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The Cultural, Ethical and Spiritual Dimensions of the Use of Human Genes in Other Organisms

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Letter from the Chair

August 2004

This document is the first major report by Toi te Taiao: the Bioethics Council to the Minister for the Environment on a dialogue with members of the New Zealand public. It focuses on the cultural, ethical and spiritual aspects of biotechnology.

“Human Genes in Other Organisms” is important both for its exploration of a topic of considerable relevance in the early 21st century and for the use of a process of dialogue, rather than consultation, to stimulate discussion.

Knowledge, of itself, is neither good nor evil. It is how it is used that matters. Recent advances in biotechnology have generated perceptions of both potential benefit and harm at the limits of human imagination. It is essential in a democratic country like New Zealand that these perceptions are examined widely, that the current level of knowledge is understood and that the boundaries to the responsible use of such technologies are determined.

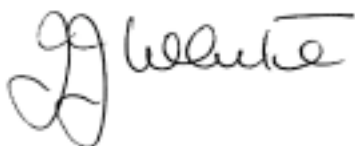
The contributions of hundreds of people went into the development of this report. The Bioethics Council is appreciative of the work of the early focus groups and hui and of the essay writers. These gave us a foundation of thoughtful, and at times passionate comments to build on. While the face-to-face dialogue meetings were invaluable and exciting, the on-line discussions engaged others as did the more traditional submissions process. The Council members and secretariat were also fortunate in the expertise in various fields we were able to call on as issues arose.

The Council became aware that New Zealanders from many backgrounds, cultures and faiths were eager to discuss biotechnologies in the context of cultural, ethical and spiritual considerations, commencing with exploration of just what it means to be human. We very much hope that the dialogue the Council embarked on will ‘ripple-out’ into wider community discussions.

We have endeavoured to make this report faithful to the range of thoughts and views that emerged through the whole process. However, the Council’s role was also to bring our conclusions to the issues around the use human genes in other organisms. A key section of the report therefore reflects the Council’s thinking and its recommendations to Government.

An aspect of the dialogue process that should be highlighted is that it requires significant resources and excellent facilitation skills. The Council is most grateful to those who facilitated and assisted in the evaluation of the dialogue process reported here. The dedicated and impressive work of our secretariat over many months is also noted with warm appreciation.

It has been a privilege for us, as Toi te Taiao: the Bioethics Council, to be in dialogue with the New Zealand public and it is with great pleasure that this report is presented to the Minister for the Environment, the Hon. Marion Hobbs, and through her to the people of New Zealand.



Jill White
Chair
Toi te Taiao: the Bioethics Council

Section 1 > Introduction

Background

The Bioethics Council was appointed by the Government in December 2002. Its goal 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”.¹

Within that role it is expected to:

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

The publication of this report to the Minister for the Environment fulfils the first of these requirements, with a focus on the cultural, ethical and spiritual dimensions of the use of human genes in other organisms. The first part of the report presents the development and results of our first extensive project to promote and participate in public dialogue. The project was developed in 2003 and had a public phase in early 2004. The second part builds on what the Council learnt from this dialogue to present its thinking and recommendations on the use of human genes in other organisms, and its wider observations on the benefits and challenges of using dialogue in this area rather than the more traditional forms of consultation.

The topic was chosen for several reasons.

- Cultural, ethical and spiritual dimensions of the use of human genes in other organisms had already been raised with the Environmental Risk Management Authority (ERMA) in relation to applications to use human genes in sheep and cattle. Some groups were not satisfied with ERMA’s decisions.
- The Royal Commission on Genetic Modification had noted that the use of human genes in other organisms raises particular concerns, and indicated it as one area where cultural, ethical and spiritual concerns needed to be addressed at a generic level.²
- There are a number of other rapidly emerging biotechnologies that involve the movement of biological material between species. The material may be tissues, cells or gametes.³ The Bioethics Council considered that a discussion on the use of human genes in other organisms might also highlight issues that need to be considered around some other biotechnologies.

The Council has already produced informational material on the use of human genes in other organisms and this is not repeated here. Anyone wishing to access this material and the various reports that have informed our thinking should visit the Council website (www.bioethics.org.nz).

¹ The Council’s formal terms of reference are available at <http://www.bioethics.org.nz/about-us/terms-of-ref-english.html>

² Royal Commission on Genetic Modification. *Report of the Royal Commission on Genetic Modification*. 2001. Wellington: Royal Commission on Genetic Modification p.129.

³ Gametes: in humans, eggs and sperm, which have half the complement of chromosomes and form a complete new cell by fusion.

Key messages

- This topic has been highly controversial, and has seen many heated debates, yet participants demonstrated a willingness to engage in sustained and respectful face-to-face dialogue about complex and challenging issues. They responded positively to opportunities to explore cultural, ethical and spiritual issues in non-confrontational and non-adversarial contexts. Many participants reported that they now think about the issues in different ways.
- Many people expressed cultural, ethical and spiritual views in a way that recognised and valued the complexity of relationships - within human communities, with other species and the environment as a whole, and over time. It was generally felt that such complexity makes it difficult to predict or control the social and environmental consequences of some decisions.
- In strictly scientific terms it is difficult to sustain any distinction between a human gene and those from other organisms. All genes are made of the same chemical materials (bases), and many human genes have the same (or very similar) sequence of bases to those found in organisms ranging from flatworms to chimps. However, genes are *more than* chemicals. They also have cultural significance, they have become symbols of what we have inherited from our ancestors (as in the Maori concept of whakapapa), as well as symbols of the *relationships* we have with each other and with other forms of life.
- The use of a human gene for the production of a *single* protein in the host organism does not raise sufficient cultural, ethical or spiritual reasons *in itself* to prevent this kind of use in plants and animals. However, 'human genes' are a culturally (although not scientifically) significant group, and their use in other organisms does require additional ethical considerations to those required for other genetic modifications.
- Making choices in such a complex context calls for decisions that honour relationships, express humility and demonstrate compassion for those who suffer. The acceptability of the use of human genes in other organisms relates not only to the effects of the technology, but the motivations behind that use. In a similar way an assessment of risk needs to look wider, to include not only the immediate biological impacts, but the wider impacts on social relationships, the distribution of benefits and profit, and the values and principles that shape our social life.
- The Council opposes certain types of modification, most notably those that would give non-human organisms the capacity for human language and associated powers of reason, and those that would cause non-human organisms to look like humans. These types of modification of non-human organisms are unacceptable over and above any suffering or discomfort they might cause the organism, or any general caution about the use of human genes described above.
- The use of human genes in other organisms to create animal models of disease may involve manipulations of animals in the first half of gestation or development, but effects expressed in the second half of gestation or after birth or hatching, that may place a burden of suffering on the resulting organisms. The Council thinks that any manipulations in the first half of gestation or development that are likely to have effects in the second half of gestation or after birth or hatching should be subject to ethical review.
- Science is valued for its contribution to the public good. However, there is considerable scepticism about the role of commerce in science. Further work is required to build the relationships between the commercial sector and the wider community, so that all partners have a stronger understanding of what is important to others.

Structure of the report

Following this Introduction, Section 2 describes the decisions made by the Council in developing this project, and the processes used for engaging with the public and identifying the key issues.

Section 3 reports on what the Council heard. In doing so it also describes the context or framework that people brought to the dialogue, and the key values and principles that appear to underlie people's assessments of the technology and its possible uses.

Section 4 presents both the Council's response to what we heard and the results of our own deliberations. On this basis we offer the Government a number of recommendations that relate to the use of human genes in other organisms, how to deal with additional and emerging biotechnologies, and how to respond to the social tensions around the commercialisation of science.

Section 5 looks at the challenges and benefits of consulting a wide audience at the start of the whole dialogue process, rather than asking people to respond to a policy document. The Government took a bold step in asking the Bioethics Council to promote and participate in public dialogue. This is an intervention that has offered the opportunity to explore issues that are often lost in the day-to-day business of policy development and implementation, and we offer some observations on the challenges and benefits of this initiative.

SECTION 2 > DEVELOPING THE PROJECT

Section 2 > Developing the project

There were three phases to the project: identifying the issues, choosing and implementing a process for public engagement and dialogue, and then developing the Bioethics Council's advice. This section reports on these processes.

Identifying the issues

Previous public discussions about the use of human genes in other organisms have largely occurred within a regulatory context, such as applications to ERMA and views expressed to the Royal Commission on Genetic Modification. This material provided some indications of the issues, but we were conscious that these political contexts would have very much shaped the discussion, and that there could be important additional considerations.

The Council was also mindful of the international research that highlights the importance of framing issues in ways that capture the concerns of the general public as well as the immediate and perhaps more pragmatic concerns of economic policy. We therefore chose three strategies to identify the full range of issues and to inform the development of the dialogue process.

- Focus groups were commissioned to work with members of the public who had no previous engagement with the issues.⁴
- A series of essays was invited from people who have already considered the issue of human genes in other organisms and related issues.⁵ The authors came from diverse intellectual, cultural and academic backgrounds.
- The Bioethics Council's Maori Working Group held a number of hui with interested and informed Maori, and explored the possible consequences for tikanga and matauranga Maori when thinking about the transfer of human genes to other organisms.

All this work, plus the expertise of the Council, informed the preparation of the written material that provided the core information for the public engagement. The two key resulting documents⁶ were:

- *Human Genes in Other Organisms*, a six-page fold-out accompanied by a submission form
- *Whakapapa and the Human Gene*, an eight-page pamphlet.

In *Human Genes in Other Organisms* the Council identified the key issues and questions that it thinks underlie the more immediate issue of using human genes in other organisms, and provided some information about the technology itself, some of the related issues to consider, and some of the views it had already heard.

We felt that it was important to begin by stepping back from the specific question of 'Is it OK to use human genes in other organisms?' because responses to that question will be shaped (to some extent) by a bigger question: What is special or unique about being human? In other words, why might we even bother to think that human genes are special in some way?

⁴ *Human Genes in Other Organisms: Qualitative Research Report*, available at <http://www.bioethics.org.nz/publications/human-genes-qualitative-aug03/index.html>

⁵ *Reflections on the Use of Human Genes in Other Organisms: Ethical, Spiritual and Cultural Dimensions*, available at <http://www.bioethics.org.nz/publications/human-genes-reflections-jan04/index.html>

⁶ These are available at <http://www.bioethics.org.nz/about-bioethics/issues.html>

We recognised that people bring to the conversation different ways of understanding the world, including cultural, ethical, spiritual and scientific viewpoints, and we invited people to talk about these. We also asked who should make the decisions. Only then were people invited to alert us to other factors we should consider.

Whakapapa and the Human Gene is a contribution by the Council, in Maori and English, to exploring the issues, particularly as they relate to Maori tikanga and matauranga Maori.

Choosing the process

Public engagement

The Council wanted a process that would:

- Create opportunities for people from a range of social groupings to explore the cultural, ethical and spiritual dimensions of biotechnology, to contribute their own understandings of the issues, and to gain an increased understanding of the views of others.
- Increase the Council's (and Government's) understanding of the challenges of creating dialogue, and to learn how this could be further improved.

We knew we could not hope to talk with everyone. We therefore made some strategic choices about the mix of people and strategies we adopted. These involved a mix of face-to-face situations and other 'open access' processes. In addition, we worked with an evaluation team in the early stage of the process to fine-tune our thinking about what we hoped to achieve. The three resulting central strategies for engagement were face-to-face dialogue groups, moderated on-line discussion and a public submission process.

Face-to-face dialogue

The Bioethics Council has been charged with promoting 'dialogue'. This is consistent with developments in a number of other countries, such as the UK, Europe, Australia, the US and Canada, where governments are recognising the need to involve the public in understanding and interpreting the social and ethical significance of the implications of new technologies and developments in science.

Often 'dialogue' is used in the sense of government consulting with the public along traditional channels of input into policy decisions (e.g., submissions to government and regulatory authorities, select committee hearings, consultation on proposals). However, the Council was determined to engage in dialogue that genuinely seeks to build understanding, rather than persuading people to adopt a fixed position.

This kind of dialogue works on the assumption that agreement on a way forward often requires not simply more information, or tighter arguments, but a deeper understanding of how others understand a situation.

Dialogue provides a 'space' in which participants can, without fear of ridicule or personal attack, examine their own and others' deeply held convictions in such a way that all parties respect the nature of those values and try to understand what shapes and gives meaning to other people's lives.

The value to government of dialogue about biotechnology is that:

- The public has an opportunity to better articulate and understand the values and beliefs that they and other citizens think should underlie government policy.
- Government can get a better understanding of what is at stake for the public, the factors that shape public responses to developments in policy and technology, and the values the public wish to see expressed in political and economic decisions.

Twenty-eight face-to-face dialogue groups were held around the country. The Council chose some specific demographic groups (e.g., young people, older citizens, rural community, and Asian and Pacific peoples, Maori) and some communities of interest (e.g., ethicists, scientists, people from faith traditions, and the disability community). Some groups brought together people from very diverse communities of interest, and on one occasion we re-convened a group to continue the dialogue in a second session. Some meetings were promoted to the public; others were by invitation to targeted groups.

The Council stressed to participants that they were being invited to a dialogue - not to an opportunity to advocate for or to debate a particular position. This was also emphasised on the day by the facilitators. The vast majority of participants responded positively to this approach.

Where possible, participants were provided with the discussion documents prior to the dialogue session. All but four of these meetings were attended by at least one Council member. Each session was independently facilitated. The Council worked with two facilitation teams, one of which specialised in facilitation in tikanga Maori contexts. The facilitation teams prepared reports to the Council.

A moderated on-line discussion

A moderated on-line discussion was offered. This was open to anyone who registered, and ran between 13 February and 8 April 2004. One hundred and four people registered, and 27 of those posted messages, some on multiple occasions. The discussion was visited 1,839 times. The discussion was initially structured around the questions in the submission form, and additional strands were generated as required. The tone was respectful, and to some extent interactive. People made thoughtful contributions and responded to issues raised by others.

A public submissions process

The public submissions process was not a dialogue - there were no opportunities for interactions or, during the process, for contributors to hear the views of others. However, the Council felt that it was important to offer this additional opportunity for people to contribute to the Council's thinking.

The Council received 130 submissions. Of these, 24 identified themselves as representing the views of an organisation or group (five of which were from school classes). Two groups were formed specifically for the purpose of making a submission. Group size ranged from four to several thousand. The age range of the groups reflected the fact that some groups were school students, others represented groups that attracted specific demographics (e.g., University of the Third Age), and yet others wider community groups (e.g., the Hemophilia Foundation of New Zealand).

An analysis of the 'open-access' activities (on-line discussion and submissions) was prepared for the Council.

The report of the original focus groups, the collection of essays, the reports of the facilitators of the dialogue process and a summary of the submissions and on-line discussion are available on the Council's website (www.bioethics.org.nz).

Promoting our activities

This was the first major project for the Bioethics Council, and therefore required not only promotion of the project but profiling of the Council itself. Strategies here included the launch of a website, letters sent to a broad range of organisations and individuals inviting them to register their interest for mailing and activities, and speeches and visits by the first chair of the Council, Sir Paul Reeves.

The project was officially launched in February 2004, and an advertising campaign was run in all the major metropolitan and provincial papers and two Asian papers, on iwi and Pacific Island radio stations, and on various internet sites. In addition, press releases and articles made their way into the general and specialised media e.g., *The Listener*, *Royal Society Alert*.

The discussion material was circulated to all who had registered an interest in the Council's activities, and, along with copies of the essay collection, distributed to public libraries, schools and Citizen Advice Bureaus. It was also available on the website.

Bioethics Council consideration and responses

The Bioethics Council working group met on several occasions during the planning and implementation of the project, and took key issues to the Council for further deliberation. The working group played a central role in identifying key issues for the dialogue and considering the breadth of the responses. The Council was also informed by the conversations we had (among ourselves as we developed the project and with the public at the face-to-face sessions), the reports prepared by the facilitation teams, and the analysis by the secretariat of the on-line discussion and submissions. From all these sources we distilled the key issues that we heard, and developed our opinions and advice to government. These are discussed in the next two sections.

SECTION 3 > WHAT WE HEARD

Section 3 > What we heard

As already noted, rather than simply asking people what they think about a particular biotechnology, we believed it was crucial to begin by exploring the context or overall framework that shapes their views. We found that participants in the dialogue responded thoughtfully to our invitation to consider the broader issues that underlie responses to biotechnologies, in particular the use of human genes in other organisms.

The resulting exchange of ideas demonstrated the range of concerns that are critical to any consideration of this (and other) biotechnologies. People brought to the dialogue:

- Their understanding of the place of humans in the universe (including scientific, cultural and religious traditions).
- Their understanding of cultural and biological concepts of what it is to be human.
- A concern to draw on history and personal experience.
- A strong appreciation of the interconnectedness of people and their environment - both in relation to the human place in the ecosystem, and to the social, political and economic dimensions of life, in a national and global context.

Seldom did one of these areas determine a person's views to the exclusion of all others. Rather, people tended to bring many or all of these issues to the table in some form, and then sought to find an appropriate response to what the technology offers.

Woven through what the Council heard were expressions of values that shaped and informed people's responses to the queries the Council raised. Much of what we heard was consistent with the observations of the Royal Commission on Genetic Modification, and more recent research, such as that of the Growth and Innovation Advisory Board⁷ and Lincoln University.⁸

The context or framework that shapes people's views

We deliberately framed our questions to open up the conversation around the cultural, ethical and spiritual dimensions of biotechnology and to explore the underlying issues. Participants in the face-to-face dialogue, in the on-line discussions and those that made submissions had the opportunity to profile and explore the issues they thought were important.

From all of these sources we identified four key themes that informed people's responses. These are presented in no particular order. All are important, all relate to each other, and all will be significant in other areas of biotechnology that raise cultural, ethical and spiritual dimensions.

The place of humans in the universe

Biotechnologies such as transgenics offer tools to manipulate life in distinctive ways. These tools have the potential to increase our understanding of the world, to intervene in or treat diseases, and to develop commercial products. These things were all valued.

⁷ Growth and Innovation Advisory Board, April 2004 Research Summary. http://www.giab.govt.nz/uploadedfiles/Documents/Reports/Research_Summary.pdf.

⁸ Hunt, LM, Fairweather, JR, and Coyle, FJ. Public Understandings of *Biotechnology in New Zealand: Factors Affecting Acceptability Rankings of Five Selected Biotechnologies*. Lincoln University, Canterbury, NZ, 2003.

However, the very power and potential of these tools also present the human community with new questions about the extent to which it should manipulate life forms (human and others), and raise profound issues about how best to conceive of the human position in the biosphere, and our associated relationships and responsibilities.

People drew on a number of different traditions in thinking about their relationships with the rest of the natural world, and often a person would refer to more than one of these. But many ideas referred back (explicitly or implicitly) to some story of origin - where have humans come from, what relationships are implied or valued by those stories of origin, and what is the pattern of which we are a part?

An evolutionary perspective on origins

There was a strong awareness of humans as the product of millions of years of evolution, and Darwinian natural selection as the mechanism for evolution was taken for granted by many. As a result there were indications that people often understood species as dynamic entities, changing over time, yet having their own integrity as a result of the particular evolutionary history that brought them to the present.

Humans were seen as one species among many, dependent on a delicate balance of relationships with others. Associated with this was a strong sense that interventions by humans in evolutionary processes (such as transferring genetic material between species) carry with them immense responsibilities, and should only be done with great care - or not at all. Humans are seen as late arrivals in the evolutionary process with only a very limited understanding of the ramifications of our actions. Often associated with this view was scepticism about science when it failed to address this wider context of genetics.

Cultural traditions of origin

Other people referred to stories of origin that inform their spiritual and/or cultural views. Quite a number of written submissions referred to creation stories from the Christian tradition, which provided various explanations or interpretations for humans' relationships with the rest of the natural world. For example, some thought it inappropriate to 'exploit' other organisms through genetic modification: humans are made in the image of God and therefore it is our responsibility to care for the rest of creation. Some from this tradition saw humans very much at the centre of the universe, while others resisted interpretations that gave humans over-riding authority. Many were also informed by an environmental and evolutionary understanding of the world.

Some participants referred to Maori stories of creation to understand the place of various organisms, and the relationships between humans and other organisms.

Common to many of these views was a strong sense of the moral responsibility of humans.

What is special or unique about being human?

The Council explicitly asked people, 'What is special or unique about being human?' We heard a range of (often intertwining) views.

Many submissions identified the significance of the human brain and rationality, language, and the ability to make choices - while sometimes pointing out that this does not necessarily lead to wise choices or good outcomes. Some identified humans as 'tool users', while other culturally defined views focused on *relationships* as the defining factor. Various traditions of religious, cultural and scientific thought were drawn on to discuss relationships.

Some referred to religious concepts of humanness - humans made in the image of God, called into relationship with one another, placed in a particular relationship to the rest of creation (stewardship or dominion). Not all those who used language from the Judaeo-Christian tradition claimed to be practising Christians or Jews, but it is to be expected that the Western cultural heritage would provide many of the important concepts that inform people's choices and spirituality.

Some referred to Maori heritage (e.g., whakapapa) as that which shapes and defines our relationships to humans and other life forms, and called for respect for wairuatanga, mauri, hinengaro, tinana. Related to this is an argument that to give special status to human genes is to perpetuate ideas of the dominance and superiority of humans that in itself denies or undermines an understanding of humans as one species among many, as sharing a common whakapapa.

Some talked in terms of the human place in the biosphere and the ecosystems of which we are a part: in biological terms humans are one species among many, occupiers of many ecological niches, and implicit in any ecological niche is a set of relationships. Relationships were also thought of in evolutionary terms: humans as inheritors of an evolutionary history with a shared genetic history. That evolutionary history is shared with other organisms, and they too, as species, should have that history and their biological identity respected.

Others also explained humanness in terms of biology, but with a focus more on the individual organism than the species as a collective. Several thought that unique human genes determined humanness. However, many held a wider view of genetics, such that genes are just one aspect of what it is to be human but do not in themselves determine humanness.

Much of what we heard was consistent with an understanding of human biology or life as something that *emerges* out of the interactions of genes - with one another, with the internal environment of the cell and organism, and with the external environment. This understanding also has a time dimension, whereby humans (and other species) emerge out of an evolutionary history with a genetic heritage which results from long interactions with an ever-changing environment. Humanness in this view is an emergent property, the result of a complex system of interactions, recognisable in its entirety rather than in any one of its parts.

The various approaches described above do not allow us to predict subsequent views about the use of human genes in other organisms, nor how people understand human responsibilities. This is because people often draw on more than one of these approaches when considering the pragmatic and specific issues associated with biotechnology, and integrate their views in various ways.

Approaches to the issues were also shaped by whether their focus was on an evolutionary or long-term perspective, or on an individual, local or medical perspective, and whether they were considering the unit of value as the 'individual' (human or organism) or the species. For instance, those keen to see medical research into diseases appeared to focus on the benefits to individual health, whereas those with an environmental concern were more likely to focus on community, societal and environmental dimensions. The tensions between these approaches were acknowledged by those participating.

History and experience

People often placed decisions associated with the use of human genes in other organisms in some sort of historical context, and brought their own previous experience and knowledge to the table.

Many indicated an awareness of the fragility of some systems based on what has happened in the past. People are very aware of the New Zealand history of imported organisms and disrupted ecosystems, as well as the international experience of the unexpected environmental and public health impacts of biotechnologies. Many also have a heightened awareness of the difficulty of predicting or controlling the impacts of what may initially appear quite small changes. As a result there is unlikely to be confidence in decision-making that fails to acknowledge this dimension adequately.

The history of government approaches to public involvement in decision-making and to consultation also influenced people's responses to the invitation to participate in dialogue. A number of people were sceptical (on the basis of previous decisions made around biotechnology and in other areas) that government would pay attention to the values of the wider community. This is particularly so when their

values are not easily explained or incorporated into a utilitarian way of thinking which focuses on pragmatic benefits and economic consequences.

People also brought a sense of the history and value of science to their considerations of the benefits of biotechnology. There was a strong sense of science as being for the public good. Knowledge should be shared and available for the wide distribution of its benefits - and people were very aware of the benefits of science.

However, there was also an often-expressed view that this traditional valuing of science is being compromised by an emphasis on the commercialisation of science, and the increasing trend for knowledge to be exploited for profit. Such views were often associated with scepticism about large multinationals, the extent to which those most in need of the advances of science would have access to those benefits, and whether any commercial benefits would stay in New Zealand. Reservations about the commercial developments of science were often related to international rather than national relationships.

Interconnectedness

This theme encompasses all of the above. Throughout the dialogue there was a strong theme of interconnectedness: biology with culture, history with socioeconomic considerations, identity with national position, and culture with a scientific understanding of the world. It was impossible to talk in one area without ideas over-flowing into others. No one set of ideas was sufficient to inform choices and judgements, and it was important to people to make the links between the various concerns.

We were impressed that people were very clear that such complexity of ideas was in fact necessary when talking about cultural, ethical and spiritual issues.

This interconnectedness is not only at a conceptual level. We heard a strong affirmation that many experience themselves as being part of a web of relationships and connections - immediate material connections through biology as well as social and economic relations, and webs of relationship and responsibility to other life forms and previous and future generations. This way of thinking appeared to be grounded in a strong awareness of the New Zealand and Pacific context.

An assumption permeating many of the conversations was that decisions are made within such a complex system. This system may be biological (genes can not be considered independent of the total life form in which they exist), social (talk of benefits needs to be considered alongside economic and political arrangements that shape the availability and distribution of those benefits), cultural (foundational myths, traditions and stories of origin shape one's sense of responsibility for the environment and/or future generations) - or some combination of them all.

Overall, participants stressed the importance of dealing with the complexity of the issues. There was strong acceptance of the need to consider the wider context for any choices made about a particular biotechnology. (Although the dialogue focused on the use of human genes in other organisms, participants frequently made links to other biotechnologies.) This wider context included both science as pursuit of knowledge, but also the social/political context, recognition of the frailty of human judgment, and the risks of choices to all these dimensions of life.

Concepts of interconnectedness, whether applied to ecosystems or to the "Pacific Way", reveal that New Zealanders think about the world around them in a multidimensional way which is entirely appropriate for the complexity of the biological, social and cultural world, and the century in which they live. This understanding of interconnectedness and its multiple manifestations is the result of sophisticated and sensitive intuition and reflective wisdom. It appears from our dialogue work that interconnectedness is as much a unifying national consciousness as it is a "unifying regional consciousness".⁹

⁹ "Pacific Cooperation: Voices of the Region". The Eminent Persons Group Review of the Pacific Islands forum, presented at the Special Leaders Retreat April 2004, p.20.

Principles and values that matter

The above themes informed or shaped how people approached the pragmatic issues of deciding how technology can best be used, and in particular the cultural, ethical and spiritual issues that should inform the use of human genes in other organisms.

However, the negotiation, balancing and interpretation of the above themes was informed by various specific values. The values we identify here are the Council's interpretation of what we heard, but they resonate with other work on biotechnology in New Zealand, and offer further definition of some of the values highlighted elsewhere.

Honouring relationships

Given the importance many people gave to the place of humans in a wider network of relationships, it came as no surprise to find that permeating much of what we heard was a *valuing* of these relationships. The relationships highlighted ranged from the individual, to the family/whanau and community, to wider human society (national and global), to other life forms and whole ecosystems.

People valued individual choice, but most often talked of this in the context of choice of access to medical treatment. There was a strong impression that people not only knew of their social and biological interdependence, but valued this, found meaning of life within such a context. This context has both social and biological aspects.

Social relationships

Social interdependence or interconnectedness was seen in terms of local (within the family or local community), national and global relationships. The choices we make, collectively or as individuals, interact with social, political and economic relationships that are seen as having implicit values. People were conscious not only of present relationships, but of the importance of past and future relationships and generations.

The assessment of those values, or the ways they are expressed, seemed to be strongly influenced by people's valuing of the common good, or the collective good of the community. We heard a strong sense of social solidarity and collective moral responsibility. Just as many people saw themselves within a complex set of biological/environmental relationships, they also saw themselves within a complex set of social relationships mediated by political and economic arrangements. They wanted those arrangements to reflect and promote the values they see as important.

For instance, many were conscious of New Zealand in a global context, and that the pressures on government and business were international. People were concerned that this international pressure could compromise the choices that are important to New Zealanders. There was a strong sense of the value of New Zealand identity and independence. People did not want there to be undue influence from other governments or from big business. Consent is about political choice as a country, as well as about an individual's access to health technologies.

Many referred in this context to the relationship between big business and science, and how the profits are distributed. We have included discussion of this below under "Science and commerce".

Environmental relationships

Biological interdependence or interconnectedness was seen in terms of our present biological relationships, but also had a dimension across time, a respect for the biological processes that had got humans to this point and that would take us into the future.

As we have seen, many people have an acute awareness that humans are dependent on and part of the environment and that environment is valued. It is valued for quite pragmatic reasons - humans are

dependent for our survival on the sustainability of biological systems - but it is also valued for itself. For some there is a spiritual dimension to their valuing of the environment.

As we have also seen, people stress the importance of viewing life as complex. It cannot be reduced to its parts. Understanding the biological world requires an understanding of the relationships between the parts, and the levels of organisation that arise out of those relationships. Life is a product of relationships at many levels of organisation.

This awareness of complexity and of humans as a part of the natural world is in tension with a sense of the specialness of humans. Our own species does have a special standing which in part is biological (we have our own species integrity), but is also about cultural understandings of humans - humans do have the ability for rational thought and language, for the pursuit of knowledge. We do often understand ourselves as separate from the rest of the biological world in same ways, and there is a cultural heritage that sees humans as 'top of the tree'.

The responsibilities we have as humans derive from bringing together all these sets of relationships and human self-understanding.

We heard many speak of *respect for the natural world*, its complexity and biological processes. Implied in this is a rejection of a world view that sees other life forms as primarily something to be used for any purposes that suit human beings. People also recognised that the human species is capable of actions that are both beneficial to and destructive of the environment.

People drew on various concepts to explore what 'respect' might mean. We heard a concern for *species integrity* - many people were concerned that we did not intervene in other species in ways that put their wellbeing as a species at risk. Some referred to stewardship, or to *kaitiakitanga*. Others referred to the sacredness of life, to ideas of *tapu*, or *taboos*. Such ideas need not be associated with rigid belief systems, but offer a language (additional to scientific language) with which to understand and make meaning or sense of the changing relationships between humans and other organisms that biotechnology makes possible. Cultural practices, protocols and *tikanga* associated with biotechnology give expression to the values that inform our relationships.

Humility

The value placed on relationships (social and biological), combined with an awareness of complexity and interdependence, leads many to an attitude of humility, or *whakaiti*. Rational thought and new knowledge do not always equate with wisdom and sufficient understanding of the consequences of the choices that are made. The high value placed on the environment, and a strong sense of history (evolution, human occupation of New Zealand, as well as recent decades of science) should lead to a sober and cautious approach to the use of new forms of human power such as biotechnology.

A precautionary approach to new technologies (particularly those released into the environment or food chain) appears to be largely motivated by a love and respect for the complexity of the biological systems of which humans are a part, and a hard-earned knowledge that knowledge and power need to be (but are not always) used wisely and well.

Such a position is not new. Many cultures (Western and Maori) have central myths which remember and convey such knowledge from earlier times: Adam and Eve, who ate from the tree of the knowledge of good and evil; and Icarus, who flew too close to the sun and melted his wax wings, and who has become a symbol for hubris and the danger of overreaching our human limits.

The Maori word for humility, *whakaiti*, literally means to make oneself small. The story of Te Tahio-te-rangi reminds us of the need to know when to *whakaiti* and when to *whakamana*; when to show the greatness of one's *mana* by being humble, and when to act with *mana* and show off one's prestige, status and position.

A compassionate response to suffering

People's approaches to the issues the Council raised were also informed by compassion - both for human suffering and for animals.

There was wide acceptance of the use of human genes in other organisms for the relief of human suffering. The argument for this use frequently had weight even with people who were uneasy with the technology, and appeared to be sufficient to over-ride their other arguments. Maori confirmed that there had already been considerable benefits to their community from biotechnologies, particularly the development of insulin to control diabetes.

There was also scepticism about how the argument to relieve suffering is used by commercial interests to persuade regulatory authorities to support particular developments. There was also concern about the importance of this argument at the research stages of a technology: there are many steps between research and the development of this knowledge into a treatment for a medical condition. At the early stages of development there is merely a *potential* for benefit, which may or may not be realised.

We also heard concerns for animal suffering. Yes, we use animals in food production, and have allowed species to be bred to meet human requirements, but this was not seen by some as sufficient justification for the use of animals as bioreactors, or as models for human disease to be used in research. Past practices are not necessarily appropriate, and using animals in research may not be an appropriate expression of our relationships with them, particularly if suffering is involved.

Even those who accepted some use of animals in research felt there needs to be a balance between the potential benefits of the research and the burden of suffering of the animals.

Utilisation of technology

In addition to the above values, participants brought three other major considerations to their discussions - the potential use or motivation for developing the technology, risk, and the relationships between science and commerce.

Motivation

People's considerations were not only with the effects of biotechnologies, but also with the motivation behind these activities. The use of human genes in other organisms pushes people's sense of what is appropriate. It matters *why* we do what we do.

The relief of suffering and the saving of lives were clearly the most acceptable reasons for the use of human genes in other organisms (and for related technologies), whereas making money was not a sufficient reason for many, even though most people recognised that the benefits were only likely to be realised through commercial investments.

There were nuances to this position. People were not comfortable with the use of technology to pursue the perfect human being - producing 'designer babies' or enhancing intelligence or normal physical characteristics. The Council was also reminded of the importance of ensuring that technological developments do not reinforce negative attitudes to disability, or imply that people with a disability are only acceptable if they overcome that disability. There was more support for the use of human genes in other organisms when there were few other options to offer those who are suffering.

The pursuit of knowledge was also seen as a possible motivation, and one valued as intrinsic to science. But once again there were caveats: knowledge, the Council was reminded, also has a social and cultural context. It is important to ask why we pursue the knowledge we do, to what social purpose it is to be put, and who will have access to this knowledge. Only then can we better consider both the ethics and the risks of pursuing a line of enquiry, or of developing particular technical abilities or powers.

Others stressed this in relation to the motivations behind why we pursue the lines of enquiry that we do. For example, the high-tech responses to medical conditions may appear exciting, but it is important to consider whether there are other interventions (e.g., changes in life style, or public health initiatives) that may be either more effective or may ensure that benefits are received by a larger number of people. There are only so many resources available (for research or for health care), and it is important to many people that the distribution of benefits supports and reflects the social values that are important to New Zealanders, and to our sense of national identity.

We also noted that there are some medical conditions that are not amenable to lifestyle changes, and that genetic technologies may provide strategies for dealing with some of these conditions. Views on this were closely related to how people think about risk.

Thinking about risk

It was clear that a number of people see risk in a much wider context than the risk management framework that ERMA deals with. This wider context includes putting at risk the values and principles that a number of people want to underpin New Zealand society, or which they perceive as having always underpinned our society, however imperfectly. For example, they see genetic modification (GM) as being profit driven and individualistic whereas they value altruism and the common good; GM as being divisive when they value relationships and solidarity; GM as reductionist when they value ecological interdependence.

This approach puts risk into a wider framework. In addition to an assessment of biological risk we need to ask, what can this technology do for society? Where does it fit with community values and social purpose? These are much wider questions than that of economic value. They are about how our choices will affect our relationships to the environment, our sense of what it means to be human, and the nature of the social relationships it has the potential to build or undermine.

Some Maori thought current decision making highlights the risk of political and business approaches which rarely reflected long term considerations, whereas Maori often thought in terms of generations.

Science and commerce

We suggest that the often-raised issue of the relationship between science and commerce needs to be considered in the light of this broader way of thinking about risk and the potential of biotechnologies.

There are tensions implicit in the relationships of science with commerce: research versus the exploitation of life forms, company profit versus community benefit, New Zealand versus global interests, environmental and social values versus economic benefits. While similar issues or concerns may be raised by other commercial developments and technologies, biotechnology disrupts many accepted understandings of our relationships with the biological world.

People also noted the tensions in the role of government as both promoter and regulator of biotechnology. Undoubtedly there is a challenge to reconcile the use of biotechnology as a key contributor to economic growth with community apprehensions and values. In particular, many Maori wanted decision making about biotechnology to be participatory, transparent and binding.

We heard strong concern that the push for economic benefits of biotechnology not compromise other values that are central to many New Zealanders' sense of national identity, as well as those values the public associates with science itself. There was considerable concern, not with profit *per se*, but with profit being made by large international companies, with few benefits being experienced by the New Zealand community.

There was some cynicism about the promised benefits to the wider community from biotechnologies, and considerable awareness that quick fixes to large problems such as world hunger will require considerably more than technological advances. In other words, people are not anti-business, but they do expect businesses to contribute to social possibilities and arrangements that are consistent with community values. A major part of this was the just distribution of benefits. Many people support the development of benefits from biotechnology, but only if those economic benefits do not accumulate in the hands of the few, and the health and other benefits are accessible to those who need them.

Overall we heard many comments about the risks to the values of science of an increasing commercialisation of research. People are concerned that the collective values of science (e.g., knowledge that is publicly available and for the common good) are being compromised by the alliances between science and commerce. We heard few comments of an absolute mistrust in science, but many about mistrust of the alliance of science and commerce.

SECTION 4 > THE BIOETHICS COUNCIL'S THINKING

Section 4: > The Bioethics Council's thinking

The use of human genes in other organisms clearly raises cultural, ethical and spiritual concerns for many people. The nature of these concerns is more complex and nuanced than a simple acceptance or rejection of their use. The Council recognises - and welcomes - the community's embracing of an understanding of both social and biological life (and the associated ethics) as emerging from a set of complex interactions.

In this section we build on the experience from the public dialogue and the Council's own work to:

- note the present and possible uses of human genes, and the questions they raise
- explore the cultural and ethical significance of 'human genes', which is additional to their scientific significance
- identify some emerging issues related to the use of human genes
- examine the importance of discussions on the relationships between science and commerce.

In the final section we discuss the contribution of dialogue to community understanding of the cultural, ethical and spiritual dimensions of biotechnology.

What the science can do,¹⁰ and the decisions that face us

The use of human genes in other organisms is about more than the transfer of a single gene and its associated regulatory regions.

The standard purpose of genetic technology using human genes in other organisms is to produce a protein in the host organism that is usually produced in a human. There are two main ways to achieve this:

- isolate and copy the DNA that makes up the gene
- isolate the RNA, which is the intermediary between DNA and protein, and from that make cDNA (which differs from the original DNA in usually being shorter, with introns removed).

The DNA or cDNA is then either inserted and cloned (copied) in bacteria, or copied using the polymerase chain reaction (PCR).

Considerable changes are made to the gene before it is inserted in the host organism. Associated regulatory sequences may be altered, or the DNA sequence of the gene of interest changed. The resulting protein will be the same, but the host organism may be able to express it more effectively or efficiently.

Increasingly, there is another way to produce human proteins in other organisms that does not require any direct physical connection to the human gene. Researchers can predict from the chemistry of the desired protein (and by reference to computer databases) what DNA sequences will produce that protein, and, of these options, which one will do it most effectively in the host organism. This cDNA sequence can then be created in a test tube and inserted into the host, which will then produce a human protein.

As the potential applications of genetic modification expand, the technology may involve single or multiple genes. The host organism may be a bacterium, a plant or animal cell line, or a living plant or animal.

¹⁰ In the following discussion we refer to a number of concepts and procedures of a fairly technical nature on the basis that this material has been covered in previous publications. Those wishing to access more information should visit the Council's website: www.bioethics.org.nz.

The modified organism may, as a result of the modification, produce a product (e.g., recombinant factor VIII) that can be used for medical or industrial purposes. Or it might produce an organism with characteristics of interest in research (e.g., a mouse that expresses a medical condition thought to parallel a disease in humans). The research may be directly medical or applied - but need not be. It may be seeking an understanding of how particular genes work. For example, by using human genes in rhesus monkeys it might be possible to understand how particular genes contribute to aspects of reproduction or development, or the function of genes associated with human speech.

There are parallels here to other work that is broadly accepted. Humans have long bred organisms to make them more useful to humans, and in science used them in various forms of research (medical, pest management, behavioural studies or agricultural production). This has included teaching chimpanzees to use sign language and hence to acquire skills usually associated with humanness.

There are also points of difference: in particular, the intervention is at the molecular rather than whole-organism level. What is crucial - and a matter for discussion - is the cultural and ethical significance of such points of difference, and how these might interact with the values that are important to the New Zealand community (see Section 3).

The significance of the 'human gene'

In strictly scientific terms it is difficult to sustain any distinction between a human gene and those from other organisms. All genes are made of the same chemical material (bases), and many human genes have the same or a very similar sequence of bases to those found in organisms ranging from flatworms to chimps. In addition the versions of human genes used in genetic modification are copies or imitations - not originals - and are often versions that have been significantly modified by deletion or alternation of some sections of DNA or the addition of different regulatory sequences.

However, genes are more than chemicals. They also have cultural significance. They have become symbols or conveyors of that which we have inherited from our ancestors. They have become symbols of the *relationships* we have with each other and with other forms of life. The DNA of which genes are made has become a cultural icon with a range of meanings to different people: the book of life, a sign of our origins, information about our identity, and an indicator of our future. Genes now carry some of the associations that have been traditionally linked to such things as lineage, blood, whakapapa or creation, as well as having associations with more reductive understandings of life as being like a machine or programme.

Currently there is a concern among some that human genes should not enter the food chain. While for some the concern is related to risk, there is also a cultural issue in that it is inappropriate that human genes be in food. We consider that this opinion should be respected.

It is therefore not surprising that for many people there are considerations about the use of human genes in other organisms that are additional to those associated with genetic modification *per se*. The use of human genes - even a single human gene - is not something to be done lightly or casually. Decisions need to take account of the various issues in addition to an immediate risk assessment. The context matters, not only for scientific understanding but also for social significance. Indeed, the purpose of the genetic modification matters, especially when human genes are being used, but the consequences for the host organism are also significant.

Therefore, the Bioethics Council concludes that human genes have a special cultural value and significance. The use of human genes in other organisms must take account of context and purpose. For this reason, the Bioethics Council supports recommendations 7.5 and 7.6 of the Royal Commission on Genetic Modification:

- That wherever possible, non-food animals, or animals less likely to find their way into the food chain, be used as bioreactors rather than animals that are a common source of food.
- That wherever possible synthetic genes or mammalian homologues of human genes are used in transgenic animals to avoid the use of genes derived directly from humans.

The significance of being human

How we use human genes, and the purposes to which they are put, says something about what it means to be human, how we express respect for humanness, and what is special about humans. This is in contrast to one scientific understanding of genetics that we are the *same* as other organisms. It is therefore important that our use of human genes in other organisms expresses and responds to what is important to the community about being human, and the relationships through which we express this.

The Council holds the view that it is not the use of human genes *per se* that is the issue. Rather, what is important is how our use of human genes demonstrates respect for what is special about human life, and our relationships with each other and with the rest of biological world. Humans are both 'just another organism' *and* an organism to which we give special significance. Humans express that special nature of the human body (of which genes are just one expression)¹¹ in part through the protocols, social norms, tikanga, and scientific practices around the use of human genes.

Ethics is about how we give expression to our values, including how we manage the technologies that are available. The social practices humans develop, and the values that inform our choices, reflect our interpretation of the wider social and biological context, our learnings from past experience with technology, and the account we take of the potential for biotechnologies to disrupt or contribute positively to social and environmental relationships.

Maori called for respect for wairua (spirit), mauri (life-force), hinengaro (mind), tinana (body) and mana ake ma wairua (influence over spirit) when progressing future sciences.

Therefore, the Bioethics Council concludes:

- That it is not sufficient for protocols, norms or practices to be amenable to scientific justification, or to be related to risk considerations. They are also important for cultural and symbolic reasons, and to give expression to what is seen as ethically or culturally appropriate for a society.

¹¹ But so also will be cells, gametes, embryos, tissues and organs. Schedule One, Prohibited Actions in The Human Assisted Reproductive Technology Bill 2004 bans the development of in vitro or hybrid embryos.

Such protocols, norms and practices may well change over time, but this is no reason to diminish their current importance.

In addition, we wish to highlight two areas where we think additional ethical concerns remain, both associated with the genetic modification of animals:

- the limits on the *type* of acceptable genetic modifications
- the ethical review of research that creates genetically modified animals for the purpose of research or production.

Limits on genetic modifications involving human genes

There are certain types of modification to which the Council is unconditionally opposed.

The Council opposes, most notably, those modifications that would give non-human organisms the capacity for human language, and associated powers of reason, and those that would cause non-human organisms to look like humans. These types of modification of non-human organisms are unacceptable over and above any suffering or discomfort they might cause the organism, or any general caution about the use of human genes described in the preceding section and recommendation.

Consider, by contrast, a genetic modification that would make an animal develop a specifically human disease that would aid the development of a treatment or cure. In accordance with its other recommendations, the Council would urge caution, and a careful weighing of likely benefits against costs, but it would not necessarily oppose such a modification.

At this stage, the particular modifications the Council is here opposing are not possible and it is only relatively recently that they have become even reasonable to consider. It is consequently unsurprising that it is not yet entirely clear how we, as a society, should respond to such modifications. One point the Council wishes to make is that the questions of the ethics of hybrids requires more thought and that its recommendations are not intended to be the final word. Furthermore, the sheer novelty of this topic explains why the Council, like many of those in the dialogue process, are clearer about which modifications are unacceptable than about the underlying reasons.

That said, the Council holds that part of the reason it is unacceptable to modify non-human organisms so that they speak, think, or look like us is because these changes might well (and perhaps should) affect the moral status we ascribe to these modified non-human organisms and in ways that we cannot predict.

Therefore the Bioethics Council recommends:

- **Genetic (and other) manipulations that intend to produce social or mental capacities in animals that are recognisably human-like, or produce significant morphological changes in life forms to make them more similar to human life forms should not be pursued.**

The ethical review of research that creates genetically modified animals for the purpose of research or production

Although the ethical aspects of our relationships with other organisms are not confined to issues of animal suffering (see below), these are still important.

In relation to the use of human genes in other organisms, there is ongoing discussion about the acceptability of the use of animals in research, most often focused on the burden of suffering animals experience. Any research with sentient animals will continue to require an ethical judgement about whether the suffering of the animal is sufficiently justified by the nature of the benefits from the research.

The genetic modification of animals with 'human genes' to provide animal models for human disease has created a new dimension to this research (as do any other interventions early in gestation or development). Research is deliberately creating animal lines that could carry a significant burden of suffering as a result of the modification, quite apart from any intervention the animal will experience once born.

At present this dimension of animal ethics falls outside the scope of animal ethics review, which only considers the welfare of the organism that is the source of any gametes or embryos that are genetically modified, or the ethics of interventions once a mammalian foetus, or any avian or reptilian pre-hatched young, is more than halfway through the gestation period.

Yet the use of human genes in an animal to create an organism that can act as a 'model' for a human disease has the potential to develop an organism that will carry a significant burden of suffering, independently of and additional to any subsequent research. The Council holds the view that such interventions, where they will lead to organisms developing past the first half of gestation or development, and/or being born, should be subject to ethical review.

Therefore the Bioethics Council recommends that:

- **There be ethical review of those interventions on gametes, or mammalian foetus or avian or reptilian young in the first half of gestation or development, that may place a burden of suffering on resulting organisms, in the second half of gestation or development, or once born or hatched.**

The Bioethics Council recognises that further public dialogue is needed about the appropriate balancing of animal welfare and the benefits to medical science from the use of animals genetically modified to be models of human disease or a source of tissue for human medical treatment.

Human relationships with other organisms

Our use of human genes in other organisms reflects views of the relationships humans have with particular organisms. These relationships are complex, particularly with respect to animals.

The conversations in this area are difficult and will be on-going, beyond any discussion of the use of human genes in other organisms. Some of the important dimensions of these conversations are:

- the dependence of humans on sustainable ecosystems
- the value many in New Zealand give to ecosystems and the species within them, whether or not those ecosystems or species having immediate utilitarian value
- the historical relationships with some organisms, which have led to changes in the characteristics of some species (e.g., rice, wheat, cows, dogs)
- the ‘companion’ status of some animals for some people
- the historical use of animals in research, and the burden of suffering associated with some research
- changes in attitudes to animal suffering in recent years
- the various benefits (including food and research) derived from the use of animals.

The concerns about relationships with other organisms are not only about animal suffering. They are also about the wider relationships and interconnectedness of life forms. For instance, some plants have a particular value or significance (e.g., for cultural and/or food reasons), which would make some uses of genetic modification unacceptable.

Dealing with emerging biotechnologies

In the course of this project the Bioethics Council has become aware of a number of emerging issues in biotechnology that will raise similar ethical issues.

There is international research involving interventions such as the transplantation of human stem cells into non-human embryos or fetuses, or the creation of human-animal embryos. This research, like some uses of human genes in other organisms, involves the transplant of human material into other animals. There is the potential for considerable medical benefits from such research, but there are also concerns about the appropriate uses of such technologies, both for making animals more ‘human-like’ in culturally significant ways, or producing live animals that carry an unacceptable burden of suffering.

Such developments were almost unthinkable only a few years ago, but are rapidly moving into the ‘routine research’ category. This illustrates the speed with which new developments in biotechnology emerge (additional to those raised by genetic modification), that may involve cultural, ethical and spiritual issues.

It is difficult to predict the timing or nature of these issues as they emerge, but it is important that the Government have a mechanism available to it for when such a situation emerges. Such a mechanism would be important to the wider community, to researchers and to business in order that the cultural, ethical and spiritual dimension of any such developments be explored at an early stage in their developments, and that timely decisions can be made about what regulations, if any are required.

This needs to be additional to the mechanisms currently available in the HSNO legislation,¹² as some developments in biotechnology (in research as well as in applied areas such as medical or agricultural fields) may fall outside the jurisdiction of that or other legislation, such as the Tissues Act or HART Bill (e.g., the transfer of neural stem cells into animals).¹³

¹² Hazardous Substances and New Organisms Act 1996.

¹³ Schedule One Prohibited Actions of the Human Assisted Reproductive Technology Bill 2004. Bans the development of hybrid embryos for reproductive purposes and their implantation into animals and humans.

Therefore the Bioethics Council recommends that:

- The Government establish a mechanism in legislation for a Minister of the Crown (such as in Health, Environment, Research Science and Technology, or Agriculture and Forestry) to instruct the Bioethics Council to give high priority to developing advice on the cultural, ethical and spiritual dimensions of an emerging biotechnology.

Such a mechanism would:

- Provide time and resources for a public dialogue on the relevant issues, the development of a public position, and where necessary a regulatory position, responsive to the views of the wider community.
- Be able to cater for technological developments not envisaged within the current legislation and for those situations where case by case consideration is not appropriate.
- Function to progress cultural, ethical and spiritual considerations in a timely fashion in order that the research and business community can be given clarity about what developments it is acceptable/unacceptable to pursue or utilise in New Zealand.

The commercialisation of science

There is considerable tension between the value the public places on independent science for the common good and certain commercial developments in science. A long-standing tradition of science as the disinterested pursuit of knowledge continues to be valued by many - both scientists and the general public.

Alongside this there appears to be recognition that publicly funded research should be available to farmers and other business people. The pragmatic benefits of research are valued, and many people acknowledge that some products will simply not be available without private investment and associated profit. Many are aware of the tensions between benefits to the New Zealand economy and individuals, and benefits going off-shore; and of the potential for New Zealand access to the benefits of biotechnology to be vulnerable to the choices of trans-national businesses.

Claims of enormous benefits of biotechnology to the poor and hungry are frequently dismissed as cynical public relations. While we heard only a few comments at all mistrustful of scientists *per se*, there was a strong theme of mistrust of the cooperation between science and business interests.

Whatever the actual situation, such tensions have the potential to undermine public confidence in the practice of science, and in the potential of science to deliver economic benefits to New Zealand and New Zealanders.

Therefore the Bioethics Council recommends that:

- The Government instigates research into public perceptions of science and the role of commerce, and the influence of commercialisation of science on the practice of science.
- The Government resources an appropriate organisation such as the Royal Society to promote a public conversation in science, and the contribution of science to the common good.

SECTION 5 > PUBLIC DIALOGUE

Section 5 > Public dialogue

The Bioethics Council was commissioned by the Government to “promote and participate in public dialogue”. This initiative provided an opportunity to explore new ways of holding conversations about cultural, ethical and spiritual aspects of biotechnologies, and to move beyond the adversarial approach that came to dominate much of the public debate around genetic modification.

As the Council’s first chair, Sir Paul Reeves, has commented: “We sense that dialogue is a relationship we enter into and not simply a method we understand. Knowledge is not a fixed thing. It is not out there waiting to be discovered; it is part of a process and arises out of interaction.”¹⁴

The Bioethics Council has made a number of observations about the process of dialogue. These observations will inform our ongoing work. They may also be useful to others working in areas where there are strongly held views and conflicting values involved.

What we experienced

Framing the issues

For the Bioethics Council, the process of dialogue began as we listened to the essay writers and the participants in the focus groups. These contributions opened up the conversation in ways we had not fully anticipated. Our thinking was provoked and stretched, and we were challenged to consider wider questions than the immediate possibilities of a particular technology. It became clear that the particular technology of the use of human genes in other organisms raised philosophical and cultural issues that are at the core of human self-understanding at a time when technology gives us powerful choices.

The collection of essays served to emphasise that much of the unease with some biotechnologies goes well beyond pragmatic considerations of technical risk, to profound questions about the place of humans in the biosphere, the appropriate relationships of humans to the non-human world, and our use of technological power.

It became clear that discussions about the science - and even agreement about the nature of the technical risks involved - would be insufficient to resolve the public discussions. What is central to the conversations (while also often invisible) is a cultural, ethical and spiritual quest to understand what it might mean to be human at this point in human history. This is not a conversation separate from science, but in part a conversation *generated* by science as it gives humans different understandings of the biophysical world, and what we can achieve in it.

The Council’s thinking was affected by what we heard, and the discussion document and pamphlet on *Whakapapa and the Human Gene* reflect the thinking that input stimulated.

This experience confirmed to us the value of initiating a conversation in a spirit of enquiry, seeking to open up a dialogue rather than seeking agreement to a position. We were struck by the willingness and generosity of those who contributed to that work.

The Council then sought to engage with various communities (as described in Section 2), and to promote and participate in a wider dialogue that both included and extended beyond those groups and individuals who have an established interest in the field.

¹⁴ Speech to FRST Symposium on Impacts of Biotechnology, September 2003. <http://www.bioethics.org.nz/news/speeches/6-september-03.html>

Public participation: what worked

The face-to-face dialogues

We observed a high level of interest in public participation in dialogue on biotechnologies, and an appreciation of the opportunities this provided. There was a great willingness to participate and a desire for and appreciation of situations where issues could be unpacked and explored in a respectful way. People demonstrated an ability to enter into respectful dialogue with one another even when their views were extremely diverse. Participants wanted to be listened to, but were also able to listen to others. Many reported that the process had changed how they thought about the issues.

Processes of engagement/facilitation were, however, critical in establishing a respectful context for dialogue. Few had experience of constructive sustained conversation on such difficult issues, but skilled facilitation made a positive experience possible for most. The presence of Bioethics Council members at dialogue events was appreciated by many.

We observed the importance of people having access to the appropriate tools and contexts for them to be able to participate. These tools include information, language and understanding, help in articulating concepts, techniques for ensuring conversations that honour different approaches, and creating culturally appropriate situations to explore the significance of biotechnology for a person's own cultural identity and traditions.

Participants recognised and engaged with complexity, and were interested in testing views. One-liner responses were recognised as inadequate. People recognised that the complexity of the issues calls for additional democratic processes, with different processes for public engagement with political decision-making: they expected opportunities for input as well as access to information.

People expected their participation to make a difference - to the decisions taken, and to the understanding of others. Some were willing for respected others to participate on their behalf, but these needed to be trusted individuals, people with mana in their communities. However, people are also discriminating about their participation - there was a reluctance to engage in dialogue where there were any expectations of confrontation or advocacy-based discussions. More pressing political agendas took the attention of some (particularly Maori) who had indicated interest in participation.

We observed the value of established networks to draw people into dialogue. Sometimes participants may have trusted the individuals who approached them (e.g., members of their faith community) rather than the relatively unknown Council. People were more interested in attending events when there had been prior opportunity, often on a personal basis, to clarify that the purpose of the event was dialogue not advocacy.

A number of communities expressed surprise, and pleasure, at being invited to participate. Clearly, not all communities have the same expectation of contributing to New Zealand-wide processes.

Overall, the history of conflict and advocacy around genetic modification has made many wary of talking with others about the cultural, ethical and spiritual dimensions of biotechnology, and there is some cynicism about any possibility of making a difference to decision-making at governmental or business levels. A considerable investment in relationship building with various sectors was necessary, and the process was successful because of the willingness of participants to trust the Bioethics Council to facilitate processes that did not replicate the earlier experience of many in consultative processes.

The on-line discussion

The on-line discussion was a valuable initiative, and enabled dialogue in a way that the more traditional submissions do not. There was an exchange and development of ideas through the six weeks, and significant numbers of people 'listened in' to the conversation. People presented their views strongly, but with respect for others.

The public meetings

The on-line discussion was well supported, in contrast to the publicly advertised meeting, which was not well attended. This may reflect the history of the debates around genetic modification - there are fewer opportunities to explain that an event is dialogue rather than advocacy when one is relying on public advertising rather than direct invitation.

The submissions

The submissions process, although lacking any sense of conversation, was valuable for the Council to hear the views expressed, and the extent to which similar issues were highlighted by submitters and participants in more interactive processes. However, we recognise that, unlike an interactive process, the submissions process gives no opportunity for submitters to develop their thinking as they hear from others with different approaches to the issues.

The information sources

People were keen to have opportunities to develop their understanding of the issues. The material the Council produced was distributed widely. The initial essays from various interested parties were well read by some who participated in the dialogue events. The pamphlet on *Whakapapa and the Human Gene* was well received, the discussion document widely circulated, and there was stimulating discussion on the on-line discussion. We noted that people choose their sources of information with care, and select where they put their trust. There will continue to be a need for more information, including information presented in trustworthy and culturally appropriate ways.

Setting the stage

The Council has had a number of indications that the influence of the project has extended outside the immediate circle of participants. The essays have been promoted (e.g., to science teachers), and participants talked of taking the issues back to their communities and of drawing others into the dialogue process. Various media stories (e.g., in the *Listener*) have profiled the issues to others.

The Council has established itself with a range of communities in New Zealand, and built an initial network of contacts. This is a good starting point, and it looks forward to extending the dialogue into other sectors, including the business world.

Finally, it should be noted that the process of public dialogue is resource intensive. Considerable time is required to build the relationships and credibility required, to develop a project plan and discussion materials, and to contract facilitation and communication teams. This all takes considerable investment of skills as well as secretariat and financial resources. (See below for further discussion and recommendations on resource requirements.)

Benefits of dialogue

The Bioethics Council's approach to dialogue enabled the identification and exploration of the complex issues associated with the cultural, ethical and spiritual dimensions of the use of human genes in other organisms (as discussed in Sections 3 and 4).

In addition, the Bioethics Council recognises two other key benefits of the public dialogue - benefits that will be of on-going value. A different quality of conversation about biotechnology became possible, and the project has developed relationships and understandings that will contribute to future conversations about biotechnologies with cultural, ethical and spiritual dimensions.

The quality of conversation

Conversations about the cultural, ethical and spiritual dimensions of biotechnology have often been fraught and confrontational. There have been strong advocates for particular positions, and the issues have often been the focus of adversarial political and regulatory processes. Such contexts are a key part of New Zealand political life, but rarely function to build understanding across cultural and political divides.

What a *dialogue* process was able to achieve, and add to the social mix, was the creation of social situations that enabled a different quality of conversation. In part this was because there was no need to defend a position, and no immediate case-by-case decision that rested on the outcome of the conversation. People were able to put their concerns on the table, to propose some responses or questions, and to enquire about the positions of others without any climate of attack. It was possible to explore new ideas and approaches, to try ideas on for size.

In such a context it was possible for people to acknowledge the values of other's views and perspectives, to hear the challenges to their own positions, and to think about the issues differently.

The Council observed a very positive response from most participants to such a context. People embraced the opportunity to explore complex ideas in a respectful and open manner.

There is enormous value in such situations for a participatory approach to democracy. In the context of biotechnology, citizens are more than consumers of the products, or voters at elections. We observed a strong desire to participate in identifying and exploring the values, perspectives and relationships that underlie government policy on particular issues. We also observed an expectation that this is an appropriate role for a citizen in a democracy.

The development of relationships and future capacity

Emerging biotechnologies are likely to continue to raise cultural, ethical and spiritual issues. There will continue to be challenging conversations and difficult decisions to be made by government and regulatory authorities.

The Bioethics Council believes that the experiences of dialogue will make a significant contribution to those future conversations.

- Relationships have been established across some divisions. People with quite opposing views now know each other as people rather than as symbols of those with whom they disagree. Having experienced respectful dialogue, they know it is possible to have constructive conversations together.
- Most participants were able to experience a respectful dialogue where hard issues were raised, and ideas were able to be explored. Respect did not have to be sacrificed to rigour. This experience and knowledge will be taken to other discussions and situations. People will know there are alternatives to confrontation and aggression, which had previously sidelined many from participation.

These learnings about the importance of relationship-building and experience of respectful dialogue need not be confined to issues associated with biotechnology. The Council would suggest they are also significant in other areas where there are widely divergent views and/or a history of conflict.

Resource requirements

Public dialogue does require a significant investment of time, energy and financial resources.

As a new organisation, the Council needed to develop its own profile and build relationships and credibility with a wide range of communities and interested groups. This took time, and will require a continuing investment of effort. We plan, in future projects, to build on the networks and relationships we have established.

The practicalities of a public dialogue process cannot be implemented overnight. It requires a considerable investment of time and expertise in preparing the resources, and it takes time to create and promote opportunities for public dialogue. The processes of dialogue require skilled facilitators, especially where there is a history of conflict. A large amount of time was required of Council members, particularly the members of the working group, and the secretariat needed to employ additional capacity.

We believe the investment in such work is a prudent one. Many of the conversations around cultural, ethical and spiritual issues are difficult - they raise challenging intellectual questions as well as passionate opinions - and they will continue to question approaches to policy that reduce issues to technical decisions. Many people expect their involvement in these conversations to be as citizens, not just as consumers. They expect the diversity of values and perspectives of the community to influence policy.

Some emerging technologies have the potential to be as controversial as any aspect of genetic modification. It will be helpful to government decision-making to have not only a well-informed community, but one where there are established and respectful relationships between those who disagree or approach the issues in different ways - and where people know that respectful dialogue is possible.

Therefore the Bioethics Council recommends that:

The Minister notes the many benefits delivered by the dialogue process, which:

- Developed constructive relationships between people with opposing viewpoints.
- Revealed the subtlety, complexity and nuances of New Zealander's thinking around biotechnology.
- Provided opportunities to test and develop people's thinking.

The Minister notes the resources of time and expertise required to achieve such benefits.

Summary of recommendations

The Bioethics Council supports the recommendations 7.5 and 7.6 of the Royal Commission on Genetic Modification:

- That wherever possible, non-food animals, or animals less likely to find their way into the food chain, be used as bioreactors rather than animals that are a common source of food.
- That, wherever possible synthetic genes or mammalian homologues of human genes are used in transgenic animals to avoid the use of genes directly derived from humans.

The Bioethics Council

- Recommends that genetic (and other) manipulations that intend to produce social or mental capacities in animals that are recognisably human-like, or produce significant morphological changes in life forms to make them more similar to human life forms should not be pursued.
- Recommends there be ethical review of those interventions on gametes, or mammalian foetus or avian or reptilian young in the first half of gestation or development, that may place a burden of suffering on resulting organisms, in the second half of gestation or development, or once born or hatched.
- Recommends that Government establish a mechanism in legislation for a Minister of the Crown (such as in Health, Environment, Research Science and Technology, or Agriculture and Forestry) to instruct the Bioethics Council to give high priority to developing advice on the cultural, ethical and spiritual dimensions of an emerging biotechnology. Such a mechanism would:
 - Provide time and resources for a public dialogue on the relevant issues, the development of a public position, and where necessary a regulatory position, responsive to the views of the wider community.
 - Be able to cater for technological developments not envisaged within current legislation and for those situations where case by case consideration is not appropriate.
 - Function to progress cultural, ethical and spiritual considerations in a timely fashion in order that the research and business community can be given clarity about what developments it is acceptable/unacceptable to pursue or utilise in New Zealand.
- Recommends that Government instigates research into the public perceptions of science and the role of commerce, and the influence of commercialisation of science on the practice of science.
- Recommends that Government resources an appropriate organisation such as the Royal Society to promote a public conversation about the role of commerce in science, and the contribution of science to the common good.
- Recommends that the Minister notes the many benefits delivered by the dialogue process that: developed constructive relationships between people with opposing viewpoints; revealed the subtlety, complexity and nuances of New Zealander's thinking around biotechnology; and provided opportunities to test and develop people's thinking.

Membership of the Bioethics Council

- **Sir Paul Reeves - Chair - December 2002 to May 2004**
- **Jill White - Chair - From May 2004**
Former MP, former Mayor of Palmerston North and former Chair of the Environmental Risk Management Authority (ERMA).
- **Dr Helen Bichan**, a medical practitioner with specialist qualifications in psychological medicine and in public health, has considerable experience in the health services, most recently with community participation in health issues.
- **Eamon Daly**, an independent researcher and PhD candidate in information technology ethics, and information privacy issues.
- **Anne Dickinson**, Executive Officer of the New Zealand Catholic Bishops Conference and final chair of the disestablished Independent Biotechnology Advisory Council (IBAC).
- **Dr Gary Raumatī Hook - December 2002 to May 2004**
An experienced scientific researcher who trained as a biochemist. CEO at Te Whare Wananga o Awanuiarangi in Whakatane where he also teaches environmental studies. A board member of the Foundation for Research, Science and Technology.
- **Professor Sidney Hirini Mead**, (Ngati Awa, Ngati Pahipoto) appointed by the Bioethics Council as Kaumatua in December 2002. An eminent kaumatua, scholar and expert in Tikanga Maori.
- **Waiora Port**, (Te Aupouri [Ngati Pinaki], Te Rarawa [Ngati Maroki]), a respected kuia with long-standing community knowledge of Maori health issues. A PhD candidate investigating the cultural and spiritual issues around DNA testing for Maori with a genetic predisposition to cancer.
- **Graham Robertson**, a self-employed farmer and a former member of the Independent Biotechnology Advisory Council (IBAC).
- **Professor Ian Shirley**, Professor of Public and Social Policy, Auckland University of Technology.
- **Dr Martin Wilkinson**, a senior lecturer in Community Health and Philosophy at the Auckland School of Medicine.