

1. The Challenge for the Bioethics Council and the Role of Public Participation



Toi te Taiao: the Bioethics Council (the Council) was established after New Zealand's Royal Commission of Inquiry on Genetic Modification. Its purpose is to consider the cultural, ethical and spiritual issues raised by biotechnology. In this role, the Council provides information, promotes and participates in public dialogue, and gives advice to Government.

The Council was scheduled to report to the New Zealand Government in May 2008 on the issue of pre-birth testing. Because pre-birth testing is an issue which touches the lives of so many men, women and children, the Council opted for a very public and participatory approach to framing the issue and developing its recommendations. ***The end goal was to ensure that the views and values of New Zealanders were reflected in the recommendations that the Council will make to government – while ensuring that these recommendations were just, reasonable and practical.***

1.1 About the Issue

During pregnancy, a woman and/or her unborn baby may undergo tests for various reasons. The term 'pre-birth testing' applies both to relatively common antenatal procedures, such as ultrasound examinations, and also to more specialised tests, such as those used to detect rare genetic conditions or illnesses. Another kind of pre-birth testing is preimplantation genetic diagnosis (PGD), where cells from embryos created outside a woman's body through in-vitro fertilisation (IVF) are tested for certain conditions and illnesses.

Some forms of pre-birth testing are already commonly used in New Zealand. However, certain emerging forms of pre-birth testing, particularly those involving PGD, are not yet permitted there. Others are permitted only with oversight by the government-appointed Ethics Committee on Assisted Reproductive Technology (ECART). New guidelines covering the use of PGD are currently being developed. Meanwhile, the range of conditions and illnesses that can be tested for is expanding all the time. Overseas, the uses of PGD (potential and actual) are broadening as knowledge of genetics develops.

In light of these developments, important questions arise: How far might we go with pre-birth testing? What might the consequences be? Who decides whether to test a foetus, and in what circumstances? Who decides what to do once test results are known, and what choices are acceptable? The Council strongly believed that these very complex questions were not only for the Government, medical and scientific communities to consider, but that they also had significant cultural, ethical and spiritual dimensions that concern all of society. As such, during 2007 and early 2008, Toi te Taiao: the Bioethics Council talked with New Zealanders to find out what they thought about pre-birth testing.

2. The Approach: Public Participation Methods

The Council made a commitment to make its public engagement processes more deliberative and more focused, while enabling open and frank dialogue and deliberation on the issues – and yielding usable and informed citizen input. The decision to adopt a participatory deliberative approach for this initiative was a strategic one, motivated by a number of key objectives:

1. To increase the public's general awareness of issues related to pre-birth testing, primarily through the media and Council communications initiatives;
2. To raise awareness and understanding among participants of pre-birth testing issues and of possible policy approaches to this question;
3. To obtain informed and useable input that would help shape the Council's recommendations to Government on pre-birth testing;
4. To develop the Council's internal capacity and skills in the areas of public deliberation, both online and in-person;
5. To increase the perceived value of deliberative approaches, both within the Council and by third parties (e.g., Government, policy and decision makers, the general public, the media);
6. To establish the foundation for an ongoing dialogue between and amongst the Council and interested individuals on the issue of pre-birth testing and other bioethics issues.

2.1 Design, Delivery and Evaluation

Design: Framing the Issues

A comprehensive information gathering exercise was undertaken to inform the Council's thinking and contribute to the understanding of the issues. This included a literature review, expert briefings, and interviews with thought leaders and subject matter experts in various fields related to pre-birth testing. The result was a brochure outlining pre-birth testing's important scientific, cultural, ethical and spiritual aspects.

Fifty-six participants — each of whom had interviewed at least five other people beforehand — attended what were referred to as ‘framing days’. Six sessions were held around the country during July and August 2007. The goal of the issue-framing exercise was to bring ordinary members of the public together so they could create a document that expressed the basic concerns behind the way they viewed the issues.

Who gets born? Pre-birth testing

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.

PREVIOUS Click NEXT to continue NEXT

Step 18 of 38

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.

Learn more!
Fact 2: How pre-birth testing is funded in New Zealand

Facts < 1 2 >

From the issue framing sessions, four distinct approaches emerged that reflected different and competing ways of dealing with pre-birth testing. These approaches – and the issues associated with them – were presented in a document referred to as the **Choicebook**.

The **'Who Gets Born? Pre-Birth Testing Choicebook'** was completed by participants before the face-to-face and online deliberative dialogue events and served as a focal point for the conversations. In addition to the four distinct approaches, the Choicebook also contained background information on the scientific, ethical and social aspects of pre-birth testing, targeted at laypeople.

To the left is a screen capture that illustrates one of the four perspectives presented in the online Choicebook.

Delivery: The Deliberative Events

The Council delivered a mix of in person and online public participation events. The goal was to encourage large-scale participation that included citizens and stakeholders by providing multiple opportunities to participate.

The Council recruited people for a series of face-to-face deliberative events around the country, identifying potential participants with help from NGOs, organizations and community groups with an interest in pre-birth testing and also using the Council's own databases. In some areas, participants self-selected by responding to newspaper advertisements. Eighteen events were held, including four hui and a Pacific fono (events specifically designed for New Zealand's Māori population), with 256 people attending. Each event lasted three hours and was guided by an independent facilitator; Council members also attended. Participants worked their way through the Choicebook, discussing the advantages, disadvantages and consequences of each approach. They were encouraged to examine positions different from their own views, and to identify any common ground for policy recommendations. Sometimes, groups found it easy to make explicit recommendations; at other times, this was more difficult and discussion focused mainly on people's responses to issues posed by the different approaches to pre-birth testing.



From November 2007 to February 2008, those who could not attend the face-to-face events had the option of taking part in an online deliberation — moderated online conversations that aimed to further explore the issues and approaches presented in the Choicebook in a similar way to the face-to-face deliberative events. The goal was to broaden the reach of the deliberative process, enabling new voices to be heard in new ways.

Before they deliberated online, people were asked to complete an electronic version of the Choicebook; 406 began doing this and 281 completed all the questions. Participants also contributed more than 60 personal stories and ideas about pre-birth testing, and a further 58 people took part in three online deliberation groups. Those who participated in the online processes were recruited by several methods, including high-profile online advertisements on New Zealand's popular TradeMe website (see "click-through" web ad at left).

The online deliberation was hosted using the *dialoguecircles.com*TM platform, an internet-based toolkit developed by Ascentum Inc., custom-built for online deliberation.

To the left is a "click-through" web ad posted on New Zealand's popular TradeMe website, to drive traffic to the online deliberation website.

Evaluation: Examining the Results

The pre-birth testing project showed that the nature of engagement generated through deliberative methods is different from that created by more traditional forms of public participation. Clearly, deliberation has an important part to play in a continuum of possible participatory techniques. Some of the key results and lessons learned from this experience, as documented through an independent third-party evaluation process, include:

- Participants rated the planning and principles underpinning the deliberative events highly, and were very positive about representation at the events, their lack of bias, clear purpose and resourcing. They said the events provided the chance for open and free discussion, and allowed them to meet interesting and diverse people. However, some expressed frustrations about time constraints, the structure or facilitation of events, and a lack of diversity in some groups.
- Participants were clearly enthusiastic to be involved. As well as being keenly interested in the topic of deliberation, pre-birth testing, they had also become interested in the deliberative process itself. Some compared it favourably with other public consultation processes they had been involved in, and said deliberation was a better way to get the public involved in decision-making about important issues.
- The evaluators noted that the capacity of the public to participate in such events also needed to be developed. This could likely be achieved with more opportunities to tackle public issues through deliberation, and with tangible evidence that the effort is worthwhile.
- Recruiting participants for deliberative events is challenging. For example, recruiting Māori and Pacific participants, and people from new migrant communities, was a particular challenge. Community groups were extremely helpful in recruiting participants, but with this approach comes the challenge of achieving sufficiently diverse representation.
- The online deliberation forums attracted participants who had not previously been involved with the Bioethics Council. Placing online advertisements generated considerable interest. Participation in online deliberation is most available to people who have access to computers and familiarity with accessing information online.
- Many participants in the face-to-face events felt the time allowed was too brief, especially for exploring the trade-offs inherent in various approaches. This was in contrast to the online forums where, over several weeks, participants' positions and attitudes visibly moved. However, even online participants felt frustrated by time constraints.
- Participants and those running deliberative events need good information, both about the topic under discussion (material presented in everyday language that is still technically accurate) and about the deliberative process itself. Facilitators need to have a good understanding of the principles of deliberation, and must be able to adapt and use them in a range of situations.

3. What Made This Project Special

Over the course of a year, Toi te Taiao: the Bioethics Council engaged New Zealanders through a process of intensive deliberation, encouraging people to move beyond individual preferences to consider the needs of the whole community. More than 700 joined in – both in person and online. This was the first time such an approach had been used to inform New Zealand policy makers on public opinion.

While few participants changed their thinking about pre-birth testing, they did acknowledge some shifts in outlook — more compassion for people facing difficult decisions associated with pre-birth testing, more openness to the views of others (although this did not necessarily mean willingness to change their own), and a greater interest in public dialogue in general.

Toi te Taiao: the Bioethics Council considers that the public deliberative approach used to produce this report could be a model for government agencies interested in involving citizens in the development of public policy and regulation in many different fields. This initiative was a first of its kind for the Council in many ways:

- Members of the public helped developed the public deliberation framework by participating in a **public issue framing exercise** (56 citizens contributed to identifying the issues and approaches that were outlined in the 'Who Gets Born? Pre-Birth Testing Choicebook');
- A series of **18 'in-person' public deliberative dialogue events** were organized to gather input from New Zealanders on the approaches under consideration (including in-person events specifically for Māori: an issue framing event and four deliberative dialogue events);
- A parallel **online deliberation** process was created to create further opportunities for public deliberation.
- Combining online and in-person events greatly expanded the reach of the public deliberation process, allowing new voices to be heard in new ways. It created an opportunity for the public to deliberate and offer its informed views on what is a complex and sensitive issue in a way that proved positive, productive and avoided the pitfalls of polarization.

Pre-birth testing is a complex issue, fraught with an explosive mix of science, values and emotions. Presenting this issue in a way that was both accessible to the average citizen, yet didn't over-simplify and polarize it, was necessary – but challenging. Considerable time and effort was therefore invested in framing the issues, with great care being taken to ensure accessible language and the provision of balanced information and perspectives. The inclusion of multiple perspectives was also a means to make the consultation materials more inclusive – an effort to ensure that everyone could see a little bit of themselves in at least one of the approaches under consideration.

4. Project Results and the Role of Public Participation

This was the first time Toi te Taiao: the Bioethics Council had used deliberation to engage the public. People came together face-to-face or online to identify the issues raised by pre-birth testing, to reflect deeply, to explore their own and others' thinking, and to develop common ground that could form the basis of future policy. The deliberations provided valuable input into the development of recommendations to Government in key areas:

- The challenges of decision-making about pre-birth testing;
- The need for equitable access to testing for all New Zealanders;
- The need for high-quality, appropriate and diverse information about pre-birth testing for parents and the wider community;
- The need for people with disabling conditions (including those detected through pre-birth testing), and their families, to be supported; and
- The need for an administrative and legislative framework that can respond to new and challenging developments in PGD in ways that balance individual freedoms with wider cultural, ethical, spiritual and social concerns.

The Council plays an advisory role to government and as such, does not have binding authority. However, as it embarked on this journey, the Council actively – and successfully – sought assurance from the Government that it would provide formal response to its report and recommendations. Following the launch of the Council's final report on June 18 2008, the Honourable Nanaia Mahuta, Minister for the Environment (and minister responsible for the Council), stated the following in her media release:

It is often difficult for people to move beyond their personal views and beliefs. As a result, dialogue may end up polarised and adversarial. Many New Zealanders gave up their time to engage with others on the issue of pre-birth testing. I'd like to publically acknowledge those of you in this room and beyond who took part [...]. The [Council's] report shows that there are ways to work through these sorts of issues constructively, ways which offer policy and decision makers a much richer understanding of where people are on these difficult issues, and of what people would be prepared to do, or not. This allows the public to make a genuine contribution to more robust and sustainable decision making. I certainly applaud the work of the Council and intend to initiate a process whereby report findings can contribute to policy work in this area, and better inform the Government's decision making process. To that end, I look forward to the ad-hoc ministerial group meeting to consider the report findings and the framing of a Government response.

5. Attitudes and Actions that Reflect IAP2 Core Values

5.1 A Right to be Involved in the Decision-Making Process

The Council demonstrated its strong belief that not only do ordinary citizens have the right to express their views about developments that affect them, but that they can also offer insights and knowledge that complement and enlarge the knowledge of experts. In this regard, the Council was motivated by the conviction that science and technology are not just specialist and technical forms of knowledge — they have social, cultural and spiritual dimensions as well, which need to be reflected in policy decisions. For all these reasons, *public deliberation* was identified as an effective way for decision-makers, experts and the public to approach especially challenging problems, including those linked to biotechnology. Deliberative forms of engagement require people to learn about the issues, explore and compare a range of viewpoints or approaches, and find courses of action that work in the best interest of many different people.

5.2 Public's Contribution Will Influence the Decision

The process was open, participatory and transparent, from start to finish. Participants shaped the deliberation framework through issue framing sessions and their contributions made during both the face-to-face and online deliberations informed the Council's final recommendations. Assured listening was demonstrated through the development of personalized participant reports for online Choicebook respondents (personalized reports that highlighted how each individual's responses to questions in the online Choicebook linked to the Council's final recommendations), and proactive distribution of the Council's final report to other participants and the general public. In addition, the Minister's commitment to formulating a formal response to the Council's report and to ensuring that this public input finds its way into the policy making process signal that this report is not destined to remain on a shelf.

5.3 Sustainable Decisions

While the recommendation contained in the Council's report did generate some criticism by certain stakeholder groups, feedback on the value of the deliberative process itself was generally positive. The issue framing exercise was designed such that the resulting framework reflected participant voices. This is a key to developing sustainable decisions as participants are able to help shape the conversation, making the deliberation open, transparent and respectful of their positions.

5.4 Involvement by Those Affected or Interested

The mix of online and face-to-face deliberations was key to extending the opportunity to participate to a broad range of stakeholders, allowing hundreds of people to participate who may normally not have participated. There were additional sessions customized to include and accommodate unique needs of Māori population (language and culture). An extensive recruitment process was also undertaken to extend the invitation to participate to as many citizens and stakeholders possible. To begin engaging the public and initiate the issue framing process, a mailing list was compiled to identify interested parties. A wide range of government and non-government organizations were also asked to publicize the project and the opportunity to participate at this stage of the project. A brochure was prepared outlining the scope of the topic and details around a day-long 'framing' meeting in their town or city. Those receiving invitations were also provided with a questionnaire to gather the views of friends, family and colleagues that could be shared at the issue-framing session.

5.5 Input from Participants in Designing How They Participate

In the first stage of this project, the Council led members of the public in an issue framing exercise. The purpose of the framing was not to 'solve' pre-birth testing, but to create a framework for public deliberation. To this end, participants were asked to share their perspectives on and experiences with pre-birth testing. Together, they then developed distinct approaches to pre-birth testing that reflected the underlying values and principles expressed by the group. They also began to identify the benefits, drawbacks, actions for implementation and (unintended) consequences for each approach. The issue framing exercise 'framed' the deliberations, both face-to-face and online. The project also included a comprehensive evaluation that will help guide the design of future initiatives by incorporating participant feedback.

5.6 Information Participants Need for Meaningful Participation

In order to ensure access to the information required to enable a meaningful, rich dialogue, participants worked their way through the Choicebook, learning about the advantages, disadvantages and consequences of each approach. The Choicebook was developed based on the work undertaken in the issue framing sessions, expert contribution and a comprehensive literature review. Participants were encouraged to examine positions different from their own views, and to identify any common ground for policy recommendations. The focus – both in-person and online – was on evaluating (and augmenting) the alternatives that had been developed during the participatory issue-framing process. In this regard, citizens were being called upon to validate ideas (checking them against on-the-ground reality) and reconcile ideas (weighing values, making tradeoffs, and prioritizing).

5.7 Communicating How Input Affected the Decision

The Council undertook a number of activities to communicate the results to participants. A personalized participant report was prepared for participants who completed the online Choicebook. It is a powerful way to report back to participants and close the feedback loop. The report contains customized excerpts for individual participants based on their responses to specific questions. The Council also compiled a comprehensive mailing list to which a copy of the final report was sent to. The initiative was also covered by a number of media outlets in New Zealand, including the country's leading radio programs, newspapers and magazines. Council members were often available to discuss results, including how public participation shaped their final recommendations.

A Final Word...

This was a first for the Council, but the Pre-birth testing project is already cited in New Zealand government circles – and abroad – as a best practice in engaging the public on complex issues, and an example to learn from. For example, members of the Council's Secretariat who led this project have already been invited to share their experience and lessons learned in high profile public engagement conferences sponsored by the Canadian Conference for Dialogue and Deliberation (C2D2 2007) and the OECD ("Building Citizen Centred Policies and Services" Conference, Slovenia, 2008), among others. Over the course of this project, the Council has built significant in-house capacity and expertise which they will now be able to apply to subsequent initiatives. Their energy, enthusiasm and commitment are infectious and their contribution to pushing the limits of and continuously enriching the public participation process cannot be celebrated enough. In every way, in their attitudes to public participation and in their actions, the Council and its Secretariat staff have embraced and live by IAP2's core values.

APPENDIX: Additional Information

1. Name, address, phone, fax, and e-mail of the contact person

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2. Award category

Project of the Year Award

3. Project name and Sponsoring Organization

Project Name:

Who Gets Born? A report on the cultural, ethical and spiritual issues raised by pre-birth testing

Sponsoring organization:

Toi te Taiao: the Bioethics Council

4. Individuals being nominated for the award

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5. Up to three publications to receive notification of winning entry

The Dominion-Post

PO Box 3740 Wellington, New Zealand

Tu Mai

62 Alexandra Street, PO Box 5417, Hamilton City, New Zealand

NZbioreport

PO Box 5580, Wellington, New Zealand

6. Two individuals, outside of the organization, who were participants in the project or program and who can serve as references

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