listed below.

Please indicate your level of agreement or disagreement with each of the following actions:

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**I don’t know**
Ensure people have access to information on pre-birth testing that is designed to meet their needs.						
Ensure medical practitioners are adequately trained to advise people about pre-birth testing.						
Ensure information about pre-birth testing includes cultural, ethical and spiritual aspects as well as medical facts.						
Involve families and the public in the development of information about pre-birth testing.						
Provide access to suitably trained people who are able to answer any questions and concerns about pre-birth testing.						
Ensure communities are involved early on in policy and decision-making about future developments (e.g. PGD).						

30. If asked to choose, which of these proposed actions would you prioritise:
Please check only ONE.

☐ Ensure people have access to information on pre-birth testing that is designed to meet their needs.
☐ Ensure medical practitioners are adequately trained to advise people about pre-birth testing.
☐ Ensure information about pre-birth testing includes cultural, ethical and spiritual aspects as well as medical facts.
☐ Involve families and the public in the development of information about pre-birth testing.
☐ Provide access to suitably trained people who are able to answer any questions and concerns about pre-birth testing.
☐ Ensure communities are involved early on in policy and decision-making about future developments (e.g. PGD).
☐ None of the above

Part 3: The way forward

31. Now that you've explored some of the approaches for addressing pre-birth testing, we'd like to know what you see as the best way forward.

It is likely that one of the approaches you've just reviewed more closely reflects your views than the others. You might, however, also appreciate certain aspects of the other three approaches. Imagine for a moment that you are the Minister of Finance. The total budget for the government's pre-birth testing programme is $400M "People's Dollars".

How would you invest each slice of $100M?
PLEASE NOTE: You can invest more than one 100M People's Dollars on a single option. For example, you could invest 200M People's Dollars on one item, 200M People's Dollars on another and none on the others.

My 1st 100M People's Dollars would go to:
Please check only ONE.

☐ Approach 1: My choice my right
☐ Approach 2: Life is a gift
☐ Approach 3: Tāngata whenua perspective
☐ Approach 4: Knowledge is power

My 2nd 100M People's Dollars would go to:
Please check only ONE.

☐ Approach 1: My choice my right
☐ Approach 2: Life is a gift
☐ Approach 3: Tāngata whenua perspective
☐ Approach 4: Knowledge is power

My 3rd 100M People's Dollars would go to:
Please check only ONE.

☐ Approach 1: My choice my right
☐ Approach 2: Life is a gift
☐ Approach 3: Tāngata whenua perspective
☐ Approach 4: Knowledge is power

My 4th 100M People's Dollars would go to:
Please check only ONE.

☐ Approach 1: My choice my right
☐ Approach 2: Life is a gift
☐ Approach 3: Tāngata whenua perspective
☐ Approach 4: Knowledge is power

Would you like to comment on why you invested your $400M People's Dollars the way you did? *Please use the comment box below or attach an additional sheet of paper.*

Join the deliberation!

Just a reminder that the Council will be hosting an **online deliberation** (using friendly chat technology) on the issues presented in this choicebook, starting 15 November. This will be an easy – and fun! – way to engage with others in a dialogue on the issue, to further explore, refine and prioritise possible courses of action, and perhaps identify new ones!

Sign-up now! Space is limited.
The Council will host up to 4 online deliberation groups. Sign up here if you would like to join the conversation!

I am interested in participating in the Council's online deliberation on pre-birth testing:

☐ Yes
☐ No

If yes, at what email address would you prefer we contact you for the purpose of providing you with instructions on how to join the online deliberation:

____

What would you like to be called during the online deliberation?
You may use your real first name, or the pseudonym of your choice:

____

Evaluation

We thank you for taking the time to complete this choicebook, and hope you've enjoyed the experience.
We would appreciate it if you took a few moments to give us your feedback.

Please indicate your level of agreement or disagreement with each of the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	I Don't Know
I enjoyed completing the choicebook.						
The choicebook helped me to better understand some of the issues relating to pre-birth testing.						
From a technical standpoint, I found the workbook difficult to use.						
The information and facts contained in the choicebook were easy to understand.						
Working through the choicebook led me to change my views about the best way to deal with pre-birth testing.						
Working through the choicebook led me to better understand why others might hold different positions from mine.						
Based on this experience, I would consider completing a choicebook in the future.						

Would you like us to keep you informed of the progress and outcomes of this initiative, and of the Bioethics Council's work in general?

☐ Yes ☐ No

If yes, please provide the following:

First name: ____

Last name: ____

Email address: ____

Share your story or idea!

Now that you've had a chance to reflect on the issues, we'd love to hear your stories or ideas on pre-birth testing. Your testimonies are important because they are what will allow us to place the data we are collecting through this choicebook in context, adding an important "human face" to the numbers.

Please select the category that best reflects your story or idea:

I have a story about...

☐ What taking part in this online deliberation has meant for me.
☐ How pre-birth testing has affected my life, or the life of someone close to me.
☐ What I've heard other people say about pre-birth testing.

I have an idea about...

☐ The ONE thing Government should – or shouldn't – do with respect to pre-birth testing.
☐ How to help people make informed decisions about pre-birth testing.
☐ How pre-birth testing may develop in the future and how this will affect us.

Please choose how you would like to share your story or idea:

☐ **Make it public:** use it as required in the Bioethics Council's final report and other public communications relating to this online deliberation.
☐ **Keep it private:** submit it to the research team for analysis only.

What is the title of your story or idea:

____

Please use the comment box below or attach an additional sheet of paper to share your story or idea: