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Bioethics in Research: the Ethics of Indigeneity

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Bioethics in Research

The Ethics of Indigeneity

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Similarities and Difference

The ethics of research involving human subjects is largely about the quality of relationships between individuals and communities who participate in the research, and the researchers. Underpinning the relationship is an expectation that the research will not offend the ethics of participants and will bring benefit to them or their families, if not in the short term then in the fullness of time. While research should do no harm, more important it should do some good. In that respect it is not enough to simply acknowledge the views of others; instead pathways that can lead to gains in health and wellbeing should be evident within research goals.

In considering the values, beliefs and world views of participants, there are ethical principles that have universal application. Avoiding unnecessary pain and suffering, respecting property, protecting the young, abiding by accepted community standards and conventions, and valuing people, are ideals that transcend race, ethnicity, culture and nationality. Universal values are held in common by many populations though the commonalities can often be masked by the differences that exist between groups.

It is also important to recognise that within groups there is likely to be a diversity of views and values. Not all New Zealanders for example believe there is a ‘New Zealand way of doing things’, nor do all Māori people hold the same views about culture, relationships or a distinctive environmental ethic. Many will be influenced by Christian principles and ethics and their views may have more in common with other Christians than with other Māori. People living in urban environments may have quite different attitudes to the natural environment than their rural cousins while the perspectives of Māori youth may well transcend race, religion and ethnicity to coincide with a global culture of youth.

Yet despite the diversity, and the universality, groups can bring a collective distinctiveness shaped by shared histories, common perspectives, settlements in a defined territory and a set of aspirations built around a widely held world view. Group distinctiveness can be manifest at several levels. Rural people, older people, nations, religions, colleagues often hold views that not only embrace their members but also distinguish the group from other groups. This paper, is primarily concerned with group distinctiveness as represented by indigenous peoples. They share sufficient characteristics to distinguish them from other populations.

Indigeneity

There are some 5000 indigenous groups around the world with a total population of at least 200 million, or around four percent of the global population. Often the essential characteristics of indigeneity are linked to socio-economic disadvantage, post-colonial marginalisation, and cultural difference from the majority. Certainly, compared to non-indigenous populations socio-economic disadvantage is often severe; and colonisation has resulted in resource alienation,

suppression of culture, and the imposition of foreign rule. A frequent outcome has been relative exclusion from wider society accompanied by higher rates of unemployment, lower standards of health and education, and lack of political voice.[1]

But despite socio-economic similarities and comparable experiences with colonisation and post-colonial development, the unifying feature of indigenous peoples has a more fundamental quality that depends on a sense of unity with the environment.[2] The individual is a part of all creation and the idea that the world or creation exists for the purpose of human domination and exploitation is absent from indigenous world-views.[3] Instead, an ecological approach based on a synergistic relationship, has not only led to careful stewardship of the environment and natural resources, but also to a way of thinking within which health and illness are conceptualised as products of relationships - between individuals and wider social networks, and between people and the natural world.

Adaptation to the natural environment was not only necessary for food and shelter but also gave definition to social groupings, tribal identity and a philosophy of environmental sustainability within which human survival unfolded.[4] Language, culture, and a distinctive system of knowledge was a by-product of the environmental experience and the bond with the land was reflected in song, custom, approaches to healing, birthing, and the rituals associated with death.[5]

Modern understandings of indigeneity, at least as they apply to research bioethics, encompass both the old and the new realities (Table 1). While the ecological orientation remains a key marker, and can be regarded as the fundamental characteristic, the economic and cultural

parameters associated with human encounters constitute another point of distinction. Meaningful engagement is more likely to occur when cultural protocols are observed and mutual benefits can be demonstrated. Indigenous communities also value a third characteristic - autonomy and independence. Where there has been loss of self determination, coupled with socio-economic disadvantage, vulnerability arises, generating potential for unequal power relationships with societal agents, including researchers.

Table 1 Three Characteristics of Contemporary Indigeneity

Ecological synergies	*Human encounters*	*Autonomy and self determination*
• Human survival is a function of ecological balance • The natural environment contributes to defining human identity	• Territory confers authority and obligation • Cultural protocols facilitate human encounters and meaningful engagement	• Socio-economic disadvantage precedes marginalisation and vulnerability with unequal power relationships • Autonomy and self determination strengthen capability and active participation.

Māori World Views

Māori experience is not dissimilar from other indigenous peoples who have become a minority in their own country. From an estimated population of 200,000 in 1800, by 1894 the Māori population had dwindled to 42,000 and was close to extinction. But within a century it had become more numerous than at any other time in history. Even though changes to statistical definitions of Māori make it difficult to draw exact comparisons, there is strong evidence of a substantial and sustained increase in the Māori population. In the 2006 census 565,329 New Zealanders identified as Māori with a median age of 22.7 years; 85 percent were classed as urban dwellers.[6]

After some decades of assimilatory policies and programmes by 1984 a positive approach to development had emerged. Māori language and culture were endorsed, Māori systems of service delivery emerged and despite an urban environment, new generations of Māori relished the opportunity to live as Maori. The introduction of Maori immersion education programmes, centred initially on early childhood education centres (Kohanga Reo) has led to a generation of young people who are fluent in both English and Māori and a resurgence in Maori language usage by both young and old.

Rangi and Papa – the Ecological Dimension

However, despite new environments and lifestyles typical of contemporary New Zealand, there remains a Māori sense of attachment to the natural environment. The attachment is often presented as a family analogy within which relationships between the elements, natural resources, and people can be conceptualised.

Rangi and Papa, the sky father and the earth mother, were locked in an embrace which precluded daylight and threatened to smother their children. However, as the offspring matured they sought greater independence and decided to assert their powers by pushing the sky away from the earth so that light could penetrate and they could realise their full potential. As a result the forests were enabled to stand tall, the ferns spread, fish multiplied, crops flourished, the earth was warmed and humankind took its place alongside trees, birds, plants, waters, and the elements. The parents remained but were forced to sacrifice intimacy so that others could thrive.

There are three points to the story. First it provides a framework within which environmental relationships can be better understood and the position of humans within a wider ecological context can be appreciated. Human privilege is constrained by responsibilities towards other players and by dependence on them. In this world view, human identity is grounded.[7] People cannot be fully understood without taking into account the natural environment which has

nurtured their ancestors through childhood and into adult life. The phrase tangata whenua captures some of the duality – people and the land - and recognises that in every region some people have longstanding bonds with the land that sets them apart from others who do not share those bonds.[8] The point is further emphasised by the concept of turangawaewae, a term linking individuals with a site or location that underpins their identity, as well as the identity of their relatives.

Second, the story of Rangi and Papa is predicated on an outward flow of energy. Underlying the world views of indigenous peoples and at the heart of indigeneity, is an 'ecological synergy spiral'. Basically about connecting relationships that are complementary and mutually reinforcing, the spiral moves from the small to the large, from individuals to groups, and from people, plants, fish and animals to the earth and the sky. It is based on an outward flow of energy, away from microscopic minutia, and towards an ever-expanding environment.[9] Ultimately the spiral moves towards the cosmos so that all objects, species, planets and stars can be incorporated in an interacting system that gives meaning and insight to existence. Within the spiral, knowledge comes from locating matter and phenomena within wider ecological contexts rather than attempting to understand and value objects and systems according only to their intrinsic component parts. The energy flow is centrifugal rather than centripetal.[10]

Third, just as people take on qualities derived from the natural environment, inanimate material objects possess a form of life, a mauri, which both distinguishes them (from other objects) but also unites them within a wider network of entities. Stone for instance, cannot be fully understood without recognising the wider environment within which it lies. In an indigenous world objects that appear to be inanimate are not regarded as lifeless or static since they also possess an identity of their own and are part of a wider network. Belonging to that network creates a vibrant relationship that is at odds with the view that motionless objects lack life. In the language of global warming and climate change, so-called inert objects may well have carbon credits that ultimately add to the world's equilibrium. There are energy chains within, and dynamic relationships beyond.

Human Encounters

While humans have close and synergistic relationships with the wider natural environment, land also provides a basis for protocols which guide relationships between groups. Formal exchanges, such as occur on marae (tribal meeting places), are premised on the relative roles of tangata whenua (belonging to a particular land-based territory) and manuhiri (visitors to that site).[11] Marae encounters demonstrate the distinctive psychological and behavioural activities that occur when discussions between groups commence.[12] Essentially those discussions are about negotiating relationships according to an accepted cultural format (or kawa - a consistent way of engaging in discussions). The terms of engagement are scoped in a series of speeches but are only implemented if there is general agreement.

Marae encounters also provide space and time to assess compatibility and to determine the extent of any risk. Risks do not necessarily mean that a relationship cannot continue, but they sound cautionary notes. On the other hand an encounter is more likely to have a good outcome if mutual benefits are on the agenda, agreement is reached about the terms, and when a koha (in modern times a monetary donation) is given and then accepted, a commitment to a long term relationship is made.

Autonomy and Self Determination

Vulnerability, an all-too-often marker of indigeneity in contemporary times, occurs when an indigenous population is excluded from full participation in wider society. Where colonisation has occurred, either through the aegis of a Treaty (the Treaty of Waitangi for Maori) or by sheer

force, indigenous alienation from traditional resources including language and culture has usually occurred. Loss of voice and political power has been an inevitable sequel.
Much Maori effort is directed towards regaining autonomy so that matters involving indigenous people can be decided by indigenous decision-makers. This quest for self determination has been especially evident in the provision of services to Maori (health, education, social services), the governance of Maori resources including land, fish, forests as well as intellectual resources such as language, and the management of tribal affairs.

While absolute autonomy is neither realistic nor desirable in a nation where inter-dependencies are important, and where economies of scale largely dictate the options, the underlying principle advanced by Maori is that Maori roles in decision-making should be afforded priority where those decisions concern Maori people, resources, or intellectual property.

Implications for Research Bioethics

Arising from the three characteristics of indigeneity – ecological ties, human encounters, autonomy and self determination – it is possible to identify three major ethical domains: eco-connectedness, engagement, empowerment (Table 2).

Table 2 Ethical Domains and Indigenous Characteristics

Indigenous Characteristics	*Ethical domains*
Ecological ties	The ethics of eco-connectedness
Human encounters	The ethics of engagement

Autonomy and self determination	The ethics of empowerment

The Ethics of Eco-connectedness

In a Maori world view it is not possible to understand the human situation without recourse to the wider ecological environment.[13] The impacts of research on humans cannot be considered in isolation of intended or unintended consequential impacts on the environment. A number of ethical issues therefore require consideration by researchers. An important one is linked to the effect a project may have on environmental equilibrium especially in modern times, the acceleration of climate change. Even if the aim of the research is exclusively focused on human subjects and does not have an explicit environmental impact, consideration still needs to be given, for example, to the levels of carbon emissions generated during the research and how they might be minimised. Moreover the methods by which humans adapt to their environment and manage environmental risks are matters that merit attention. An investigation into the ways in which the cells of Maori diabetics handle insulin, for example, should not be divorced from the wider question of how Maori handle contemporary food environments.

An equally challenging set of ethical questions revolve around the unique characteristics of species. Because all objects have a 'mauri', they possess an integrity that distinguishes them from other objects. Consequently many Maori have serious objections to procedures involving xenotransplantation.[14] Human integrity is compromised when the mauri from one species is introduced into another. In that view, in addition to any health risks or physical imbalances, cultural offence results from a mixing of genes between species and the generation of metaphysical imbalance.'[15] The debate is not necessarily about the sacredness of humankind but

about the uniqueness of all species and the dynamic relationships that have developed between them over time.

On the other hand, an important consideration for Maori, in the past and equally in modern times is about survival and the quality of survival. Human behaviour often revolves around ensuring that future generations will be secure and continuity of whakapapa (genealogical lines) will be guaranteed. Many of the customs that evolved after Maori reached Aotearoa 1000 years ago were geared towards survival even if they jeopardised the lives of others. Warfare between tribes over territories and associated resources resulted in extensive loss of life and there were instances where children were sacrificed least they cried and betrayed the whereabouts of a party intent on escape from an enemy. Further, early accounts of cannibalism often associated eating the organs of a captive (especially the heart) with gaining power from the victim so that the tribal superiority could be retained, both literally and symbolically. When group survival is under threat, the ends appear to justify the means.

Assisted reproductive technologies and organ transplants are sometimes seen as antithetical to Maori custom because they offend the 'principles of nature'. However, when the ethical focus shifts from attention to cellular details to the wider question of human survival, the debate takes on new dimensions.[16] Where family continuity is threatened, a new balancing point is introduced between what is 'natural' and what is possible. The balancing point is shifted even further when there are questions about survival of the tribe, or even the quality of survival of the whole population.

The possibility that diabetes will pose a threat to Maori survival for example was raised at the International Diabetes Federation's, 'Diabetes in Indigenous People' Forum in Melbourne in November 2006. Professor Zimmet from the International Diabetes Institute provided

convincing evidence that diabetes had become a major and deadly threat to the continued existence of some indigenous communities throughout the world as a result of western lifestyles and diet. Media reports in New Zealand concluded that unchecked, the diabetes problem could lead to Maori becoming extinct. Even though the claim was extravagant, the case for reinforcing human pancreatic tissue with tissue from other species takes on a new meaning when population survival rather than individual relief is the objective.

The Ethics of Engagement

Engagement with Maori for research purposes is more likely to be effective when the terms of coming together are clear and when the accepted protocols for encounter have been met. The process requires time and space and is more likely to be successful when it is aimed at relationship building rather than recruitment of subjects. Preliminary discussions with community leaders may uncover impediments or potential difficulties but may also alert communities to the benefits, thereby increasing engagement with individuals and families. Moreover, there may be expectations that the relationship will continue long after the research has been completed.

The ethics of engagement are essentially based on the development of a relationship that enhances the standing of both parties. Although Maori have often felt used and taken for granted by researchers there are instances where benefits to Maori partners have extended beyond those intended in the initial research proposal.[17] The involvement of University researchers with an extended Maori family prone to hereditary diffuse gastric cancer for example, led to ongoing close and mutually supportive relationships between the research team and the whānau community.[18]

Integral to developing a positive research relationship is the need for clarity about the purpose of engagement. There are distinctions between gaining the views of a sample of Maori and gaining views about indigeneity. Not all Maori will be familiar with an underlying indigenous world view and in any event in most interview contexts they will be inclined to give a personal perspective, especially if the issue is related to personal health. Articulation of an indigenous perspective is more likely to come from a panel of 'experts'. In much the same way a religious view might be expected to come from religious authorities rather than from those whose connection to a religion is simply based on a nominal affiliation.

The ethics of empowerment

Indigenous answers to disadvantage and vulnerability emphasise the empowerment of tribes, communities and families. Opportunities for empowerment occur across various phases of research. First, since it is a prelude to entering into a relationship, giving consent provides a space for an exchange of information, not only about the details of the research but also about the impacts of the research beyond human subjects and over a long period of time. Knowledge is power and researchers should be able to provide relevant information in ways that make sense to participants and lead to a state of enlightenment, rather than to mystification or confusion.

Second active participation in research should not be confused with being an object of research. Maori are interested in research design, the choice of methodology, protocols for involving others, and procedures for engagement with Maori individuals as well as Maori communities. Active partnership is more empowering than passive participation. Moreover, engaging Maori as

researchers and providing opportunities for Maori researchers to increase their knowledge and skills either through the acquisition of formal academic qualifications or working alongside experienced researchers will contribute to capability building, self determination and greater autonomy.[19]

Third, the role of Maori as guardians of research is a further step towards empowerment. Kaitiakitanga - guardianship – includes monitoring the integrity of the research process, and ensuring that stories, samples, and data obtained from Maori participants are protected and managed with both respect and care. A frequent concern of Maori is that the ownership of their contributions to research will be lost and that others will benefit at their expense.[20] The alienation of intellectual property, whether tribal and family narratives or detailed personal records, or the use of bodily samples for undisclosed purposes have occurred frequently enough to justify the appointment of Maori leaders as guardians of process and data.

During a national nutrition survey for example a Maori advisory group (the kaitiaki group) made up of eight elders, was appointed to assist the research team. The elders recommended changes to the research protocols by extending the food frequency questionnaire to include foods that had some special cultural value to Maori. In addition, two elders were designated as spiritual guardians for the blood and urine samples. They travelled with the specimens to the laboratories and once analyses were completed, they oversaw the burial of blood and urine remnants in the earth. In this way, the beliefs of participants were endorsed and anxieties about future misuse of bodily fluids were minimised.[21]

Maori advisory committees can also provide advice on an appropriate process for the dissemination of research findings so that indigenous communities are empowered, rather than disempowered. They can also assist in determining who might have access to research data and under what circumstances. Protocols for Maori guardianship of process and data were

successfully instituted during the national mental health prevalence study that involved large numbers of Maori participants.[22]

An Indigenous Bioethics Framework

Building on the characteristics of indigeneity a framework for considering indigenous bioethics can be constructed (Table 3).

Table 3 Indigenous Bioethics Framework

Ethical Domains	Ethical Principles	Ethical Outcomes
Eco-connectedness	• Mauri ake (Integrity of species) • Tangata whenua (People& environment) • Matatu (Endurance)	• Integrity of ecological systems • Balanced relationships between • people & environment • Resource sustainability
Engagement	• Kawa-a-iwi (Procedural certainty) • Koha (Reciprocity) • Whakamarama (Enlightenment)	• Human dignity, safety & vitality • Mutual regard • Gains for future generations
Empowerment	• Rangatiratanga (Retained authority) • Kaitiakitanga (Guardianship) • Whakamana (Capability)	• Guardianship of data & processes • Research partnerships • Increased research capability • Benefits from research

The framework is made up of ethical domains, ethical principles, and ethical outcomes. Ethical principles reflect indigenous values and world views. Arising from the ethics of eco-

connectedness are the principles of species integrity (the mauri principle), the human-environment continuum (the tangata whenua principle) and the principle of endurance (matatu). Principles relating to human encounters include procedural certainty (kawa-a-iwi), reciprocity (koha) and enlightenment while from the domain of empowerment, the key principles are retained authority (rangatiratanga), guardianship (kaitiakitanga) and capability (whakamana).

A third component of the framework comprises outcomes that might result from the application of ethical principles. For example outcomes associated with the ethics of eco-connectedness include the retention of the integrity of ecological systems, balanced relationships between people and the environment and resource sustainability. Emerging from the ethics of engagement, outcomes that can be expected relate to the preservation of human dignity, safety and vitality, as well as positive mutual regard, and gains for future generations. Finally empowerment can lead to secure guardianship of data, samples and research processes, research partnerships, increased research capability and ultimately discernable benefits from the research.

Promoting ethically sound research

Because it accords with local custom and perspectives, research which is conducted within an ethical framework is more likely to be accepted by communities and families and therefore more likely to lead to better outcomes. But the promotion of ethically sound research that recognises and endorses indigenous world views requires an active commitment of both researchers and research agencies to high ethical standards. Importantly, quite apart from possessing knowledge

about Maori cultural beliefs or the beliefs of other indigenous populations, researchers often carry attitudes which belie that knowledge. For many, ethical compliance is regarded as an intrusion on time, finances, and even academic freedom. What may not be appreciated is the opportunity to extend understanding by establishing links with people who bring other world views and other systems of knowledge to the research programme.

Similarly an undue focus on methodological issues, with increasing attention to smaller facets of the research at the expense of a bigger picture may fail to engage Maori minds because it focuses downwards and inwards (centripetal) rather than upwards and outwards (centrifugal). The intent of the research and its significance may be lost in the detail. At another level researchers who set out to recruit Maori subjects may be less successful than those who wish to foster active participation within a climate of partnership. Recruitment provides less opportunity for empowerment and engagement than a relationship where the agenda is a not already prescribed. By the same token, cursory consultation, as opposed to building a relationship based on trust and mutual interests may be a deterrent to active involvement.

Researchers will be much concerned with scientific merit, but Maori communities may be more interested in indigenous gain and contributions to indigenous advancement. Whether the findings are accepted in a prestigious journal or are the subject of a conference presentation will hold less attraction than whether they can be translated into demonstrable benefits and inform an indigenous body of knowledge. Researchers who are ready to complement enthusiasm for

scientific merit with enthusiasm for conventional indigenous ways of knowing, will encounter greater willingness for collaboration.

But rather than placing the onus on researchers to initiate protocols with Maori, recommendations have also been made that institutions involved in research should develop ethical procedures and clear guidelines to assist researchers and reduce the responsibilities on them.[23]

Indigenising Ethical Standards and Protocols.

During the past two decades there have been positive responses to indigenous concerns about research ethics. In Canada for example the Institute for Aboriginal Peoples' Health, in association with the Canadian Institutes of Health Research has produced ethical guidelines for health research involving aboriginal people.[24] In New Zealand, Maori participation in research and research ethics has been evident for more than two decades and owes much to the provision in the Health Research Council Act 1990 for the establishment of a Maori Health Committee. By 1993 two university-based Maori health research centres had been developed and four others were subsequently established.

Maori representation on health ethics committees is now the rule rather than the exception and two research funders, the Health Research Council and the Foundation for Research Science and Technology have similarly recognized an indigenous dimension that warrants a tailored approach to research.

In *Guidelines for Researchers working with Maori* the Health Research Council has identified a number of factors that will enhance the engagement process including the appropriate use of Maori language, the appointment of Maori advisory groups, regard for the principles of the treaty of Waitangi, especially the principle of participation, and respect for cultural views.[25]

The Bioethics Council has similarly urged that indigenous perspectives be accorded some priority in decisions about research involving human subjects. The Council has concluded that Maori ethical views on biotechnology are sufficiently important to warrant the establishment of a Maori expert group who could develop protocols based on Maori world views in order to make decisions about inter-species transplants and other related procedures.[26]

Maori decision-making in respect of ethical issues involving Maori has also been raised in other fields of inquiry. For more than a decade, the Waitangi Tribunal has been investigating a claim into Crown policies regarding Maori and native fauna and flora.[27] More recently the claim has been extended to consider ownership of Maori intellectual property. At the heart of the claim is a concern that Maori guardianship of the natural environment, and Maori ownership of cultural property is inadequately protected in law and practice. The possibility of a Maori Commissioner has been raised in submissions. Among other things the Commissioner would have a role in exploring the interface between Maori custom, science, and the environment.

Despite considerable progress, there is also ongoing concern about the adequacy of current forms of ethical review largely on the grounds that ethics committees typically try to accommodate Maori perspectives within a review framework that marginalises Maori values. The development of a Maori ethical framework, based on Maori values and overseen by a National Maori Ethics

Committee has been recommended as a way of introducing a parallel Maori ethical review pathway.[28]

Conclusion

The ethics of indigeneity, as they might apply to research bioethics, stem from indigenous world views, indigenous cultures and contemporary indigenous realities. While there are elements of universality, and although not all indigenous individuals subscribe to identical beliefs or hold the same values, there are nonetheless distinctive indigenous approaches to the acquisition of new knowledge that have implications for researchers from the several disciplines of western science.

Three characteristics of indigeneity shape the ethical debate: the close and enduring relationships between people and the environment; the protocols associated with encounters between groups and ways in which relationships are cemented; and the indigenous quest for autonomy and self determination – a response to vulnerability and societal disadvantage. Arising from these characteristics are three sets of ethical domains: the ethics of eco-connectedness, the ethics of engagement, and the ethics of empowerment. Together they point towards the ethics of indigeneity (Table 4).

Table 4 The Ethics of Indigeneity

	The Ethics of Indigeneity		
Ethical domains	The ethics of eco-connectedness	The ethics of engagement	The ethics of empowerment
Indigenous characteristics	Ecological ties	Human encounters	Autonomy and self determination

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