

## new developments

### *Bioethics Council: Toi Te Taiao*

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#### **Introduction: Context**

The number of socially contentious biotechnologies continues to grow. Genetic modification, gene therapy, xeno-transplantation, transgenic animals, pre-implantation genetic diagnosis and other uses of genetic testing are often in the media. On the horizon are such technologies as nanotechnology and pharmacogenetics.

These technologies offer promise of new ways of dealing with significant health issues, improving agricultural and horticultural practices and assisting with conservation and other environmental issues. But such interventions in natural systems also introduce uncertainty and new risks, and raise challenging cultural, ethical and spiritual issues.

It is now, for example, possible to have children whose genetic, gestational and social parents may all be different. It is possible to move genes and organs across species boundaries, and to alter the genetics of future generations. Such possibilities stretch our cultural frameworks and categories, change our relationships with and responsibilities to future generations, and to the non-human biological world.

#### **Government Initiatives**

The need for public consultation and discussion on the implications of biotechnologies has been recognised by Government for some time, and was further prompted by wide public concern about genetic modification technology.

In May 1999 the Government appointed the Independent Biotechnology Advisory Committee (IBAC) to help New Zealanders explore and consider issues of biotechnology. In the three years of its life, IBAC consulted with the community, and produced reports on the economic implications of a first

release of genetically modified organisms, cloning and stem cell research, and genetic testing.

However, political developments promoted further responses. In October 1999 the Green Party presented a petition to Parliament on genetic modification with 92,000 signatures, and following the election of that year, it was announced that a Royal Commission on Genetic Modification (RCGM) would be established. Their first meeting took place in May 2000, and the final report to the Governor General was presented in July 2001.

#### **Recommendations of the Royal Commission on Genetic Modification**

The RCGM was asked to consider a full range of issues around genetic modification including risks and benefits of use of genetic modification, intellectual property issues, liability, the Crown's responsibilities under the Treaty of Waitangi, the opportunities open to New Zealand from the use of genetic modification technologies, international implications of any measures New Zealand might take in relation to genetic modification, strategic options, and the adequacy of the statutory and regulatory processes.

The Commission was also asked to consider the main areas of public interest, including cultural and ethical concerns. In relation to these concerns, the final report (Royal Commission on Genetic Modification, 2001) identified:

- a shared framework of values 'that many New Zealanders would recognise as things we hold in common' (2.1)
- that 'ethical, cultural and spiritual concern underlay much of what we heard about genetic modification and biotechnology' (14.4)

- that they 'heard nothing that made us question the adequacy of current ethics committee structures for the work that they do' (6.107), and
- that 'there are two areas of concern additional to the work of ethics committees requiring more attention: consideration of cultural issues that fall outside their domain, and provision for generic policy decisions' (6.108).

The Commission then recommended that:

The 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.

Thus the need was seen for an *additional* body to address the over-arching cultural, ethical and spiritual issues that were not easily dealt with through the case-by-case review process that is typical of ethics committees and of ERMA.

### Government Response to RCGM

The government agreed to the establishment of the Bioethics Council, and an officials group was established to develop its terms of reference. The process for this included consultation with key stakeholder groups.

The Terms of Reference were agreed to by Cabinet in May 2002 (Ministry for the Environment, 2002), and Sir Paul Reeves, former Governor General and Anglican Archbishop, was appointed as the chair of The Council. Nominations for other Council positions were called for through public notice, and nominations closed in early June. Appointments are expected soon, after some delay due to the timing of the election. Council members are appointed by Cabinet on the recommendation of the Cabinet Honours and Appointments Committee.

### The Role of the Bioethics Council

The Terms of Reference of the Council are consistent with the recommendations of the RCGM and give clarity to its

role. The most significant change is the replacement of the term 'social' with 'spiritual'. Officials understood that this was the intent of the RCGM, as would be consistent with the surrounding text of the recommendation.

The goal of the Council, as specified in the Terms of Reference, 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'.

The Council will:

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

The Terms of reference further specify the tasks of the Council.

There is a strong focus on enabling public participation – the Council is expected to act as a forum, but also to develop strategies to do this effectively, and in ways that contribute to the building of trust between the public and various stakeholders. It is expected to recognise its responsibilities under the Treaty of Waitangi to consult and engage with Maori in a way that specifically provides for their needs.

Advice to government will be public, and take account of cultural, ethical and spiritual dimensions, and the values of New Zealanders – those held in common as well as identifying areas where a diversity of values and views remain.

The Council is expected to co-ordinate with other advisory and decision making bodies involved in policy development on ethics and values with a view to promoting consistency and minimising duplication of work. It is also expected to link with similar international forums in other countries dealing with similar issues.

And the Council is required to maintain a watching brief on different world views and other interdisciplinary topics related

to bio-technology, and to monitor emerging issues. It is also expected to develop the means to assess the effectiveness of its activities.

While there have been indications of the topics that various people and institutions would like the Council to consider (eg transgenic organisms, xenotransplantation, uses of genetic testing) the terms of reference leave the Council free to decide its own work programme and priorities.

### **Relationship with other Ethics Committees**

The Bioethics Council will be a ministerial advisory committee. In this respect it is similar to The National Ethics Committee on Assisted Human Reproduction, and the National Ethics Advisory Committee. These two committees report to the Minister of Health, but the Bioethics Council will report to the Minister for the Environment. The ministerial advisory structure gives the Council a level of independence, while continuing to have strong links to government.

Such a structure also makes clear that the role of the Council is to offer advice to government, and government will then have to decide what response is appropriate. The Council does not in itself fulfil any regulatory or quasi-judicial function. Thus, it does not duplicate, oversee, or replace the roles fulfilled by other committees such as the Health Research Council Ethics Committee, regional health ethics committees, animal ethics committees or ERMA.

That said, it would be surprising if the consultation and deliberations of the Council did not impact on the decisions made by those other bodies. However, that impact will be based not on the structural position of the Council, but on the quality of its discourse, and of the relationships the Council builds with key stakeholders.

### **Membership**

The RCGM recommended that the Bioethics Council not be appointed on a stakeholder basis, but rather selected for its credibility, independence, expertise and broad based representation. They also stated the importance of effective

Maori representation.

This position was picked up in the call for nominations. While the final Council is expected to have a range of expertise represented on it, individuals are to be appointed primarily for their open and inquiring mind, ability to deal with complex issues, respect and trust of peers and community, and good judgement. They also are to be people who can articulate difficult ideas and communicate them in clear language across generations and communities of interest – and have the time available, up to a day a week.

### **Future Directions**

**Toi te Taiao:** The Bioethics Council has been given a challenging task. Cultural and ethical issues associated with biotechnology have emerged as high profile concerns in many countries. Their resolution will require the integration of knowledge across many academic and professional disciplines, and attention to the perspectives of many different social players and cultural traditions. Finding effective ways to facilitate and lead the necessary conversations will be a continuing exploration.

Biotechnology is also firmly embedded in and driven by economic and commercial life. The biotechnology sector in New Zealand has a clear expectation of being a major contributor to scientific innovation and economic growth in New Zealand. Perhaps the greatest challenge ahead is the extent to which conversations about cultural, ethical and spiritual concerns can be integrated with scientific, economic and political ones, and to what extent commercial players are able to respond to and take account of the values of the wider community in which they operate. This may not be easy, but it will certainly be interesting.

### **References**

Royal Commission on Genetic Modification (2001). *Report of the Royal Commission on Genetic Modification*. Wellington: Royal Commission on Genetic Modification, 1 September 2002.

Ministry for the Environment (2002). *Terms of Reference for Toi te Taiao: The Bioethics Council*, 1 September 2002.