



**National Council of
Women of New Zealand**

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Wahine O Aotearoa

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**Submission to Toi Te Taiao: the Bioethics Council
on Human Genes in Other Organisms**

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 42 nationally organised societies. It has 33 branches throughout the country attended by representatives of those societies and some 150 other societies. The Council's function is to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ has a longstanding history of encouraging the promotion of social and health issues, particularly as they affect women.

Members of the Health Standing Committee, Branch members and other interested parties were asked for their input into this document. The following is a summary of their comments.

General Comments

This issue has generated more responses from branches, member organisations, individuals and members of the Health Standing Committee than any other issue considered by the Health Standing Committee in the last 2 years. Further, some groups and individuals wrote at considerable length on the issues raised. It was clear that some groups and individuals hold very strong and sometimes emotive views on the subject of gene transfer. It was also clear that there were disparate views and it was not possible to formulate a coherent and unanimous response. This probably reflects the widely differing views on this subject in the community.

A wide range of comments were made about the acceptability of gene transfer. At one end of the spectrum some felt that it was like playing God and the idea was absolutely abhorrent. Others, however, thought that it was acceptable with the proviso that its primary purpose was to benefit all mankind and that it was carried out under strict controls.

Some respondents stated that as New Zealand is a secular state, decisions on the issue of gene transfer must not be based primarily on religion or spirituality. An important minority of New Zealanders maintain that 'whakapapa respects the relationships between generations' and 'transferring human genes into non-humans could disturb these connections and threaten the mauri of both the human and the non-human'. However, the majority of New Zealanders probably do not subscribe to this view. Many do not see the transfer of a 'human' gene to another species as lessening our 'humanness' or having a substantial effect on the 'humanness' of the target species. This is not to say that they necessarily agreed that gene transfer was acceptable. Comment was made that those who strongly believed that gene transfer was unacceptable still retained the right to choose i.e. they would refuse treatment where the treatment involved the use of any products produced as the result of gene transfer. This could pose some difficulties for diabetics, for example.

A respondent submitted a written report from a public meeting held in South Auckland in February 2004. The following are comments from that report. Maori voiced strong views on the subject of





gene transfer. They were interested in the topic and believed that access to resources and education on these matters was desperately needed.

They were highly critical of the lack feedback following consultation, especially from the Royal Commission for Genetic Modification. Comments made included:

- “We were patronised.”
- “They said we will set up a Bioethics Council, but we will continue to do GE research.”
- “We have been down this track and we have never been listened to.”
- “The government acknowledged us and then ignored us.”

Maori also expressed concern that it was another case of the majority dictating to the minority about an important issue. Comments made included:

- “On the one hand they say you are sick and this is the medicine and only we know what’s good for you.”
- “I think they are naïve if they assume that we are naïve.”
- “We have come halfway with them; they have not even tried to meet us there.”

Further it was suggested that proponents of the technology should re-examine the economics of the so-called benefits of the technology. The perception is that large sums of money are spent on intervention rather than prevention. There was a suggestion the money would be better spent on addressing the poverty of Maori.

Although some Maori expressed strong views against experimentation in this field and gene transfer, others clearly expressed reserved approval. In general they wanted more information and assurances of rigorous controls, transparency and accountability. In particular they wanted information on the scientific rationale for genetic experiments and gene transfer. They also wanted information on how such work would benefit Maori.

In contrast there were a number of respondents who felt very strongly that Maori should receive no more consideration than people of other cultures, races or belief systems. As one respondent put it, “There is no room for Treaty obligations in this debate.”

Several respondents stated that human life has an intrinsic or innate dignity. Although humans are perceived by many as being at the top of the evolutionary tree, this does not mean that we can simply do as we please. Rather, we should aim to live in harmony and treat other animal forms with respect and dignity.

Specific Comments

What is special or unique about being human?

NCWNZ believes that this was an overly open ended question. It would have been helpful to direct it more in terms of the field to which it is being applied.

An overwhelming number of respondents chose to answer this question in biblical terms, e.g. man was created in the image of God and given dominion over all other creations; man has a soul while other species do not, etc. The answers given often depended on whether the individuals or groups believed in a Creationist or Evolutionary Theory. Not all of these respondents answered the subsequent questions in a manner consistent with their answer to this question. Some believed, for example, that the greater good of humanity was more important than their own spiritual or cultural beliefs.



Other characteristics listed by respondents included:

- Higher level of intellect
- Language/highly articulate speech
- Use of tools
- Able to plan and evaluate consequences
- Conscience
- Self-will and the ability to make choices
- An ability to reason
- Able to organise and think outside the square
- Humans have an ability to adapt nature to their needs.
- Self-awareness
- Imagination and creative ability
- Art, culture, music, religion
- Emotions
- Wearing of clothes
- Mastery over the environment
- An ability to adapt rapidly to environmental change
- Ability to wantonly destroy the environment
- Abstract thought e.g. an ability to reflect on the meaning of existence
- While numbers of animals share higher skills human beings have a larger range of skills
- Human beings have a prolonged nurturing of their young
- Mammals produce milk suitable for their own young, i.e. species specific
- An understanding of who we are and our place in our family lineage
- Human beings do not have a mating season
- Humans have the ability to think, communicate by a variety of means, act, learn, record history do research, care for others, work for the good of mankind and our environment, be selfless.
- Humans are special and unique because we can exercise freewill, maintain focus on abstracts, goal set, be creative and express ourselves in a very sophisticated manner verbally and in written form.

Most respondents accepted that humans shared many genes with other species. Indeed, direct comparisons show that coding sequences differ by only 1.2% from those in chimpanzees. Despite this, some respondents believed that it was the specific pattern of genes in the human genome that was unique to our species.

The traditional view of geneticists was that species differences could be explained by gene variation. However, comparisons have not borne this out. There is growing evidence to suggest that the differences might occur in the regions of DNA that do not code for proteins, in particular the *cis*-regulatory sequences. These are areas of the genome that interact with transcription factors to regulate when, where and how much a gene is expressed.

This supports the notion that most genes in the human genome are not unique to humans i.e. there are very few truly 'human genes'. What may be unique, however, is the way that most genes are regulated. Clearly the *cis*-regulatory portions of the genome are particularly important and some respondents urged caution in experimenting or transferring these portions of the genome without more understanding of how they operate.



What sorts of values and beliefs are important when thinking about the transfer of human genes?

The one thing that is common to all human groups is the belief in a 'creation story'. The noted anthropologist Margaret Mead stated that every culture she has ever encountered "had a creation myth". Each had a unique story that explained how things came into being and how humans fit into the scheme of things. Any discussion of bioethics is influenced by our own creation story. Some cultures believe that "earth does not belong to man, man belongs to the earth; all things are connected like the blood that unites one family; whatever befalls the earth is precious to God, the Great Spirit: and to harm the earth is to heap contempt on its Creator." It therefore follows that 'improving' on creation is "insane, sacrilegious and ultimately suicidal." However, many individuals of European descent do not subscribe to these views and the strictures they would impose.

A number of respondents thought it important that we believe in the inherent dignity of the human person and that we are also committed to uphold the dignity of the whole of created order. Further, they believed that it was vital to protect the biodiversity of this created order.

The value of our unique environment must also be considered. It was suggested that a cautious approach must be followed to prevent long-term repercussions, e.g. DDT and overuse of antibiotics. Respondents urged that we make haste slowly in implementing research outcomes to ensure that no unforeseen problems emerge.

Many respondents felt that the motivation for research and possible transfer of genes was important. Some opposed experimentation for the sake of experimentation while others believed that it was important that we gained a better understanding of gene function through controlled experiments. Some expressed a strong view that genes should not be transferred into animals simply to create a 'different' or more 'sophisticated' species. Many agreed that the transfer of genes into animals would be more acceptable if it was clear that the motivation was to assist those with incurable, fatal or debilitating disease. They felt it was essential that an identifiable benefit be demonstrated before such work was sanctioned.

Some expressed a desire to maintain an openness of dialogue wherever possible and to allow time and opportunity for those who wish to adjust to new frameworks of understanding; respect the desire of scientists, especially those with humanitarian motivation, to explore, but maintain controls to prevent exploitation; and ensure that those who violently oppose are contained.

Most respondents agreed that the ethical issues were particularly important. Some believed that spiritual issues were also important. However, this was not universally accepted. Comment was made that it is estimated that at least 50% of people have no spiritual or religious beliefs at all. Cultural beliefs and viewpoints are important to many but obviously vary within communities so the likelihood of agreement on anything is minimal, someone will always object. Opinions will change over time as each group alters, intermarries and matures, etc.

Who should make the decisions?

There was no clear consensus on who should make decisions on gene transfer or on how the decision should be made. There were, however, some common themes.

In general, most respondents supported the use of ethics committees to evaluate proposals and make decisions. It was generally agreed that each application should be reviewed and evaluated on a case-by-case basis. Several respondents suggested that such committees should be regionally based, however, this was not acceptable to all. It was stressed by some that local committees should not make decisions on their own. These respondents felt that there must be national guidelines and that the decision making process must be seen as being applied



consistently on a national basis. It was stressed by many that such committees must be seen as independent. Considerable disquiet was expressed about the possible involvement in the decision making process of any person, organisation or company likely to benefit financially from any decision. Some respondents went further and suggested that parliamentarians, scientists and commercial interests should not be involved in making the decisions. In contrast, others indicated they were comfortable with scientists being involved in the process but only in conjunction with public consultation.

Respondents stated that it was vital that careful consideration be given to the composition of the panel(s). It was seen as essential that the public have confidence in the impartiality and competence of the panel(s). There were a variety of suggestions as to the composition of any panel(s). They included representatives from the following groups:

- Major religions
- Lawyers
- Scientists
- Medical ethicists
- Other major cultural groups
- Lay members of the public

There was some opposition to the inclusion of either scientists or doctors on any such committee. However, the majority seemed to agree that some members of the committee should be experts in matters ethical, cultural, spiritual and scientific.

There was a suggestion that there should be a 2-step process. An Ethics Committee should oversee the committee hearing submissions, holding public consultations and making decisions/recommendations.

There was substantial support for the view that we should all be involved in making moral decisions on issues as important as this. This was expressed in a number of ways, including:

- Election of representatives to Ethics Committees
- Public consultation
- Community input

It was pointed out that the public could only participate in a meaningful way if they were adequately informed. Thus it is essential that the public be given the opportunity to become well informed.

Many respondents thought that any committee making decisions on gene transfer should operate within clear guidelines, be held accountable, be required to report their findings/decisions and that their findings/decisions should be open to review. It was also clear that respondents thought it vital that all decisions be open to public scrutiny before they were finalised. The issue of how such a process would operate and how it would be funded needs to be addressed.

Comment was made that it was important that feedback was available to the public. Scientists could do a much better job of 'selling' their research to the public by ensuring that information was available in a user-friendly form that was also readily accessible. This could help avert the bad press that follows the release of a 'sensational' story e.g. 'toads in potatoes'. It was recognised that the media have a role to play in ensuring the public are well informed. They must be responsible and provide a balanced view of the use of this technology rather than merely sensationalising it.

**What factors should we think about when deciding if transfer of genes is acceptable?**

A wide range of factors were identified, including:

- Safety
- Balance of advantages and disadvantages
- Sound scientific rationale
- The integrity of the research - taking into account the reputations of the scientists involved and of the institution
- Not weakening the human gene pool or unduly strengthening the plant/animal gene pool i.e. not disturbing the current balance.
- Stringent risk analysis i.e. risks/benefits
- The purpose of any gene transfer
- Whether the proposed work is ethical
- Whether there is an identifiable benefit e.g. 'cure' a disease, improve quality of life
- Who benefits from any gene transfer e.g. 'big business', sick humans
- Cost/benefit
- Side effects
- Consideration should be given as to whether the transfer of genes is the wisest use of limited research funds. The money might be better spent on other forms of research to improve the health of more people.
- The common good

What other factors that should be taken into consideration?

The following diverse suggestions were made:

A major problem is the lack of knowledge and understanding of the science by many. Consideration should be given to providing information to the public about the scientific and ethical issues in an easily understood form. Careful thought needs to be given to how this information is provided and by whom. The public must trust the provider who must be seen as an independent source of information i.e. not captured by any group with specific interests in the issue, particularly commercial enterprises.

Consideration should be given to the drafting of laws that protect us from unethical use of scientific knowledge. Concern was also expressed about human greed and whether regulatory requirements would ever be sufficient to prevent unethical behaviour by commercial interests.

All procedures need to be strictly controlled and audited to prevent sabotage and/or unethical procedures. The scientific community must keep an eye on what is happening. There must be transparency and accountability. Money and funding always helps with this.

If human genes were to be transferred into other species in order to study disease, those animals must be kept in a containment facility. They should not be able to reproduce, escape the containment facility or enter the food chain.

Concern was expressed that this technology would likely be expensive and access to it should not be restricted to those able to pay for it. Rather, access to the benefits of this technology should be based solely on need and the likely benefits for the patient.

Human genes transferred into cows may have a potential for good in the management of some diseases through proteins produced in the milk. However, some expressed disquiet that such gene transfers could further reduce levels of breastfeeding. Any reduction in the level of breastfeeding has devastating effects on nutrition, well-being and fertility for women especially in



colonised countries. The World Health Organisation strongly advocates against cross species lactation in order to support breastfeeding.

Some held strong views that if this technology could be used to 'cure' or prevent diseases, then no one had the right to prevent its development. Moral, spiritual or cultural idealists should not be able to block appropriately controlled research and regulated application of those research findings.

Comment was made that a lot of medical things are 'gross' but that does not make them wrong. The example of the production and use of insulin for the treatment of diabetes has been accepted for years and works well and safely. It can be said to be a forerunner for the furtherance of alternative uses of human genes to effect treatment of/for people.

Concluding remarks

Many respondents appeared to oppose carrying out experiments merely for 'curiosity sake'. However, this ignores the fact that many major advances in science have been serendipitous. Most scientists would argue that 'safety' would be improved by increased research activity in understanding fundamental issues such as gene regulation. Such research might be perceived by some as being carried out purely for 'curiosity sake' because there might be no obvious or immediate application. This does not mean, however, that the research is unimportant or that it should not be carried out.

Some respondents demanded guarantees of safe outcomes from research and gene transfers. They seem to believe that the issues are black and white. Guarantees cannot be given as there will always be some element of risk. This should not necessarily mean that the research should not proceed. Rather, the important issue is that an appropriate risk analysis is carried out and that the work only proceeds if the risks are outweighed by significant benefits.

Strong objections were voiced by many respondents about the potential involvement of 'big business' and the possibility that they might profit from the commercialisation of this technology. However, this ignores the reality that the only substantial funding sources available for this work are the Government, investors (providing venture capital) and 'big business'. If there is no return on investment the funding simply won't be available. The important issues are that profits remain reasonable and that the fruits of this technology are not denied to many because of cost.

Only one respondent acknowledged the importance of issues relating to the management of intellectual property. Most respondents expressed a wish to have access to information about proposed research work and the research outcomes. Clearly much of this needs to be treated in a sensitive way so that the individuals or institution can appropriately manage the intellectual property involved. If all information is available to any who wish to access it, then the field is open to others to simply 'rip it off'. There needs to be some degree of trust between the public and the individuals or institution involved in the work so that critical intellectual property can be protected. Intellectual property rights need to be spelt out to the public, as they generally do not understand the issues. The development of partnerships and the provision of appropriate information were seen as vital.

NCWNZ thanks you for this opportunity to make comment and we look forward to viewing your findings.

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