

## Executive Summary

### Formation of the Toi te Taiao: the Bioethics Council

Toi te Taiao: the Bioethics Council<sup>1</sup> (the Council) was appointed in December 2002, as a result of recommendation 14.2 of the 2001 Royal Commission on Genetic Modification. The Commission recommended ‘that Government establish Toi te Taiao: the Bioethics Council to:

- act as an advisory body on ethical, social and cultural matters in the use of biotechnology in New Zealand
- assess and provide guidelines on biotechnological issues involving significant social, ethical and cultural dimensions
- provide an open and transparent consultation process to enable public participation in the Council’s activities.’<sup>2</sup>

The Government agreed in its response to the Royal Commission to establish the Council. In doing so it extended the scope of the Council’s oversight to include all biotechnology, not just genetic modification.

Toi te Taiao: the Bioethics Council was established as a Ministerial Advisory Committee. [CAB Min (01) 33/22 refers.]

### Background

Toi te Taiao: the Bioethics Council (the Council) was established as an independent advisory body reporting to the Minister for the Environment. The goal of the Council is:

*To enhance New Zealand’s understanding of the cultural, ethical and spiritual aspects of biotechnology, and ensure that the use of biotechnology has regard for the values held by New Zealanders.*

### Terms of Reference

The Council’s Terms of Reference direct it to:

- Provide independent advice to Government on biotechnological issues involving significant cultural, ethical and spiritual dimensions.
- Promote and participate in public dialogue on cultural, ethical, and spiritual aspects of biotechnology, and enable public participation in the Council’s activities.

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<sup>1</sup> ‘Toi te Taiao’ in Maori means the meeting of the spiritual and natural worlds.

<sup>2</sup> *Report of the Royal Commission on Genetic Modification: Report and Recommendations 2001*, p.346, Recommendation 14.2.

- Provide information on the cultural, ethical and spiritual aspects of biotechnology.

## **Review of the Council**

At the time of its establishment, Cabinet directed that the Council be reviewed after two years. The State Services Commission undertook this review of the Council in April 2006. The reviewers held discussions with a range of key stakeholders.

Key findings and recommendations contained in the report;

- joint Ministers confirm the continuing value and existence of the Council
- an ad hoc Ministerial Coordination Group on Bioethics (convened by the Minister for the Environment) should be confirmed to receive Council reports and oversee the Governments' response to Council initiatives

The ad hoc Ministerial Coordination Group on Bioethics was formed in 2006 and has met on three occasions to consider the work and recommendations of the Council.

## **Resources**

The Council currently has nine members, four of whom are Maori. The Council is serviced by a secretariat made up of one Manager and three senior advisors who are housed within the Ministry for the Environment. The secretariat is thus able to draw on the Ministry's administration and communications resources. As part of the Ministry, it must meet public service standards and follow the procedures and regulations of the Ministry.

The annual budget is \$1.5 million, and covers secretariat salaries, operational expenses, Ministry overheads and Council members' honoraria.

## **Future Watch**

Problems may occur with biotechnologies if they 'arrive unannounced', catching the public by surprise. To overcome the surprise element the Council, among a number of other government agencies has been tasked with a future watch role; this will involve monitoring emerging issues and developments in biotechnology.

## **Achievements**

The Council has prepared a large number of reports, discussion documents, pamphlets and submissions. [See appendix 1]. Major reports based on the Council's public engagement activities are:

1. The Cultural, Ethical and Spiritual Dimensions of the Use of Human Genes in Other Organisms (August 2004),
2. The Cultural, Ethical and Spiritual Aspects of Animal-to-Human Transplantation (xenotransplantation) (October 2005)
3. The Cultural, Ethical and Spiritual Aspects of Pre-birth Testing (June 2008).

## **Major Achievements 2008**

### **The Cultural, Ethical and Spiritual Aspects of pre-birth testing**

In 2008 the Bioethics Council undertook a project on issues to do with pre-birth testing. The objective of the project was to allow ordinary people the opportunity to frame the questions and issues about pre-birth testing that are important and relevant to their lives. From here the Council proceeded to involve as many new Zealanders as possible from around the country to take part in face-to-face and online deliberative events. The outcomes from these participatory events aimed to give policy makers and government a clear set of recommendations on how the current pre-birth testing system might be improved and to raise any cultural, ethical and spiritual questions where new forms of pre-birth testing such as pre-implantation genetic diagnosis (PGD) are concerned.

### **Deliberation: A new approach to public engagement**

The world over, there is a trend to greater public participation in government decision-making. In our own country, legislation such as the Resource Management Act 1991, the Local Government Act 2002 and the Human Assisted Reproductive Technology Act 2004 require mandatory public input into a wide range of government activities. Citizens have come to expect a voice in policy decisions that affect them.

In recent years, new approaches have emerged which more actively involve the public in agenda setting and issue framing. Rather than being the subjects of consultation, ordinary citizens are able to identify and explore alternative approaches to an issue in deliberation with decision-makers and other members of the community. Public deliberation is not just about promoting better understanding; it is a way to make the public decisions that allow people to act together. By weighing the costs and consequences of a variety of possible actions and ‘working through’ the often volatile emotions that are a part of making public decisions, participants are often able put aside areas of difference and identify areas of common ground from which to make collective recommendations.

### **Face-to-face Deliberation**

#### **Stage 1 Framing Events**

Fifty-six participants attended what were referred to as ‘framing days’. Six were held around the country during July and August 2007, including a hui for Māori and a Pacific fono. The goal of issue-framing is to bring ordinary members of the public together, so they can create a document that expresses the basic concerns behind the way people see an issue.

### **Stage 2: Face-to-face events**

The Council recruited people for a series of face-to-face deliberative events around the country. Eighteen events were held, including four hui and a Pacific fono. In total, 256 people attended.

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. Online deliberation

### **Stage 3: Evaluation**

Evaluation plays a critical role in determining the success of deliberative events, in terms of participants' perceptions, how engaging the public leads to improved policy making, and where lessons can be learned for the future. To ensure the Council put the pre-birth testing project under scrutiny and analysis it contracted an established reputable research organisation to conduct an independent evaluation.

## **Online Deliberation**

From November 2007 to February 2008, people could also take part in online deliberation. This enabled a broader mix of people to participate, contribute and develop recommendations for future policies. It also provided a mechanism to get feedback on the face-to-face events. The online interactions were designed to closely mirror those events.

- 281 completed the online Choice book
- Participants also contributed more than 60 personal stories and ideas about pre-birth testing
- 58 people took part in three, three week long online deliberation groups

## **Future Work**

- Exploring the cultural, ethical and spiritual aspects of nanotechnology
- Tikanga and Biotechnology. The Council will seek to develop a range of resources to assist Maori to be better informed about new and emerging biotechnologies, and provide Maori with some tools when considering whether such technologies raise questions for tikanga
- Further work with Pacific Island Communities on pre-birth testing.
- Further research on protection for tissue matched siblings

## Appendix 1

### About the Bioethics Council

- [Briefing to the Incoming Minister](#) [November 2005]
- [Bioethics Council Progress Report](#) [May 2005]

### Engaging with the public

- [Evaluation reports on the deliberation process used for the 'Who gets born? Pre-birth testing' project](#)
- [How to encourage public engagement in technology related dialogue processes](#) [September 2006]

### Human embryos for research

- [Analysis of online discussion on the cultural, ethical and spiritual aspects of human embryo research](#) [March 2007]
- [Attitudes to Embryonic Stem Cell Research in New Zealand](#) [February 2006]
- [Human embryo research - qualitative research report](#) [October 2006]
- [The Cultural, Ethical and Spiritual Aspects of Using Human Embryos for Research](#) [July 2006]

### Human genes in other organisms

- [The Cultural, Ethical and Spiritual Dimensions of the Use of Human Genes in Other Organisms \(Final report\)](#) [August 2004]
- [Analysis of Submissions and On-line Discussion on the Use of Human Genes in Other Organisms](#) [August 2004]
- [Report to the Bioethics Council on the Dialogue Events focusing on Human Genes in Other Organisms](#) [June 2004]
- [The Transfer of Human Genes into other Organisms: A dialogue with Māori](#) [May 2004]
- [Whakapapa & the human gene](#) [February 2004]
- [Human genes in other organisms: Discussion booklet](#) [January 2004]
- [Reflections on the Use of Human Genes in Other Organisms: Ethical, Spiritual and Cultural Dimensions](#) [January 2004]
- [Human Genes in Other Organisms: Qualitative Research Report](#) [August 2003]

### Nanotechnology

- [Report on nanotechnology to the Minister for the Environment](#) [September 2003]

### Neuroethics

- [Neuroethics - A literature review prepared for Toi te Taiao: the Bioethics Council](#) [July 2006]

## **Pre-birth testing**

- [Who gets born? A report on the cultural, ethical and spiritual issues raised by pre-birth testing](#) [June 2008]
- [Online Deliberation: Who Gets Born? Pre-birth testing](#) [March 2008]
- [Stories and ideas about pre-birth testing submitted to the Council](#) [February 2008]
- [Transcripts of pre-birth testing on-line deliberation groups](#) [November 2007 - February 2008]
- [Who Gets Born? Pre-birth Testing Choicebook](#) [October 2007]
- [Brochure on pre-birth testing issues](#) [July 2007]

## **Evaluation reports on the deliberation process used for the ‘Who gets born? Pre-birth testing’ project**

- [Pre-birth Testing Project Evaluation Phase 2](#) [February 2008]
- [Pre-birth Testing Project Evaluation](#) [August 2007]

## **Submissions**

- [Submission to the Health Select Committee on the Public Health Bill](#) [March 2008]
- [Submission to ACART on Aspects of assisted Reproductive Technology](#) [September 2007]
- [Submission to Health Select Committee on the Human Tissue Bill](#) [March 2007]
- [Submission to ACART on embryo research](#) [March 2007]
- Submission to the National Screening Unit on Newborn Blood Spot Cards: Consent, Storage and Use [March 2007] - A copy of the Council's submission is available on request. Please email [info@bioethics.org.nz](mailto:info@bioethics.org.nz) and quote the reference number 306439.
- [Comments to the Ministry of Health on the “Guidelines on Using Cells from Established Human Embryonic Stem Cell Lines for Research”](#) [March 2006]
- [Submission to the Health Select Committee on the Human Assisted Reproductive Technology \("HART"\) Bill SOP No. 80](#) [July 2003]
- [Submission to the Education and Science Select Committee on New Organisms and Other Matters Bill](#) [June 2003]

## **Xenotransplantation: animal-to-human transplants**

- [The Cultural, Ethical and Spiritual Aspects of Animal-to-Human Transplantation \(Final report\)](#) [August 2005]
- [The Cultural, Spiritual and Ethical Aspects of Xenotransplantation: Animal-to-Human Transplantation \(Discussion document\)](#) [January 2005]
- [Whakapapa & xenotransplantation: animal-to-human transplantation](#) [January 2005]

