

**Āhuatanga ū ki te tika
me te pono mō te
Rangahau Māori**

**Māori Research Ethics
An overview**

November 2012

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Mihi

He honore, he kororia ki te Atua
He maungarongo ki te whenua
He whakaaro pai ki ngā tāngata katoa
Tihei mauri ora

Kororia ki te wāhi ngaro
I te tīmatatanga te kupu, ko te kupu te Atua
Ko te Atua anō te kupu o te timatatanga
Nāna ngā mea katoa i hanga

O tatou tini aitua
Hoki atu ki te Putahi-nui-a-Rehua
Takahia te ara a Tāne ki te huinga o te kahurangi
Haere oti atu e

E ngā mana, e ngā reo, nei ra te mihi maioha ki a koutou
Koutou e ngakau nui ki te kaupapa o te mātauranga
Kotahi tonu te hiringa i kake ai Tane ki Tikitiki-o-rangi
Ko te hiringa i te mahara

Kake mai ki ngā pitopito korero kua kohia
He tā kakaho e kitea, he tā ngakau e kore e kitea
Kapohia ngā kupu whakamarama mo te tika me te pono
Hei tohu arahi i ngā rangahau

No reira, tena koutou, tena koutou, tena koutou katoa

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1 Introduction

1.1 Purpose

Māori Research Ethics: An overview summarises writings on and issues for Māori research ethics, with a particular focus on health and disability research. The te reo title is *Āhuatanga ū ki te tika me te pono mō te Rangahau Māori*, which translates to the conditions or aspects that keep people or one true, honest and ethical.

This document is designed as a resource. It has drawn on information from existing literature, previous project work, interviews and consultation (see Appendix 1 for a timeline of selected developments in Māori research ethics and additional background work for this document).

While the information contained in this document will be of broad interest, it will be of particular value to researchers and members of ethics committees. To this end, this resource is intended to assist those working in research to:

- facilitate research with a positive outcome for Māori
- improve research quality and support excellence in research
- assist communities to advance Māori health development through research
- provide practical assistance, coordination and support for Māori health and disability researchers, research institutions and others involved in health and disability research with Māori.

1.2 Development of *Māori Research Ethics: An overview*

Māori Research Ethics: An overview has been developed over several years by the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC), an independent advisor to the Minister of Health. One of NEAC's broad and strategic statutory functions is to determine nationally consistent ethical standards across the health sector.

The development of this resource has been part of a wider collaboration on Māori health and disability research ethics involving NEAC, the Health Research Council and Ngā Pae o te Māramatanga (the National Institute of Research Excellence for Māori Development, based at The University of Auckland). This collaboration brought together experts in ethics policy, research, and ethics committee review, who have worked to encourage discussion on ethical issues among Māori communities, researchers and others involved in research ethics.

Māori Research Ethics: An overview has been prepared as a background resource to assist in the development of *Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members*, which was published by the Health Research Council on behalf of the Pūtaiora Writing Group (Hudson et al 2010). *Te Ara Tika* outlines a framework for addressing Māori ethical issues within the context of decision-making by ethics committee members.

1.3 Māori research and ethics

Ethics is concerned with the values, customs and codes of conduct that matter – and how to best act on or live by them. It includes interpreting the concepts of right and wrong, benefit and harm,

and thinking about how these concepts translate into behaviour. Ethical reasoning is therefore an important and necessary process that informs and reflects how we view the world and, in this way, contributes to the decisions we make.

Ethical principles, codes, frameworks and guidelines have been developed across a range of spheres within modern society – for example, social ethics, business ethics, environmental ethics, health ethics, research ethics and cultural ethics. According to Beauchamp and Childress (1994), there is a set of universal biomedical ethical principles that apply to health and to health research. These principles are:

- respect for autonomy (free will, individual choice, power to make decisions)
- beneficence (doing good)
- non-maleficence (doing no harm)
- justice and fairness.

In health research ethics, such universal principles guide practice in order to protect research participants and are adapted to form part of internationally recognised codes such as the Nuremberg Code, the Declaration of Helsinki and the Belmont Report. In New Zealand, these principles feature in codes such as the Code of Health and Disability Services Consumers' Rights 1996 and the Health Information Privacy Code 1994. When these codes are then applied in both research and health care, the principles become evident in practices such as informed consent, confidentiality and privacy, and maximising the benefits of research (or treatment) while minimising possible harmful side effects. Ethics committees have also been developed in order to ensure appropriate approval is gained for research proposals.

A universal approach to ethical principles, however, may not take into account the extent to which cultural traditions influence and enhance ethical study and practice. For example, creation stories are a primary reference for Māori ethics. These stories have often highlighted the nature of relationships, how the world is perceived, and the way in which people interact with each other. These interactions further inform tikanga Māori, and the components of tikanga (such as the values of tapu and noa, and relationships to whakapapa and wairua) which in turn provide a framework through which Māori can actively engage with ethical issues, determine rights and wrongs, and analyse harms and benefits (Hudson et al 2010). Some have expressed concerns that if New Zealand adopts a 'universal research ethic', specific cultural issues and the existence of a Māori research ethic may be overlooked (Cram 2003; Hudson 2004).

Historically, ethics have often been constructed through Western frameworks that may not necessarily be transferrable to other contexts and times (Munshi et al 2011; Tupara 2011). Furthermore, Western ethical research perspectives have tended to focus on legal requirements and institutional codes of ethics which commonly centre on ensuring benefits and fairness to individuals and protecting individual rights. Therefore, researchers design documents such as information sheets for prospective participants, privacy statements and consent forms. This focus on the individual rather than on the collective, and written documents rather than on oral statements, may not adequately address ethical principles for Māori, and has been described as unsafe for whānau (Chetwin et al 2000).

Additional relationships, principles and values critical to Māori ethical practice will be explored further in section 3.

Indigenous populations have long traditions of conducting their own research and experiments. Yet recent research on these communities, conducted by Western researchers with a poor understanding of indigenous ethical principles, has strengthened the sense of disempowerment, exploitation, and a lack of regard for indigenous cultural values, beliefs and knowledge systems

(Cram 1997; A Durie 1998; L Smith 1999; L Smith 2012; Humphrey, 2000; Blundell et al 2010; Cram and Kennedy 2010; Pringle et al 2010; Wyeth et al 2010). In New Zealand, Māori have been the subject of research where the objectives, methodology and outcomes have failed to address many issues for Māori including power, equity and the validity of alternative understanding of knowledge (Cram 1997; G Smith 1997; Bishop 1998b; Humphrey 2000; Pringle et al 2010).

However, social changes over the past 30 years have both increased awareness of the value that research contributes to development, and led to a reconstruction of what is considered ethical research practice within Māori communities. The Māori research community has worked to develop more respectful research relationships and to become agents of research that is grounded in Māori concepts, values and priorities. New Zealand's system of ethical review has also been challenged for not adequately considering Māori interests and ethical perspectives, including the rights of the collective, principles of tikanga and mātauranga Māori, and culturally significant ethical boundaries (Te Awēkotuku 1991; Te Puni Kōkiri 1994; M Durie 1998b; Cram 2003; Hudson 2004; Moewaka Barnes et al 2009; Tupara 2011).

Non-Māori researchers have also had to respond to the challenges of research from indigenous people. Many have participated in debates about Māori research ethics, and have adapted the way they conduct research to ensure respectful research relationships, to align research with Māori priorities and to contribute to improved outcomes for Māori.

The Māori research workforce continues to expand, as does the available body of Māori research literature. That literature commonly draws on a hierarchy of Māori research (described by Cunningham and Durie 1998) that differs according to the extent to which Māori are involved in developing and controlling the research. The following are examples of Māori research within this hierarchy, moving from the lowest to the highest level of involvement.

1. **Research not involving Māori** does not seek Māori participation or data and does not consider either to be relevant. The results are thought to have no impact on Māori. In New Zealand, however, all research is potentially of interest to Māori, every research project can offer a training opportunity for a Māori researcher, every research project may carry risks or produce benefits for Māori, and all research has the potential to help Māori achieve their aspirations. Every research project in New Zealand therefore should consider the degree to which it addresses Māori issues (Cunningham 2000).
2. **Research involving Māori** may involve Māori as participants, subjects or researchers. Māori data are commonly sought and analysed, and researchers often attempt to collect information in a way that is appropriate for Māori. However, the research process is controlled from a non-Māori perspective, Western modes of analysis are often applied and, while the outcome may include knowledge about Māori, it usually contributes predominantly to non-Māori knowledge (Cunningham and Durie 1998).
3. **Māori-centred research** usually involves Māori at all levels. The methodology and analysis are appropriate for Māori, with research questions that focus on outcomes for Māori. This type of research often has dual accountability – to both non-Māori (often an institutional body such as a university) and Māori – although commonly the knowledge outcomes are measured against non-Māori research standards and methodologies.
4. **Kaupapa Māori research** has been defined as 'Research by Māori, for Māori and with Māori' (L Smith 1995). It is grounded in Māori tradition, legitimises Māori knowledge, is controlled by Māori and is accountable to Māori expectations and quality standards. The very nature of Kaupapa Māori research resists Western definitions or criteria, and permits a

broad range of research methodologies in order to fulfil such objectives (IRI and Te Rōpū Rangahau Hauora a Eru Pōmare 2000; Pihama et al 2002).

In 2003 Ratima described Māori research methodologies in two broad categories. The first aligns with Māori-centred research as described above: it is developed from a Western paradigm but may be adapted as Māori-centred and applied in a way that is consistent with a Māori paradigm. The second category is developed from a Māori world view (Ratima 2003). This developmental process for Kaupapa Māori research is commonly described as characteristic of this type of research. Other common characteristics (Irwin 1994; L Mead 1996; Bishop 1996a, 1996b, 1997, 1998a, 1998b, 2011; G Smith 1997, 2003; Reid 1998; Moewaka Barnes 2000; Pihama et al 2002; Cram 2004, 2009) include:

- 'by-Māori for-Māori'. There is debate over the role of non-Māori in Kaupapa Māori research (L Smith 2005; Moewaka Barnes et al 2008). However, fundamental elements of Kaupapa Māori research are Māori ways of knowing and seeing the world, and therefore being Māori is often described as a necessary component. Māori are significant participants in the research and typically make up all of the research team. Non-Māori are not necessarily prevented from being involved in research as long as it is consistent with a Kaupapa Māori approach (G Smith 1995; L Smith 1995, 1996, 2000, 2005). To this end, Graham Smith has described four models for enabling non-Māori to participate: tiaki (mentor), whāngai (adoption), power-sharing and empowering outcomes (G Smith 1997). See section 5 for further discussion on the role of non-Māori in Māori research ethics
- cultural safety, and connections to Māori philosophy and principles such as whakapapa, te reo, tikanga Māori, rangatiratanga and whānau; recognition of Māori cultural and value systems
- guidance/mentoring by kaumātua and the importance of Māori cultural structures such as the extended family and collective responsibility
- empowerment – the duty to enhance and improve the lives of research participants, which is consistent with the idea that research should fundamentally contribute to broader Māori development aspirations
- rangatiratanga (self-determination), autonomy and legitimacy for Māori processes and ways of working, with Māori control over the research process, analysis and outcome; Māori analysis undertaken to produce Māori and mainstream knowledge.

Descriptions of Kaupapa Māori research continue to evolve. Although a number of high-level principles and concepts have been suggested and are promoted, a consensus view has yet to emerge. For some examples and definitions of Kaupapa Māori research, see the References and Appendix 2.

Since the mid 1990s the Māori Health Committee of the Health Research Council of New Zealand (HRC) has documented issues of Māori health research ethics and has discussed this topic with Māori researchers and communities. These discussions have coincided with discussions in the wider Māori research community and in other indigenous communities (particularly Australia, Canada, the continental United States and Hawaii). Ongoing policy debate regarding indigenous research ethics, human rights, health equity and distributive justice has also continued within international agencies including the United Nations and World Health Organization (WHO 2003; Hunt 2007; United Nations 2007).

Throughout these discussions in New Zealand, Māori researchers and others have identified particular areas requiring attention within the current system in which ethics committees review health and disability research. These areas include:

- inadequate recognition of Māori concepts of health, values and customs in health research
- a lack of knowledge, respect or understanding of either Māori research goals or the implications of the Treaty of Waitangi for those reviewing health research proposals
- a lack of understanding about emerging Māori research methodologies or the inclusion of mātauranga Māori within research
- poor value of the research for Māori, leading Māori to refuse to participate in the research development process.

These are issues that relate to the ownership, control, appropriation and exploitation of knowledge; collective rights; cultural safety in health research; health inequalities; and the relationship between health research and health. Addressing them presents an opportunity to improve the ethical review system for all researchers, both Māori and non-Māori. It is intended that this document will provide all researchers with an opportunity to consider the resources available relating to Māori research ethics and to apply them to their own practice.

1.4 Content overview

The remainder of this resource covers the following issues:

- **Section 2** describes five key elements of Māori research ethics.
- **Section 3** identifies principles and values that commonly inform Māori research ethics (formal and informal).
- **Section 4** discusses currently established mechanisms for addressing Māori research ethics.
- **Section 5** outlines specific issues identified by Māori as relevant to research ethics.
- **Section 6** summarises the main points made in the above sections.
- A glossary of key Māori terms used in this resource follows section 6.

2 Context of Māori Research Ethics

At least five elements have contributed to the increasing engagement of Māori with research and subsequently to the development of Māori-specific understandings and perspectives of research ethics:

1. the Treaty of Waitangi
2. indigenous rights
3. Māori health models
4. health inequalities
5. cultural safety.

Ethical behaviour for research with Māori usually involves addressing aspects of these key elements and emphasises the need for consultation with Māori (leading to more meaningful forms of participation, partnership, collaboration and engagement), a greater recognition of Māori collectives as well as individuals, and the desire to protect Māori traditional knowledge and intellectual property.

This section describes in greater detail the five key elements identified above.

2.1 The Treaty of Waitangi

The Treaty of Waitangi, signed in 1840, provides a foundation for policy development in New Zealand and formalises the relationship between Māori and the Crown such that Māori values, traditions and practices are protected (Cram 2003). It is made up of three articles.

- Under Article One, the Government (kāwanatanga) has a responsibility to govern. This notion has been applied to health research and as a means of ensuring that all New Zealanders experience fair outcomes.
- Article Two guarantees Māori sovereignty (rangatiratanga). The Waitangi Tribunal has interpreted this guarantee to include sovereignty over traditional health knowledge and medicinal plants (rongoā) as well as lands and other material assets (M Durie 1998a).
- Article Three guarantees to Māori all the rights and privileges of citizenship (M Durie 1994; Reid 1999).

In 1988 the Royal Commission on Social Policy developed Treaty-based principles of partnership, participation and protection. One reason for this initiative was to reduce any potential tension between interpretations (Māori and English) of the Treaty; another was to improve the applicability of the original intentions of the Treaty in a policy environment (B Robson and Reid 2001). These principles have been widely adopted in developing policies, programmes and projects in New Zealand so that they can be more responsive to the Treaty.

Māori view the Treaty of Waitangi as a vital component of Māori research ethics, and view greater Māori involvement in the area of health research ethics as an important contribution to fulfilling the responsibilities of the Treaty of Waitangi (Cram, 2003; Hudson 2004; R Robson 2004; Kennedy and Wehipeihana 2006; Hudson and Russell 2009). The Treaty and its principles are included in a number of key documents that guide ethical review in New Zealand, demonstrating how the Treaty ensures research is responsive to Māori.

- The Terms of Reference of the National Ethics Advisory Committee (NEAC) require it to carry out its tasks in a manner consistent with the principles of the Treaty of Waitangi (www.neac.health.govt.nz).
- The Health Research Council of New Zealand's *Guidelines on Ethics in Health Research* (HRC 2005) state that all researchers must respect and incorporate Treaty principles in research proposals.
- The Treaty principles of partnership, participation and protection in relation to research ethics have been integrated into *Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members* (Hudson et al 2010). These principles are familiar not only as Treaty principles but also as common principles running through the range of international guidelines on indigenous research ethics (Kennedy and Wehipeihana 2006; Hudson and Russell 2009).

2.2 Indigenous rights

Indigenous rights have been key drivers for the development of frameworks, declarations and guidelines on ethical research practice. This concept emphasises self-determination by indigenous peoples, the protection of their heritage, traditional knowledge, plants and genetic material, and their right to 'maintain and strengthen their distinct political, economic, social and cultural characteristics' (United Nations Commission on Human Rights 1993, 2000). These rights are incorporated into the World Health Organization's guidance on indigenous peoples and participatory health research, as well as a range of United Nations conventions and guidelines on the rights of indigenous peoples (United Nations Commission on Human Rights 1993, 2000; United Nations 2007). Indigenous rights also underpin the Mataatua Declaration (see section 4 and Appendix 5).

The rights of indigenous people in New Zealand, or tāngata whenua, have been summarised by Bridget Robson (2002) as the rights to:

- self-determination
- equity of values
- collective wellbeing
- equal quality of information
- policy based on evidence that is valid for Māori.

2.3 Māori health models

The primary focus of this resource is on Māori research ethics in health and disability. At the same time, it is important to recognise that the definition of health for Māori, as for many indigenous cultures, encompasses much more than the domains of illness or disease and that models of Māori health are important for Māori health ethics.

All models of Māori health embrace similar themes. These themes include: wider understanding of health or wellbeing; the importance of culturally significant terms; relationships and balance among physical, biological, cultural, ancestral and sociological components; access to cultural resources; and a secure Māori cultural identity (M Durie 1998a, Ratima 2001; Waldon 2010). These models have shaped discussions around culturally appropriate health practices including research.

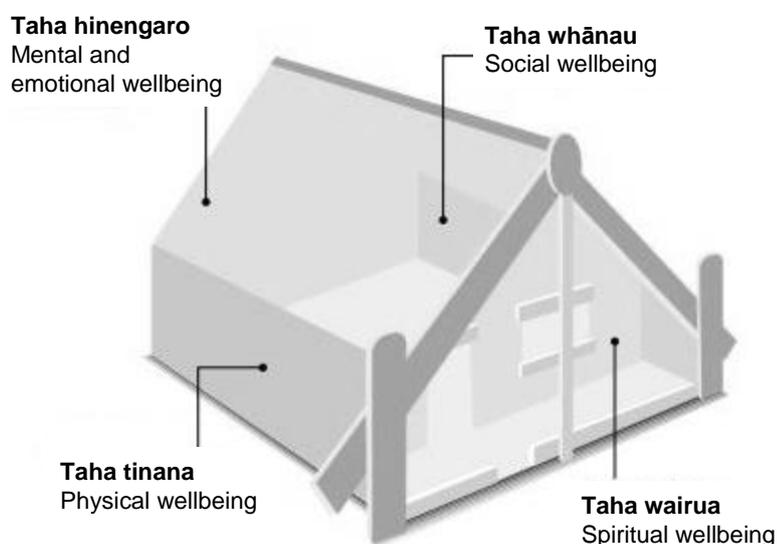
One commonly accepted model of Māori health is Te Whare Tapa Whā (or four-sided house) (Figure 1 and Table 1). It incorporates four key elements: te taha wairua (spiritual wellbeing); te taha hinengaro (mental wellbeing); te taha tinana (physical wellbeing); and te taha whānau (family wellbeing and identity). For Māori to be healthy, there must be a balance and synergy among all four of these domains (M Durie 1985, 1995).

Table 1: Components of Te Whare Tapa Whā

	Taha wairua	Taha hinengaro	Taha tinana	Taha whānau
Focus	Spiritual	Mental	Physical	Extended family
Key aspects	The capacity for faith and wider communion	The capacity to communicate, to think and to feel	The capacity for physical growth and development	The capacity to belong, to care and to share
Themes	Health is related to unseen and unspoken energies	Mind and body are inseparable	Good physical health is necessary for optimal development	Individuals are part of wider social systems

Source: M Durie (1994), p 70

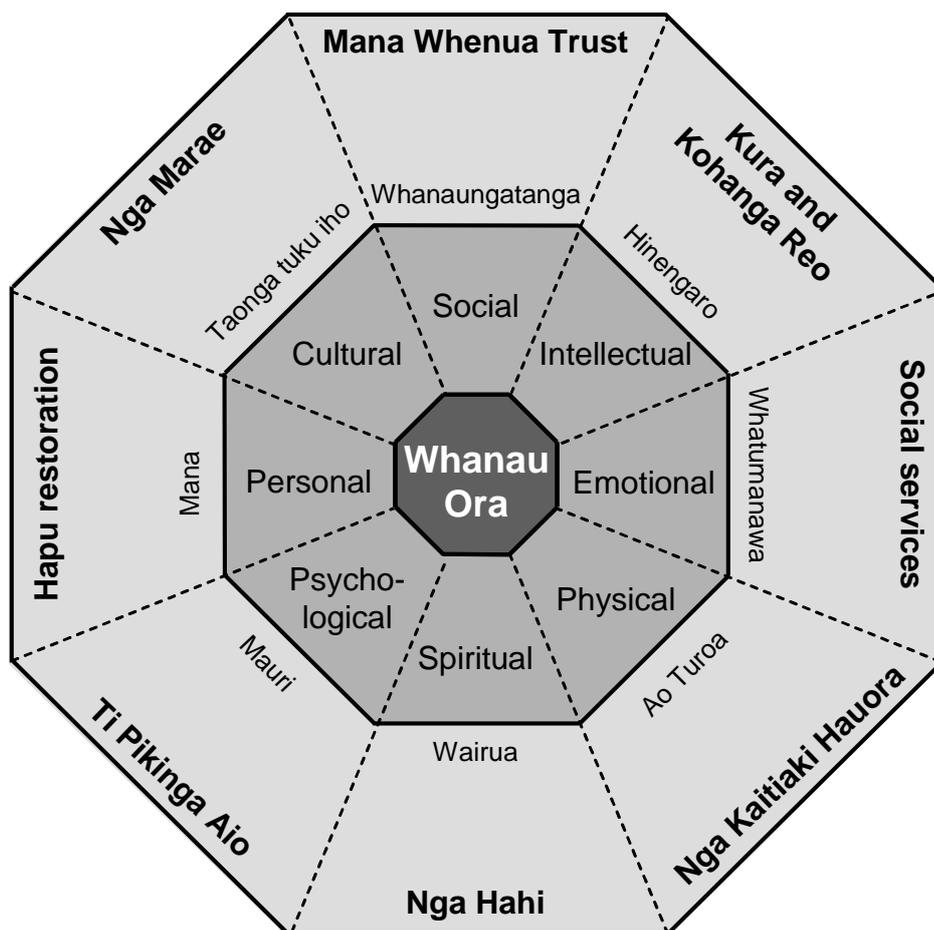
Figure 1: Te Whare Tapa Whā



Source: Adapted from M Durie (1994), p 70

Other models of health reflect the same holistic and integrated principles. One such model is Te Wheke (the octopus), which has eight dimensions of health (Figure 2). These dimensions are whanaungatanga (social), hinengaro (intellectual), whatumanawa (emotional), ao tūroa (physical), wairua (spiritual), mauri (psychological), mana (personal) and taonga tuku iho (cultural).

Figure 2: Te Wheke



Source: R Pere (2003)

Māori perspectives on disability extend beyond a focus on physical and psychological impairment. Support for disabled Māori focuses on ensuring access to an environment that is conducive to attaining balance between spiritual and emotional wellbeing, maximum functioning, strengthening positive interdependence (particularly within whānau), and maintaining and reinforcing a secure cultural identity (B Robson and Harris 2007).

For more information on Māori models of health, visit the Ministry of Health’s Māori Health website (www.health.govt.nz/our-work/populations/maori-health). The idea of wellbeing as complex, interdependent relationships among physical, psychological, spiritual and collective social contexts is recognised in *He Korowai Oranga: Māori Health Strategy* as the overall aim of Whānau Ora (Minister of Health and Associate Minister of Health 2002). The Whānau ora approach describes the need for ‘whānau ora’ as a balance of social gains (such as health, education and societal inclusion), economic gains (such as an expanding asset base), cultural gains (including participation in Te Ao Māori) and collective gains. These gains are strengthened by reciprocal commitments between and across generations, and between the ambitions of individuals and the shared hopes of the whānau (M Durie et al 2010).

2.4 Health inequalities

There are significant inequalities in health status between Māori and non-Māori (Ajwani et al 2003). Researchers (Jones 2001; Arroll et al 2002; Bramley et al 2004; Reid and Robson 2007) have identified some of the reasons for these inequalities as:

- differential access to the determinants of good health (such as economic security, good-quality housing, safe and secure employment, good-quality education)
- differential access to health and disability services
- differences in the quality of care received.

These persistent and significant health inequalities between Māori and other New Zealanders have been described as an ongoing breach of the Treaty of Waitangi and as avoidable, unethical and unjust (Whitehead 1990; Woodward and Kawachi 2000; Reid et al 2000; Reid and Robson 2007). This is a further argument supporting a focus on Māori health aspirations in the ethical review of all health research. An important step in addressing inequalities is to identify them, which is only possible through consistently collecting and analysing complete and accurate information. The appropriate collection of ethnicity data, and the source of comparative data used can influence the outcome of research, research recommendations, and the ability for research to contribute to improving Māori health outcomes and reducing inequalities (Cormack and Harris 2009).

Given such inequalities, health research has an additional responsibility to determine how it will contribute to and improve health outcomes for Māori. Research is important for achieving Māori development aspirations and also as justification for resource allocation. Research that produces high-quality evidence is critical to ensuring the advancement of Māori health goals. Cram (1993, p 2) stated:

[t]he next big challenge is to recognise ethnic inequalities and the need to actively eliminate them ... they are an ethical dilemma that if every ethics committee doesn't ask 'how will this maintain or reduce ethnic inequalities, and if not, why not?', our ethical practice is part of the ongoing maintenance of the acceptability of inequalities.

2.5 Cultural safety

Cultural safety within a Māori context is an inherent component of Māori health and research. The concept of cultural safety extends beyond cultural awareness and cultural sensitivity, and has an outcome that is not offensive to any individual or collective (Ramsden 1992, 2000). Cultural safety links to knowledge and understanding, self-exploration, recognition of diversity and power relationships, and in research considers those who participate in the research process. Cultural safety in health research requires recognition of and respect for differences in world views, values and knowledge between different groups – whether based on ethnicity, religion, age, disability, socioeconomic status, sexuality, gender or other differences.

Cultural safety in Māori research ethics relates to the quality of the interaction between researchers and participants. This may involve observing culturally specific protocols (tikanga) and adequately recognising Māori concepts of health. An ethical review system that meets Māori research ethics standards is consistent with the ethical principles of respect for persons and benefit for all.

3 Principles and Values of Māori Research Ethics

Previous literature on ethical guidelines for health and disability research in relation to indigenous people has identified a number of principles that contribute to Māori understanding of ethical practice in research (Powick 2002; McAullay et al 2002; Cram 2003; Hudson 2004; Kennedy and Wehipeihana 2006; Tupara 2011). Many of these principles are derived from tikanga and mātauranga Māori.

While there is insufficient scope within this document to describe mātauranga Māori and tikanga Māori in detail, a brief introduction is offered here. First, there is a growing body of literature on the place of tikanga Māori in modern times and within the health and disability sector. Tikanga Māori can be described as Māori customary values, beliefs, traditions, customs and practices or Māori standards to strive towards (Pere and Barnes 2009). It commonly expresses moral judgements about appropriate ways of behaving and acting (H Mead 2003a), and can therefore be used to guide practice, to indicate what is fair, true or just, and to protect the interests and wellbeing of groups and individuals. In addition, traditional customary practices for Māori have been receptive to change over time, while remaining true to their basic beliefs (E Durie 1998). The second concept, mātauranga Māori, is the intellectual property and knowledge accumulated by Māori throughout the generations (Hudson 2004).

Dynamic systems of tikanga and mātauranga provide frameworks and principles for social, economic and political interactions within communities and the wider environment. These systems therefore align with ethical decision-making processes (H Mead 2003a) and tikanga-based principles remain relevant in informing contemporary decision-making about Māori research ethics (Hudson 2004). This document identifies four key tikanga-based principles as the primary ethical principles of Māori research ethics: whakapapa, tika, manaakitanga and mana (Table 2). The choice of these key principles was guided by workshops with Māori members of ethics committees (Pūtaiora) and their subsequent work on a framework for Māori research ethics, *Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members* (Hudson et al 2010).

Table 2: Key principles of Māori research ethics

Principle	Definition
Whakapapa	<p>Within the context of decision-making and Māori research ethics, whakapapa refers to the quality of relationships that are developed, why these relationships have been formed, and the structures or processes that have been established to support these relationships.</p> <p>Ethical issues that whakapapa aims to address include concerns about the quality of any consultation or engagement process involved with Māori, and monitoring the progression of relationships through various stages of the research, from beginning to end.</p>
Tika	<p>Tika refers to what is right and what is good for any particular situation. In the context of Māori research ethics, tika relates to the design of a research project, and whether the research achieves proposed outcomes, benefits participants and communities, and brings about positive change.</p> <p>Tika also links to the Treaty principles of partnership, participation and protection and requires respectful relationships with Māori and mana whenua in all research projects, whatever approach the research team decides to use.</p>
Manaakitanga	<p>Manaakitanga involves caring for others, nurturing relationships and being careful in the way others are treated. Aroha (respect, love), generosity, sharing and hosting are essential parts of manaakitanga, as is upholding the mana of all parties.</p> <p>In the context of Māori research ethics, manaakitanga is associated with cultural and social responsibility and respect for persons. This principle requires an understanding of the appropriateness of privacy and confidentiality to safeguard any harmful effects from disclosure of information, the importance of collective participation in establishing the goals and benefits of a research proposal, and empowering research partnerships.</p> <p>Researchers are expected to learn as well as gather data in Māori research, to collaborate and to give back to the community (for example, through koha and sharing of ideas).</p>
Mana	<p>Mana in a Māori context refers to power, prestige, leadership and authority bestowed, gained or inherited individually and collectively. Mana can influence the balance and management of leadership, interpersonal and inter-group relationships so that knowledge is shared and the mana of participants is upheld.</p> <p>In the context of Māori research ethics, mana relates to equity and distributive justice in terms of the potential or realised risks, benefits and outcomes of the research. It also acknowledges issues of power and authority in relation to who has rights, roles and responsibilities when considering such risks, benefits and research outcomes. Finally, mana ensures that appropriate aspects of tikanga Māori are upheld within the research process, and that local protocols are respected.</p>

Typically, values of objectivity, honesty and integrity are also described as essential to good (and ethical) research. Table 3 identifies other values and principles associated with Māori research ethics in particular. They link to the principles defined in the Treaty of Waitangi, to tikanga and to discussions on indigenous rights and equity. There are also important relationships between these principles and the core Western biomedical ethical principles of autonomy, beneficence (doing good), non-maleficence (doing no harm) and justice.

Table 3: Additional principles and values of Māori research ethics

Principle	Definition
Acknowledgement and respect	Research should be carried out with respect, and with acknowledgement of the wider human good. This principle also includes respect for Māori as tāngata whenua.
Benefit for Māori	Good research provides for optimal outcomes for Māori study participants, their communities and Māori health development.
Building capacity	Research should be viewed as an opportunity to develop capacity. Young people interested in research should be nurtured to develop such skills within a safe environment in order to develop further capacity and to minimise the increasing demands on Māori with expertise and experience in Māori research ethics. Older research participants should also be given the opportunity to develop skills and knowledge through their research participation.
Getting things right from the very start	Researchers need to answer certain questions right from the start. For example, 'What might this research offer to communities?', 'What questions should the research try to answer?' and 'What methods can best, and should, be used?'
Guidance on Māori health research should be led by Māori	As described in the Hongoeka Declaration for Māori Health Researchers (Appendix 6), '... we believe Māori health research should be determined and coordinated by Māori, working with Māori for Māori'.
Interconnections and relationships between sectors	Research areas (such as health, social and environmental research) can link together to align with Māori concepts of health, wellbeing and health protection.
Kaitiakitanga	Kaitiakitanga describes guardianship, preservation, protection and connection with the elements that link the spiritual and physical world. It is our collective responsibility (and the responsibility of Māori research) to nurture the physical environment, language, culture and wisdom that have been passed down over generations to ensure sustainability.
Kotahitanga	Kotahitanga considers solidarity and oneness. It also links to the holistic nature of health from a Māori perspective where the physical, spiritual, psychological, environmental and social aspects must be in balance to achieve wellbeing. One piece of policy work that identifies Māori values alongside other values is the National Ethics Advisory Committee's <i>Getting Through Together: Ethical values for a pandemic</i> (NEAC 2007). In this work respect and manaakitanga, and neighbourliness and whanaungatanga are related values, which are applicable to pandemic planning and response. These ethical values have consequently been established in the New Zealand Influenza Pandemic Plan: A framework for action (Ministry of Health 2010a).
Protection of cultural knowledge	Cultural integrity, acknowledgement and protection of indigenous traditional knowledge and intellectual property are important principles, particularly in the context of increasing globalisation and commercialisation of health and disability research.
Realistic and achievable	Research should be realistic and achievable within the terms of reference and resources available.
Reducing inequalities	Māori research, and indeed all health research in New Zealand, must emphasise health gain, reducing health inequalities and avoiding the creation of new inequalities. The persistence of inequalities in Māori health is itself unethical, so it is important that any ethical review of research in New Zealand does not accept inequalities and strives to actively reduce or eliminate them.

Principle	Definition
Self-determination and community involvement	This principle includes addressing Māori rangatiratanga, ownership and control of the information and research process. Communities need to be meaningfully engaged and empowered in all aspects of decision-making with discussion and debate by kaumātua involved in developing Māori research and its ethical principles. This engagement also involves partnering research in its 'formal' and 'informal' senses. For example, partnerships among academics, kaumātua and community members should be integral to the research process.
Tapu and noa	Tapu can relate to sacred values, and noa to restoring balance. These principles remain important in modern practice as influencing actions and beliefs, particularly in relation to ceremonial activities.
Te reo Māori and the value of oral tradition	Māori research ethics recognise the value of sharing information in te reo Māori as well as a responsibility to promote te reo Māori as a critical aspect of Māori culture and a connection to Māori history, knowledge and beliefs. Research with Māori communities must also recognise the value of kanohi ki te kanohi (face-to-face) methodology where appropriate.
Utu	Utu involves compensation or reciprocity, and the maintenance of harmony and balance.
Wairuatanga	Wairuatanga and accommodation of Te Ao Wairua is the connection to the spiritual realm, which is a fundamental dimension of Māori ethics.
Whanaungatanga	Whanaungatanga recognises the pivotal role of kinship bonds and whānau (family, relations) for Māori research. It therefore encompasses whakapapa and includes relationships to non-kin who have become kin-like through shared experience and connection. This value requires the culturally appropriate identification of relationships, engagement, connectedness and commitment to others.

4 Established Māori Research Ethics

At present, processes for Māori ethical review of health research are embedded in the general processes for ethical review of research through:

- reference to the Treaty of Waitangi and Treaty principles (section 2.1)
- requirements for research and ethics committees
- recommendations for Māori research in the key health research guidelines and protocols
- professional codes of ethics for researchers.

Elements of established Māori research ethics discussed in this section are:

- the ethical review system (section 4.1)
- existing guidelines and models (section 4.2)
- indigenous declarations (section 4.3)
- existing laws and regulations (section 4.4)
- government health and disability strategies (section 4.5)
- existing Māori health research partnerships (section 4.6)
- international guidance (section 4.7).

4.1 The ethical review system

There are Māori-focused health organisations and research organisations, as well as Māori research committees and Māori advisors in various organisations. However, there is no separate body at a national level charged solely with advising on Māori health and disability ethics or to review proposed research with a focus on Māori research ethics. Instead, ethics committees are responsible for reviewing health and disability research ethics (including in relation to Māori research principles). Many of these committees are regional health and disability ethics committees (HDECs) or institutional ethics committees within tertiary institutions, private sector organisations (such as Zenith Technology) and other public sector organisations (including district health boards). These organisations may be assisted by guidelines and documents produced by other organisations, such as this resource.

4.1.1 The National Ethics Advisory Committee

The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) was established under section 16 of the New Zealand Public Health and Disability Act 2000. Its statutory functions are: to provide advice to the Minister of Health on ethical issues of national significance regarding health and disability research and services; to determine nationally consistent ethical standards; and to scrutinise health and disability research and services.

NEAC has produced a number of statements and guidelines (available at www.neac.health.govt.nz) relevant to Māori research ethics. These include the following.

4.1.1.1 Goals, objectives, and desired outcomes of an ethical review system

NEAC's statement of *Goals, Objectives, and Desired Outcomes of an Ethical Review System* (GODO; NEAC 2003) identifies that the ethical review system should:

- facilitate research and innovative practice that contributes to knowledge and better health outcomes
- protect participants in health and disability research and innovative treatment
- find a balance that minimises risks and maximises benefits arising from health and disability research
- ensure consistency with the Treaty of Waitangi.

GODO advises that a system of ethical review should be enabling of Māori participation. It is particularly important to:

- develop and implement a Māori ethical framework
- consult with Māori in collaborative, genuine, inclusive and appropriate ways
- facilitate Māori participation in decision-making
- recognise and respect the potential for diversity of opinion across iwi and regions
- facilitate Māori research capability (NEAC 2003, pp 35–38).

4.1.1.2 Ethical guidelines for specific study types

The *Ethical Guidelines for Observational Studies: Observational research, audits and related activities* (NEAC 2012) address all aspects of the ethical conduct of observational studies. In an observational study (which includes audits) the investigator observes and analyses information but does not control the care or services that people receive. Similarly, NEAC's *Ethical Guidelines for Intervention Studies* (NEAC 2012) aim to assist researchers, ethics committees, study sponsors, organisations that host research and others with an interest in intervention studies, such as clinical trials. Both sets of guidelines were updated in 2012 to fill any gaps and remove any inconsistencies with the Ministry of Health's (2012) new *Standard operating procedures for health and disability ethics committees* (the standard operating procedures).

The *Ethical Guidelines for Observational Studies* advise that:

- investigators should respect the Government's commitment to fulfilling the special relationship between iwi and the Crown under the Treaty of Waitangi
- issues relating to Māori culture and ethical values should be addressed in discussion with Māori concerned, including appropriate whānau, hapū or iwi
- there should be due recognition of Māori as the tāngata whenua and indigenous people of New Zealand (NEAC 2012, p 8, 9).

The *Ethical Guidelines for Intervention Studies* also highlight the importance of comprehensive, high-quality Māori health research and information in order to meet government and Māori development goals. They recognise the need to acknowledge Māori as the tāngata whenua and to engage with Māori whānau, hapū and iwi in a manner appropriate to the scope and method of the study. These guidelines also discuss the validity of collective consultation (NEAC 2012).

Both sets of guidelines advise researchers that they should be aware of New Zealand guidelines on research involving Māori and discuss the principles of the Treaty of Waitangi, which were appended to the previous *Operational Standard for Ethics Committees* (Ministry of Health 2006). The principles are explained as follows:

- partnership: working together with iwi, hapū, whānau and Māori communities to ensure Māori individual and collective rights are respected and protected in order to achieve health gain
- participation: involving Māori in the design, governance, management, implementation and analysis of research, particularly research involving Māori
- protection: actively protecting Māori individual and collective rights, and Māori data, cultural concepts, norms, practices and language in the research process.

4.1.2 Ethics committees

New Zealand has four regional HDECs, established under the New Zealand Public Health and Disability Act 2000, that review individual health and disability research proposals. Their primary role is to secure the benefits of health and disability research by checking that it meets or exceeds established ethical standards. Each HDEC has its own terms of reference (available at www.ethics.health.govt.nz), which states that at least one member should have a recognised awareness of te reo Māori and understanding of tikanga Māori.

In addition, all ethics committees (both HDECs and institutional ethics committees) that consider applications for research funded by the HRC involving clinical trials or accessing New Zealand Health Information Service data require accreditation by the HRC Ethics Committee under the Health Research Council Act 1990. Ethics committees must also abide by the Code of Health and Disability Services Consumers' Rights 1996 and the Health Information Privacy Code 1994.

The HRC Ethics Committee must have members with diverse knowledge and experience, including in relation to tikanga Māori. Institutional ethics committees accredited by the HRC must have a member with expertise in tikanga Māori and two members with links with the Māori community. Each member of each ethics committee in New Zealand plays an important role in assessing the validity and justification of research proposals, working towards improving Māori health outcomes and reducing health inequities, and thus giving value to the principal provisions of the Treaty of Waitangi. In this assessment, each ethics committee member will make their own ethical decisions based on their own experience, values, norms and learning. Their own values (including cultural values) will influence how they consider ethical principles and prioritise some over others, as well as how they prioritise the legitimacy of particular knowledge (such as clinical advancement) over other knowledge (such as indigenous development).

4.1.2.1 HDEC requirements

HDECs are required to comply with the procedural rules contained in the standard operating procedures (Ministry of Health 2012). The standard operating procedures define the role of HDECs, the review process and what research proposals require review. Paragraph 17 of the standard operating procedures states that researchers are responsible for ensuring that Māori are consulted when developing and conducting studies that are relevant to them. Where the *Guidelines for Researchers on Health Research Involving Māori* (HRC 2010) require formal consultation with Māori, HDECs should check that researchers have done so or will carry it out appropriately. However, HDEC review does not constitute or replace such consultation.

Applicants may appeal any HDEC decision to the HRC Ethics Committee. The appeal decisions of the HRC Ethics Committee are final and binding on HDECs.

The standard operating procedures also set out the requirements for HDEC review of tissue bank applications. Section 13 (Ministry of Health 2012) makes it clear that applications for a

tissue bank should include information on how the researchers will address cultural issues that may arise for Māori and other relevant population groups around the storage and use of tissue.

The standard operating procedures are available at www.ethics.health.govt.nz/operating-procedures.

4.1.2.2 HDEC ethical approval process for researchers

Researchers apply to an HDEC for ethical review of their study using the HDEC application form. In relation to Māori, section P of the form requests the following information.

p.4	Population groups, particularly Māori, should be consulted in the design and conduct of research that is of relevance to them.
	Consultation with Māori
p.4.1	Please describe whether and how your study may benefit Māori. [<200 words] <input type="text"/>
p.4.2	Please identify the main cultural issues that may arise for Māori who may participate in your study, and explain how these issues will be managed. [<200 words] <i>If Māori will be excluded from participating, please state this. You will be asked to explain your inclusion/exclusion criteria in the next section of the Form.</i> <input type="text"/>
p.4.3	According to the Health Research Council's <i>Guidelines for Researchers on Health Research Involving Māori</i> , is formal consultation with Māori required for your study? <input type="checkbox"/> Yes <input type="checkbox"/> No
p.4.3.1	Please <i>either</i> describe your study's consultation process, <i>or</i> explain why you do not consider that formal consultation with Māori is required. [<200 words] <input type="text"/>
p.4.4	Does your study involve kaupapa Māori research methodologies? <input type="checkbox"/> Yes <input type="checkbox"/> No

In addition to completing the application form, each researcher is required to obtain locality authorisation. This is a standard condition of all HDEC approvals. The central issue in gaining this authorisation is that the locality is suitable for conducting the study safely and effectively. Before authorisation is given, the locality checks that applicants have taken reasonable steps, particularly consultation with Māori where appropriate, to identify and adequately address local cultural issues that may arise from the study. This authorisation also attests that appropriate arrangements are in place for providing information to potential participants in the study who may not adequately understand information in English.

The locality review provides another opportunity for researchers to better engage with local Māori and to consider how their research might impact on tāngata whenua. For more information about locality assessment, see section 10 of the standard operating procedures (Ministry of Health 2012).

4.2 Existing guidelines and models

4.2.1 Specific guidelines for Māori research ethics

In 1998 the Health Research Council first published *Guidelines for Researchers on Health Research Involving Māori*, developed by the Māori Health Committee of the HRC. This document was revised in 2010 and is available from the HRC website (www.hrc.govt.nz).

The intention of these guidelines is to assist researchers (particularly those applying for HRC funding) to ‘establish research practices which ensure that the research outcomes contribute as much as possible to improving Māori health and well-being, while the research process maintains or enhances mana Māori’ (HRC 2010, p 2). These guidelines aim to help researchers to develop:

- research partnerships between health researchers and Māori communities or groups on issues important to Māori health
- research practices that ensure biomedical, clinical and public health research effectively contributes to Māori health development wherever possible.

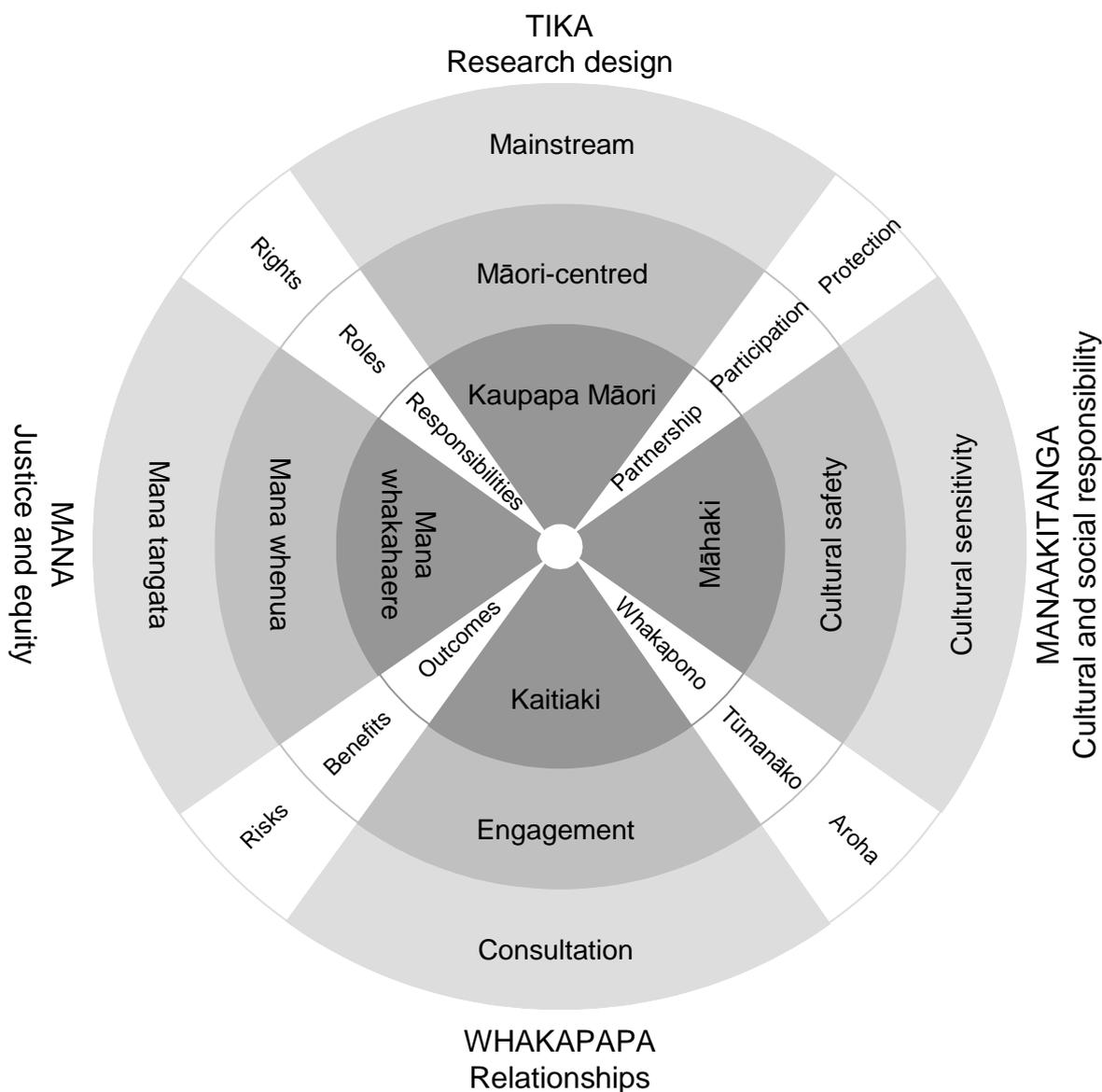
The guidelines reinforce the importance of the Treaty of Waitangi and of high-quality research for Māori development, and they focus on consultation with Māori. Moreover, these guidelines discuss the development of research partnerships as a vital step for research projects in New Zealand. The criteria contained as part of the guidelines are taken into account during the HRC’s research proposal review processes, and applicants for HRC funding should read them before applying for ethical approval from HDECs.

In order to provide more updated and specific advice regarding Māori research ethics, *Te Ara Tika: Guidelines on Māori Research Ethics: A framework for researchers and ethics committee members* (HRC 2010) has been published and is appended to the HRC *Guidelines for Researchers on Health Research involving Māori*. This specific guideline for Māori research ethics emerged from a partnership of NEAC, HRC and Ngā Pae o Te Māramatanga (NEAC 2004). A writing group, drawn from the Māori members of ethics committees (Pūtaiora), was resourced to describe key principles of Māori research ethics and also to offer practical assistance to researchers and ethics committee members regarding Māori research ethics. *Te Ara Tika: Guidelines on Māori Research Ethics* assists Māori and non-Māori researchers and members of ethics committees by:

- clarifying key ethical concepts for Māori
- clarifying the kaitiaki functions of Māori ethics committee members, and providing some supportive processes to achieve this goal
- outlining a framework for decision-making about Māori ethical issues
- identifying strategies or techniques for addressing Māori ethical concerns (NEAC 2004; Hudson et al 2010).

These guidelines frame issues of Māori research ethics within four tikanga-based principles: whakapapa, tika, manaakitanga and mana. Each of these principles heads a segment of the framework developed in this guideline (Figure 3).

Figure 3: A framework for Māori research ethics



Source: Hudson et al (2010), p 4

Each segment of the framework (moving in towards the centre) is divided into three parts that relate to progressive expectations of ethical behaviour.

- The outer ring relates to **minimum standards**. Researchers are expected to have met these standards before ethics committee members consider ethical approval for the research project.
- The middle ring refers to **good practice** which indicates a more Māori-responsive approach to the research project.
- **Best practice**, in the centre, extends the ethical consideration to align with expectations of behaviour within Te Ao Māori.

The axes between the segments provide further opportunity to link the ethical values and principles described to: the rights, roles and responsibilities associated with the Treaty of Waitangi; the Treaty principles of partnership, participation and protection; a risk–benefit–outcome continuum; and the Māori values of whakapono, tūmanako and aroha. *Te Ara Tika* proposes five steps in the process of ethical review (Hudson et al 2010):

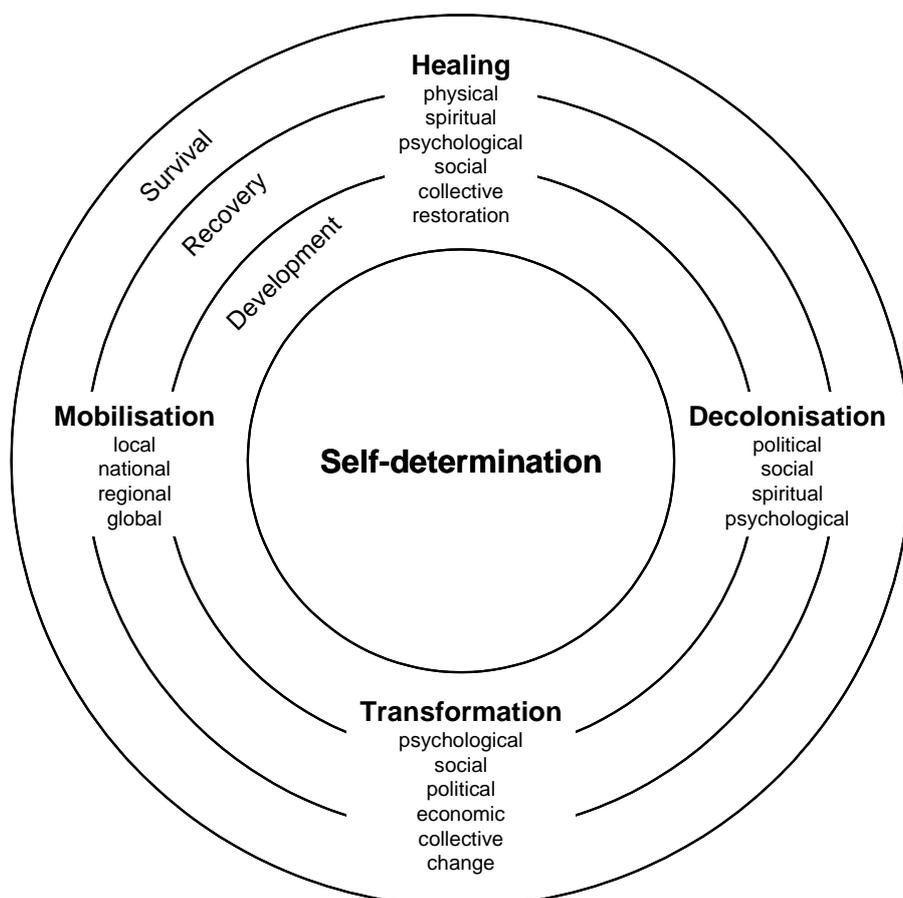
1. kia tūpato (be careful; consider the value of your research)
2. kia āta whakaaro (analyse precisely)
3. kia āta kōrero (have robust discussion)
4. kia āta whiriwhiri (determine the appropriate conditions)
5. kia āta haere (proceed with understanding).

This framework for ethical appraisal has been recommended for use by the Faculty of Medical and Health Sciences at The University of Auckland. It is available from the HRC's website (www.hrc.govt.nz).

4.2.2 Indigenous research agenda

Linda Smith (2012) has defined the research agenda set out in Figure 4. The agenda acknowledges that research contributes to moving towards the ideal of a self-determining indigenous world, and is situated within the decolonisation politics of the indigenous people's movement. The diagram uses imagery of the natural elements such as the directions of the wind to depict the four processes: decolonisation, healing, transformation and mobilisation. These are processes that can be incorporated into practices and methodologies. Similarly, the four tides are depicted as survival, recovery, development and self-determination, which represent conditions that indigenous communities experience within an indigenous research agenda (L Smith 2012).

Figure 4: Indigenous research agenda



Source: L Smith (2012)

4.2.3 Other sectors and frameworks

Recognising the holistic nature of Māori health and knowledge is a key issue in Māori research ethics, and therefore discussions of Māori ethics in other sectors are valid for health and disability. A growing body of literature by Māori academics and researchers in aligned sectors is informing and influencing institutional ethics and research frameworks.

4.2.3.1 Education

L Mead (1996) and G Smith (1997) describe a number of considerations for Kaupapa Māori research in education and research involving Māori, particularly by Māori researchers. These considerations have since been formulated as guidelines for Māori research ethics (Cram 2001, 2009) and include the following.

- **Aroha ki te tangata** (a respect for people). Research participants need to define their own space and to meet on their terms without a hierarchy of researcher over participant. This space may include physical, cultural, knowledge-base and spiritual dimensions. There are appropriate ways to mediate this space, which include negotiation with community leaders such as the kaumātua of iwi, hapū and whānau, rather than with individuals.
- **Kanohi kitea** (the seen face). Meetings with research participants should be face-to-face in order to signal that the researcher is again willing to negotiate the space described above. The research participants should be enabled to define the most appropriate time and place for such meetings, and how information is to be recorded.

- **Titiro, whakarongo ... kōrero** (look, listen, speak). The researcher must be patient, and listen carefully first in order to develop trust and shared understanding, and to ensure that the true meaning of participants' stories is understood.
- **Manaaki ki te tangata** (share and host people, be generous). This concept relates to that of the 'tuakana–teina' (older sibling – younger sibling) relationship. Both the researcher and participants have something to learn and something to contribute – knowledge flows from both directions. Such collaboration again mediates the space between the research partners. In 'giving back', the researcher not only acknowledges what they have to learn from the participants, but also shares the results and research outcomes and gives a koha to the iwi or whānau.
- **Kia tūpato** (be cautious). This key concept, for both Māori and non-Māori researchers, relates to cultural safety.
- **Kaua e takahia te mana o te tangata** (do not trample over the mana of people). Respectful research ensures that the views and knowledge of every member of the research community are valued, and that the research benefits Māori.
- **Kia māhaki** (be humble, don't flaunt your knowledge). It is important for the researcher to be patient and cautious, but not to flaunt their own knowledge and skills. Knowledge should be shared in an empowering process.

Bishop and Glynn (1999a, 1999b) describe the principles of Kaupapa Māori Educational Research as the ability to answer important questions during the research process. These include questions such as:

- Initiation
 - Who initiates the project and who sets the goals or research question?
- Benefits
 - What benefits will there be and for whom?
 - What system of evaluation will be used?
 - How does this research support Māori cultural and language aspirations?
 - What difference will this study make for Māori?
- Representation
 - Whose interests, needs and concerns are represented? Whose voice is heard?
 - Who will do the work? How were the tasks allocated?
- Legitimation
 - Who is going to process the data and consider the results?
 - What happens to the results?
 - Who defines what is accurate, true and complete?
- Accountability
 - Who is the researcher accountable to?
 - Who can access the research findings?
 - Who has control over distribution and knowledge?

4.2.3.2 Law

In 1998 Chief Judge Eddie Durie described the following ethics and values that need to be incorporated along with general ethical principles such as informed consent, confidentiality, minimising harm, and truthfulness:

- mana tangata (dignity, power, authority of the people)
 - dignity of the individual and the groups, which includes respect for cultural identity
 - safety – physical, mental, spiritual, personal and social wellbeing
 - mutuality – mutual benefit for all involved in the research project
- mana whakahaere (governance)
 - collaboration, including balance between individual and group perspectives
 - control over the direction, process and outcomes of the research
- mana motuhake (self-determination, separate identity, autonomy)
 - outcomes for future Māori development and vision
 - evidence of benefit for Māori.

4.2.3.3 Social development

The Ministry of Social Development has developed guidelines for research and evaluation with Māori: *Ngā Ara Tohutohu Rangahau Māori* (Ministry of Social Development 2004). The guidelines are structured around the following practice principles:

- planning for Māori involvement
- engaging with Māori participants and stakeholders
- developing effective and appropriate methodologies
- protecting knowledge
- encouraging reciprocity
- supporting Māori development.

4.2.3.4 Other models

The '**Community-up**' **Māori Ethical Framework** was first outlined by Linda Smith and Fiona Cram in 2001. It includes the following values, many of which have been previously discussed and described in this resource (Cram 2009):

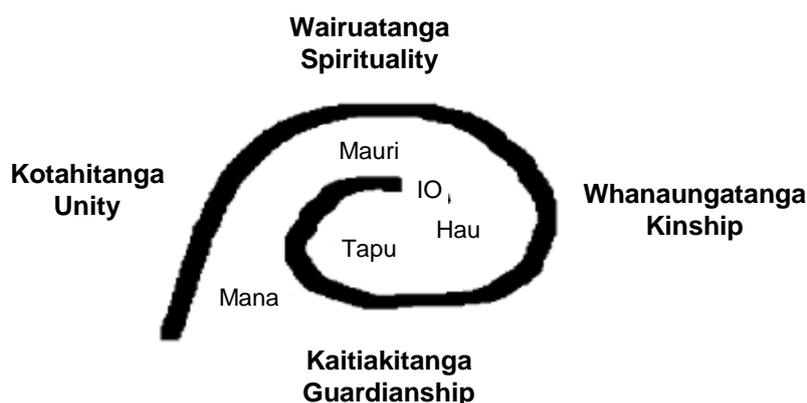
- whanaungatanga
- manaakitanga
- aroha
- kia māhaki
- mana
- titiro, whakarongo ... kōrero
- kia tūpatō.

In 2003 Hirini Mead developed a **Tikanga Māori Framework** for Māori research ethics based on tikanga Māori and mātauranga Māori. This framework uses the following five 'tests' that researchers can use to assess their approach to an issue.

- **Test 1: The Tapu aspect.** When evaluating ethical issues, it is important to consider whether there will be a breach of tapu and, if there is, whether the gain or outcome achieved by breaching it will be worth it.
- **Test 2: The Mauri aspect.** Mauri refers to the life essence of a person or object. In an ethical context, one must consider whether the mauri of an object or a thing will be compromised and to what extent.
- **Test 3: The Take-utu-ea aspect** – take (issue), utu (cost), ea (resolution). Take-utu-ea refers to an issue that requires resolution. Once an issue or conflict has been identified, the utu refers to a cost or action that has been mutually agreed to and that must be undertaken to restore the issue and resolve it.
- **Test 4: The Precedent aspect.** This refers to looking back at past examples of similar issues and how they have been resolved. Precedent is used to determine appropriate action for now.
- **Test 5: The Principles aspect.** This refers to a collection of other Māori principles or values that may enhance and inform an ethical debate. Issues considered here include manaakitanga, mana, whanaungatanga and noa (H Mead 2003b).

The **Koru of Māori Ethics** is a framework of Māori ethical issues developed by Manuka Henare (1998). Mana, mauri, tapu, lo and hau are depicted in the centre of the koru as the founding values that inform the ethical concepts and practices of kotahitanga, wairuatanga, whanaungatanga and kaitiakitanga (Figure 5).

Figure 5: The koru of Māori ethics



Source: Henare (1998)

In this model, the traditions in society dictate ethical and moral behaviour. Traditional society for Māori involves connection to all things, which are intrinsically sacred, through genealogical links to the gods and Io (the supreme being, the source of life) and all other living things. Core elements of life within this model (which are similar to those described elsewhere) are:

- mauri – life essence
- tapu – the sacredness in all things
- hau – the breath of life
- mana – the embodiment of all these things, which can be either enhanced or diminished by our behaviour.

From these core elements and concepts spring the behaviour described in this model as good and right, tika and pono:

- whanaungatanga – the ethic of belonging
- wairuatanga – the ethic of spiritual connection and spirituality
- kotahitanga – the ethic of solidarity
- kaitiakitanga – the ethic of guardianship.

Bioethics. In 2004 (before it was disestablished in 2009) the Bioethics Council approached a range of people and organisations that had expressed interest in the area of genetic modification, and invited them to contribute a short essay outlining their approach to this issue. From these contributions, the Council published *Reflections on the Use of Human Genes in Other Organisms: Ethical, spiritual and cultural dimensions*. One contributor, Kaa Williams, describes Te Pā Harakeke o te Tangata, which outlines the following key aspects of Māori ethics:

- te whakapapa
- te ira tangata
- te whanaungatanga, te matemateaone, te manaaki, te tiaki, te atawhai
- te wairua, mauri, tapu
- te mana.

Hutchings (2009) also set out a framework for exploring the bioethical use of health-related new technologies. This framework describes a range of questions about Māori values and principles which should be asked when considering the ethical impact of new technology. The questions from this framework include the following.

- **Papatūānuku.** How does this technology protect the uha of Papatūānuku?
- **Kaitiaki.** As kaitiaki, do Māori women approve the use of this technology? What are the key elements the mana wahine kaitiaki role protects?
- **Te Tiriti o Waitangi.** Do the development and implementation of this technology endorse our Tiriti rights? Has this technology been developed with the full participation of Māori exercising their Tiriti rights? Is Te Tiriti o Waitangi being used as one of the decision-making tools in the development of this technology?
- **Decolonisation.** How does this technology assist in the decolonisation of Māori?
- **Intellectual property rights.** Is our biodiversity protected from commodification?

Descriptions of some of these ethical frameworks are available at Rangahau (www.rangahau.co.nz/ethics), a website funded by the Tertiary Education Commission. It has been developed collaboratively by Te Whare Wānanga o Awānuiurangi, Ngā Pae o te Māramatanga and Māori and Indigenous Research Institute (IRI) at The University of Auckland.

4.2.4 Formal institutional consultation processes

A number of universities, other tertiary institutions and district health boards (DHBs) have taken on the responsibility of formalising consultation processes with Māori, advising on Māori research ethics, and facilitating locality assessments for research projects taking place at their facilities. Some examples of this include:

- the ‘Research Consultation with Māori’ policy at Otago University (www.otago.ac.nz/research/maoriconsultation)
- the Waikato Institute of Technology’s policy on ‘Principles and Procedures: Conducting Research in a Māori context’, which includes a checklist for the structure of the research project. This policy also includes a summary of the implications of the Treaty of Waitangi for different research processes, originally developed by the University of Waikato’s Department of Psychology in 1997
- ‘Te Noho Kotahitanga – the Partnership’ (2001) of Unitec in Auckland (see www.unitec.ac.nz/aboutus/values/thepartnership/tenohodoc/the-partnership_home.cfm), which expresses Unitec’s commitment to the Treaty of Waitangi and describes five principles that underpin Unitec’s goals, including its research goals:
 - rangatiratanga – authority and responsibility
 - wakaritenga – legitimacy
 - kaitiakitanga – guardianship
 - nohotahi – cooperation
 - ngākau māhaki – respect.
- the Māori Research Review Committee at the Auckland DHB, which has been involved in reviewing research proposals in its area (Sporle and Koea 2004a; see also www.adhb.govt.nz/researchoffice/mrrc/mrrc.htm), and the Kaumatua Kaunihera at Waikato DHB, which performs a similar role
- iwi-based Māori research committees that undertake ethical review as well as other functions, for example, Ngāi Tahu’s research committee and Ngāti Kahungunu’s Hauora Board.

4.2.5 Health inequalities, health impact assessment and health equity assessment tools

Using health equity tools when developing research proposals can help to identify and address inequalities and therefore be more responsive to Māori research ethics, as described in section 2.4. The Waikato DHB Kaumatua Kaunihera Ethics Committee requests that all research applicants use the ‘Health Equity Assessment Tool (Equity Lens) for Tackling Inequalities in Health’ to consider the impact of their research on inequalities. This tool (reproduced in Appendix 3) asks 12 questions of a research proposal in order to prompt researchers to consider the most appropriate interventions to reduce inequalities (Signal et al 2008).

Another useful tool is the ‘Whānau Ora Health Impact Assessment (HIA) Tool’ (Ministry of Health 2007, available at www.health.govt.nz). Even the most well-meaning research proposals or policy development can have unintended negative impacts on Māori and contribute to inequalities. Researchers can use HIA to identify and mitigate these negative effects. The health systems in some countries (including Australia) use HIA to evaluate policy and the impact of policy and programmes on the equity of health outcomes, and the World Health Organization supports its use (New South Wales Health 2004).

Another tool to examine Māori research ethics in relation to reducing inequalities is the *Reducing Inequalities in Health Framework* (Ministry of Health 2002; see also www.health.govt.nz/publication/reducing-inequalities-health). This framework describes how best to prioritise policy, programmes and research in order to improve health and reduce inequalities through focusing on the root causes of inequalities (see Appendix 4). In this framework, best practice interventions, policies, programmes and research outcomes:

- do not make inequalities worse
- increase people's control over their own lives
- actively involve users of health services and communities
- favour the least advantaged
- take a comprehensive approach, targeting individuals, whānau, population groups and the environment
- foster social inclusion and minimise stigmatisation
- are effective both in the short and long term
- adapt to changing circumstances
- work with and build the capacity of local organisations and community networks (Ministry of Health 2002, p 23).

The growing body of well-designed, well-supported equity assessment tools that are simple to apply is likely to assist health research, and in turn make valuable contributions to Māori research ethics.

4.3 Indigenous declarations

4.3.1 The Mataatua Declaration

The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples (United Nations Commission on Human Rights 1993; see Appendix 5) was adopted at the first International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples, held in Whakatane in June 1993. The declaration clearly indicates the issues and concerns about intellectual and cultural property rights that many indigenous people throughout the world have. The Mataatua Declaration states that:

- Indigenous Peoples of the world have the right to self-determination, and in exercising that right must be recognised as the exclusive owners of their culture and intellectual property
- Indigenous Peoples are capable of managing their traditional knowledge themselves, but are willing to offer it to all humanity provided their fundamental rights to define and control this knowledge are protected by the international community
- the first beneficiaries of indigenous knowledge (culture and intellectual property rights) must be the direct indigenous descendants of such knowledge.

These aspects of the Mataatua Declaration have implications for the development, implementation, analysis and monitoring of Māori research.

4.3.2 The Hongoeka Declaration for Māori Health Researchers

The Hongoeka Declaration for Māori Health Researchers (1996; see Appendix 6) serves a similar purpose to a code of ethics for Māori research. It incorporates the principles of the Treaty of Waitangi as the basis for partnership between Māori and the Crown. This declaration has been adopted by a wide range of researchers. Principles contained within the Hongoeka Declaration include:

- the rights of Māori over their cultural and intellectual property
- that Māori health research should be determined, controlled and coordinated by Māori, and accountable to whānau, hapū and iwi
- the use of health research that will benefit Māori
- the promotion and development of Kaupapa Māori methodology, te reo Māori and tikanga Māori for Māori health research
- the need to evaluate and discuss all research impacting on Māori health.

4.4 Existing statutory examples

New Zealand has two main pieces of statutory guidance that include specific provisions on Māori health research: the New Zealand Public Health and Disability Act 2000 and the Code of Health and Disability Services Consumers' Rights, which is a regulation issued under section 74 of the Health and Disability Commissioner Act 1994.

4.4.1 New Zealand Public Health and Disability Act 2000

Part 1 of the New Zealand Public Health and Disability (NZPHD) Act 2000 (available at www.legislation.govt.nz) recognises and respects the principles of the Treaty of Waitangi with a view to improving Māori health outcomes. The legislation was important as the first piece of social policy legislation that included Treaty of Waitangi principles. It also clearly articulated the manner in which the Treaty principles were interpreted.

Part 3 of the Act was designed as a means through which the principles could be applied. It offered mechanisms through which Māori could contribute to decision-making on, and participate in the delivery of, health and disability services – specifically at a DHB level.

- An objective of DHBs is '... to reduce health disparities by improving health outcomes for Māori and other population groups' (NZPHD Act section 22(1)(e)).
- A function of DHBs is '... to establish and maintain processes to enable Māori to participate in, and contribute to, strategies for Māori health improvement' (NZPHD Act section 23(1)(d)) and '... to continue to foster the development of Māori capacity for participating in the health and disability sector and for providing for the needs of Māori' (NZPHD Act section 23(1)(e)). Relevant information must also be provided to Māori for the purposes of paragraphs (d) and (e).
- In making appointments to a board, the Minister must endeavour to ensure that (a) Māori membership of the board is proportional to the number of Māori in the DHB's resident population (as estimated by Statistics New Zealand); and (b) in any event, there are at least two Māori members on the board (NZPHD Act section 29).

4.4.2 Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996

The Health and Disability Commissioner's Regulations are known as the 'Code of Rights' (available at www.hdc.org.nz) and include specific reference to Māori. Right 1(3) states that:

Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori.

Further legislation relevant to health and disability research is available at the New Zealand Legislation website (www.legislation.govt.nz). This includes legislation to protect research participants, and to ensure the privacy and confidentiality of their health information, such as the Human Rights Act 1993, New Zealand Bill of Rights Act 1990, the Health Information Privacy Code 1994 and the Health Research Council Act 1990. Specific protection for participants taking part in clinical trials or medical research involving new technologies, gene therapy or other highly invasive procedures is also offered under the Medicines Act 1981, Human Assisted Reproductive Technology Act 2004, Injury Prevention, Rehabilitation, and Compensation Act 2001 and the Human Tissue Act 2008.

4.5 Government health and disability strategies

The principles and values of Māori health are represented in key government health and disability strategies. The need to improve Māori health is reflected throughout the New Zealand Health Strategy (Minister of Health 2000). Among its key goals are to reduce inequalities in health and focus on Māori health development. The objectives of the New Zealand Health Strategy include:

- ensuring accessible and appropriate services for Māori
- building capacity for Māori participation in the health sector at all levels
- enabling iwi/Māori communities to identify and provide for their own health needs
- recognising the importance of relationships between Māori and the Crown
- collecting high-quality health and disability information to better inform Māori policy and research, and focus on health outcomes.

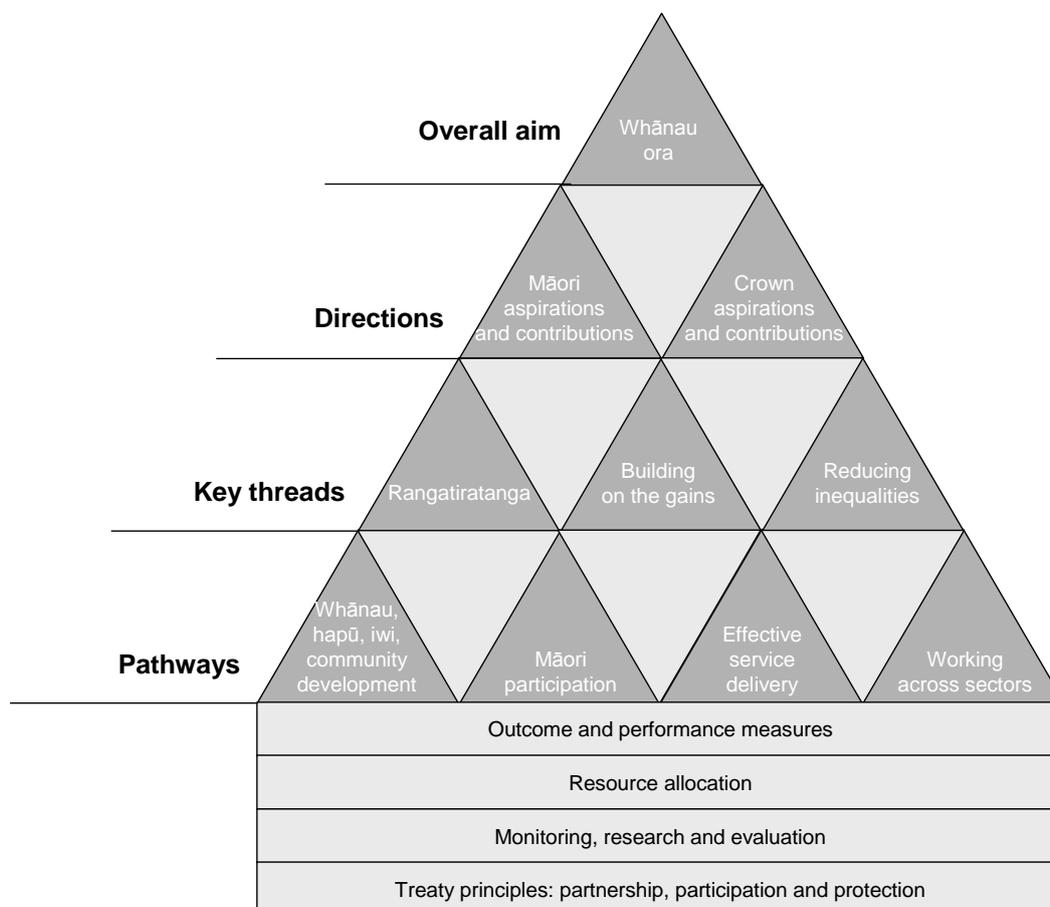
The New Zealand Health Strategy (Minister of Health 2000) sits alongside the New Zealand Disability Strategy (Minister for Disability Issues 2001) and both documents recognise the central role of the Treaty of Waitangi in their development and implementation. The New Zealand Disability Strategy provides for improved capacity of disabled Māori through the equitable allocation of resources, disability support services designed and provided by Māori for Māori, culturally appropriate services, and improved Māori disability workforce capacity (Minister for Disability Issues 2001). The Māori Disability Research Agenda aims to support research on Māori living with disability and their whānau/family (Ministry of Health 2011).

The Ministry of Health's Strategic Research Agenda is driven by the framework set out in He Korowai Oranga (Figure 6), the Government's Māori Health Strategy (Ministry of Health 2005). The overall aim of He Korowai Oranga is whānau ora, which is linked to the following three strategic research objectives:

1. Continue to build an evidence base that contributes to the achievement of whānau ora, more effective service delivery for Māori and improved health and disability outcomes for whānau.

2. Invest in high-quality research and evaluation that contributes to the achievement of whānau ora, more effective service delivery for Māori and improved health and disability outcomes for whānau.
3. Build Māori health research capacity that contributes to the achievement of whānau ora, more effective service delivery for Māori and improved health and disability outcomes for whānau.

Figure 6: How He Korowai Oranga works



This figure depicts the directions (which acknowledge the partnership between Māori and the Crown), key themes and pathways that set out how whānau ora will be achieved within He Korowai Oranga.

Source: Ministry of Health (2005), p2

4.6 Existing Māori health research partnerships

Significant developments are occurring in the area of community–researcher collaboration and there is potential for these collaborations to benefit Māori research with improved information sharing and documentation in this area.

Māori research partnerships can take many forms. Box 1 gives examples of three particular kinds of partnership: whānau–researcher; hapū–research organisation; and iwi–research organisation.

Box 1. Māori Health Research Partnerships

Whānau–researcher partnerships

In 2003, the New Zealand Listener reported on an extended partnership between a New Zealand genetic scientist and a Māori whānau that had suffered the loss of seven baby boys in two generations, most living for just a few hours after birth. The cause of the syndrome affecting the boys was discovered to be a single gene mutation called FLNA (Stirling 2003). As a whānau member explained:

Throughout the whole seven years of searching, [he] has kept in touch with us ... letting us know how he was doing, even when he was getting nowhere ... he would ring and track us down all over the country, and not just because he needed more blood. It has been very good for us as a family ... This was a very tender spot, none of us wanted to talk about it. It was a very freaky thing to have this keep happening in our family and not know why. ... What this research did for us is take away that overwhelming guilt, when you hold your baby and think, 'What did I do wrong? ... And it gave us choices. (Stirling 2003)

This research collaboration between the whānau and researcher was discussed with a health and ethics committee, which advised that the research could proceed without formal ethics approval.

Hapū–research organisation partnerships

A project to improve the quality of drinking-water in the Hokianga was conducted by a cross-cultural collaboration involving the Institute of Environmental Science and Research (ESR), a community health trust (Hokianga Health Enterprises Trust) and local hapū in the Hokianga. A report of the processes involved in this collaboration, *Learning from the Stories of Ngā Puna Wai o Hokianga*, describes trust as a key issue between the two collaborative parties:

... the fact that the hapū research participants were able to trust the non-Māori researchers in the research team was more important than being bilingual and bicultural. We found that just as Māori genetic make-up does not automatically qualify a person to research Māori, the ability of a non-Māori researcher in te reo and tikanga Māori does not automatically qualify them to be able to work with hapū. What hapū participants seek, in our experience, is that the researchers are trustworthy, and that they build credibility through their integrity as people and by their actions, whether they be indigenous or not, bi-cultural or not. In the process of forming cooperative research relationships, the researcher must prove their genuineness, worthiness, integrity, appropriateness, and any number of characteristics that may be desired by the potential research subjects.

This research described the following features of establishing trust.

- Appropriate research methodology is not only participatory but also based on Kaupapa Māori concepts.
- Non-Māori researchers released control of the research by allowing the research to be situated in Te Ao Māori, and by having the research led and the research data owned by hapū members.
- ESR and hapū co-researchers had a tuakana–teina relationship. This relationship was fluid, allowing each member to learn from the other, depending on the specific focus and the expertise required for each part of the research.

The researchers concluded that relevant cross-cultural aphorisms in this research included 'good things take time' and 'ka tika ā muri, ka tika ā mua' (if the process is right in the first place, then everything else will follow suit) (Hepi et al 2007).

Iwi-research organisation partnerships

Some iwi have developed elements of their own approach to research. For example, Ngāi Tahu and the University of Otago have a memorandum of understanding that '... gives effect to a Treaty of Waitangi based partnership' (University of Otago undated). This is one example of the potential ways in which iwi could develop their own approaches to research.

4.7 International guidance

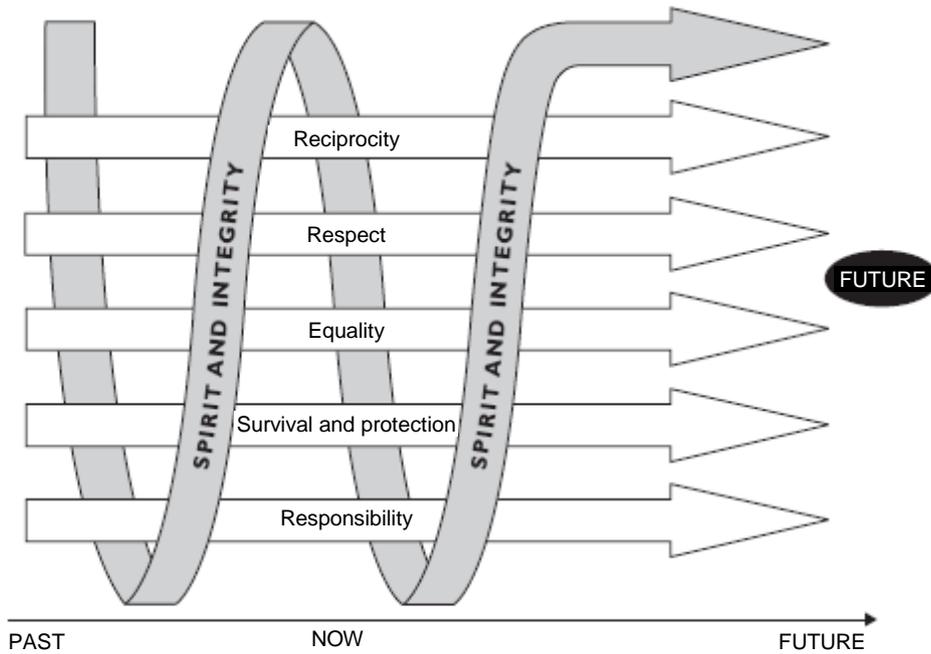
Internationally, a number of guidelines on research with indigenous communities have been developed. These guidelines tend to cover similar areas such as the importance of consultation, community involvement, cultural appropriateness, data and information ownership, appropriate publication, feedback and dissemination, and the need for research to benefit the researched community (McAullay et al 2002).

International research on indigenous perspectives of research ethics is also expanding. Examples of this include the World Health Organization's guidance on Indigenous peoples and participatory research (WHO 2003) and the principles and guidelines from the United Nations' Human Rights Commission, the *Protection of the Heritage of Indigenous People* (Daes 2000).

In 2003 the National Health and Medical Research Council of Australia published *Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. These guidelines were developed over an extended period and in consultation with Aboriginal and Torres Strait Islander communities. In accordance with guidance from these communities, this document is written around a framework of Aboriginal and Torres Strait Islander values and principles. Within this document there are details of six core values that drive ethical assessment for Aboriginal and Torres Strait Islander research. These principles (which are also represented in Figure 7) are:

- reciprocity
- respect
- equality
- responsibility
- survival and protection,
- spirit and integrity (National Health and Medical Research Council 2003).

Figure 7: Aboriginal and Torres Strait Islander peoples' values relevant to health research ethics



Source: National Health and Medical Research Council (2003), p 9

This Australian document suggests how researchers can demonstrate attention to each value, and aligns these suggestions to the Australian National Statement requirements for researchers (National Health and Medical Research Council 2007). The emphasis of these guidelines is to move from compliance with rules and regulations towards trustworthiness of both research and researchers as a product of ethical negotiation and engagement between people (National Health and Medical Research Council 2003).

There is no scope within this resource document to detail in depth the other international indigenous perspectives on ethical research. A number of other indigenous peoples have developed their own guidelines or agreements for research with or by their people. Examples include those from the Canadian Kahnaikehaka Nation and Mi'kmaq People of Nova Scotia (Kennedy and Wehipeihana 2006), and *The Ethics of Research Involving Aboriginal Peoples* (Ermine et al 2004), a report developed through a joint initiative of the University of Saskatchewan, the University of Regina and the First Nations University of Canada. These international indigenous perspectives commonly align with the themes of Māori research ethics discussed throughout this resource, including respect for cultural knowledge and traditions, indigenous partnerships, control over research protocols and participation, and ensuring benefits to indigenous communities from research.

5 Current and Future Issues

This section describes a number of issues identified in the literature as relevant to Māori health ethics, and for consideration by researchers (Reid et al 2000; Cram 2003; Powick 2002; R Robson 2004; Hudson 2004; Sporle and Koea 2004b; Kennedy and Wehipeihana 2006; Hudson et al 2010).

5.1 Ethnicity data collection

In recent years, a number of initiatives and activities have been undertaken to improve the quality of ethnicity data in health sector datasets, including the development of the Ethnicity Data Protocols for the Health and Disability Sector (the Ethnicity Data Protocols) (Ministry of Health 2004). See www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector. The Ethnicity Data Protocols describe procedures for the standardised collection, recording and output of ethnicity data for the New Zealand health and disability sector. They have been developed with input from a wide range of sector and government organisations.

It is intended that the promotion of the Ethnicity Data Protocols and their adoption by the health and disability sector will improve the accuracy and consistency of ethnicity data over time, and across the different collections of data and various uses of data analysis within the sector. From this reference document, materials more suitable for front-line data collectors and/or data providers can be generated. Standardised training and educational materials are also being developed and will be provided through the New Zealand Health Information Service.

On 1 July 2009 the ethnicity classification codes to be used in conjunction with the 2004 Ethnicity Data Protocols were updated to align with the Statistics New Zealand Statistical Standard for Ethnicity 2005. Supplementary Notes to the Ethnicity Data Protocols and a revised Codeset have been published to reflect this change and should be used in conjunction with the Ethnicity Data Protocols.

Also see www.ethnicity.maori.nz/discussion_papers/healthanddisability.php

5.2 Equal explanatory power

In Māori research, equal explanatory power refers to the power of research to generate findings and to offer explanations that are specific to Māori participants and their communities, alongside equal power to provide the same for non-Māori participants and their communities (Te Rōpū Rangahau Hauora a Eru Pōmare 2000; B Robson 2002).

In quantitative research of the general population, such as population surveys, this approach may require an over-sampling of Māori participants in order to achieve equal power for Māori and therefore produce information to improve Māori health to at least the same depth and breadth as that obtained to improve non-Māori health. Historically, research has typically involved a representative population sample (that is, approximately 15 percent Māori and 85 percent non-Māori), or even under-sampled for Māori due to inappropriate and/or ineffective methods to encourage Māori participation (such as using only postal questionnaires written in English). The conclusions and recommendations from such research therefore favour the rates or views of the numerically dominant non-Māori.

Equal explanatory power in both quantitative and qualitative research in New Zealand is important to ensure that research conclusions do not contribute to increasing inequality.

5.3 Age standardisation

The Māori population has a very young age structure, particularly compared with non-Māori. When researchers standardise data by applying 'older' standard populations such as the commonly used Segi's or the WHO world standard, the analysis favours health events that occur in older ages. However, where they use an indigenous standard, such as standardising to the Māori 2001 Census population, they produce rates that closely approximate crude data and therefore keep the Māori experience at the centre of the research analysis (B Robson et al 2007; Simmonds 2008).

Although further work is needed to assess the stability of the indigenous standard over time, the ethical incentive to use it remains. The Māori 2001 Census population standard has been applied in several key health publications (B Robson and Harris 2007; Ministry of Health 2010b; B Robson et al 2010, Ministry of Health 2012).

5.4 Deficit thinking

The concepts of deficit thinking and victim blame analyses (Valencia 1997; Ryan 1976, cited in Reid and Robson 2007) link closely to concerns about the way research is framed and focusing research on improving outcomes for Māori. The health disadvantage of Māori (such as consistently worse health outcomes) should not be considered as inherent to Māori ethnicity (based on cultural stereotypes or beliefs); nor should Māori be 'blamed' or held responsible for this health disadvantage. Instead, any analysis of the causes of these disparities should include a focus on the consequences of systemic and systematic disadvantage (Nazroo 1999; Reid et al 2000; Reid and Robson 2007).

Ethical Māori research should provide analysis and opportunity to advantage Māori and therefore help to counteract negative stereotypes. Avoiding deficit thinking is an important component of Māori research design and analysis. Including Māori researchers in the research team can assist in mitigating this risk.

5.5 Individuals and collectives

The expression of individual and collective rights within research is often framed as an 'either/or' situation. Many codes of ethics (such as those from universities or professional bodies) focus on the interests of individuals. It is therefore common practice for researchers to design materials such as privacy statements and consent forms with the aim of protecting the rights of individual research participants. This focus on the individual, and an emphasis on written over oral materials, may not always adequately address ethical principles for Māori, and indeed may at times be unsafe (Chetwin et al 2000). However, it has also been suggested that individual rights to consent and collective rights to consent serve different functions and can be used alongside each other (Hudson 2009). Individual consent to participate involves assessment of personal benefits and risks, and weighing these against the purpose of the study. Collective consent is a function of consultation with communities, via their nominated leaders or representatives who assess the benefits, risks, safety and usefulness of the study for their community.

The importance of Māori collectives (such as whānau, hapū and iwi) reflects key values of Māori research ethics described in this resource, such as whanaungatanga and kotahitanga.

One publication that attempts to address some issues involving both individuals and collectives is the *Ethical Guidelines for Observational Studies* (NEAC 2012, p 17-18). These guidelines state that:

6.30 For communities in which collective decision-making is customary, communal leaders can express the collective will. However, the agreement or refusal of individuals to participate in a study has to be respected: a leader may express agreement or refusal on behalf of a community, but an individual's agreement or refusal of personal participation is binding. When an individual wishes to participate in a study that community leaders have objected to, individuals should be given information to this effect and the reasons why community leaders have declined to take part. Having considered this information, the individual then has the right to decide whether to participate.

Paragraphs 6.31–6.35 should be interpreted in light of this paragraph.

6.31 Investigators who initiate a study within a whānau, a hapū or an iwi, when the investigators and participants are members of that same group, may prefer to provide, via a kaumatua or other person of authority in the group, a statement in the study proposal that group consent for participation was obtained from the representatives or participants in hui.

6.32 An individual's right to decline to participate in the study, expressed in hui, should also be noted. The statement of group consent obtained in hui should allow for study participants to withdraw at any time from the study if they so wish.

6.33 When the study is initiated from outside the whānau, hapū or iwi, or when the investigators do not have a representative from that group within their number, the usual procedures for informed consent to participate in the study are expected. In addition, a system of accountability of the investigators to the whānau, hapū or iwi concerned should be instituted after full discussion with and agreement by the participants and investigators. The group's right to decline to have a study proceed within their whānau, hapū or iwi if the study is unacceptable to them is paramount.

6.34 Not all Māori have contact with whānau, hapū or iwi, and the usual requirements for fully informed consent to participate in a study proposal will be expected in such cases.

6.35 When it is not possible to request informed consent from every individual to be studied (for example, in a community study of the effects of water fluoridation), the agreement of a representative of a community or group may be sought, but the representative should be chosen according to the nature, traditions and political philosophy of the community or group. Approval given by a community representative should be consistent with general ethical principles. When investigators work with communities, they will consider communal rights and protection as they would individual rights and protection.

Consideration can (and should) be given to collective consents in appropriate circumstances. Caution should be exercised to ensure that appropriate representation is fostered within the research process.

5.6 Cultural safety and cultural knowledge

Ensuring Māori ownership and control of cultural knowledge is a key principle in Māori research ethics. Traditionally, Māori knowledge was often passed on in an oral form and 'recorded' in memory. Those who received such knowledge were often specially chosen (H Mead 2003a). Research practices now rely almost exclusively on the written format, which makes it harder (particularly in the context of the globalised technological world) to protect cultural knowledge against misappropriation by others.

Kaupapa Māori research continues to emphasise the oral tradition. However, the current ethics committee system may not recognise the importance of this approach to maintain cultural safety and cultural integrity.

Māori continue to assert their cultural and intellectual property rights through a range of mechanisms, including: the Treaty of Waitangi (Article Two: protection of taonga), the United Nations Declaration on the Rights of Indigenous Peoples, the Waitangi Tribunal and the Mataatua Declaration (an affirmation of kaitiakitanga in relation to the intellectual property rights of Māori; see Appendix 5). Of particular concern to Māori is research that uses traditional plants and other natural resources. Specific concerns for Māori also arise from claims of intellectual property over natural and cultural properties, and the potential exclusionary nature of these intellectual property provisions (Gardiner 1997; Hudson 2004; Reynolds 2004; A Mead and Ratuva 2007; Tucker 2011).

5.7 Ethics for non-Māori researchers

Models of, and frameworks for, Māori research ethics such as those described in this resource are often developed to provide guidance to non-Māori researchers. Although Kaupapa Māori research methodologies advocate research by Māori for Māori, non-Māori **should** be involved in Māori research (particularly 'Research involving Māori'; and 'Māori-centred research') for many reasons. Through their involvement, non-Māori can help to fulfil Treaty of Waitangi obligations, foster the developing Māori research workforce and Māori development, and gain a form of professional training and culturally appropriate experience that increases the understanding and capacity of the non-Māori research workforce (Bishop 1997). As the Māori research workforce develops, the 'equal analytical power' (or the ability to analyse the outcomes of Māori research from a Māori viewpoint) will also improve. This in turn is likely to enhance the contribution Māori research can make to improving outcomes for Māori.

Māori research undertaken by non-Māori does, however, require caution, effective partnerships and application of ethical research principles such as those described in this resource. Where non-Māori with experience of te reo Māori and/or tikanga Māori are undertaking this research, they also need to recognise that non-Māori interpretation of these experiences may influence the effectiveness of research methodology and outcomes for Māori. Furthermore, the use of Māori consultants, advisors or research team members may not constitute an effective research partnership unless the principles of Māori research ethics described in this resource are valued and implemented, there is careful consideration of issues regarding power and cultural safety, and research guidance comes from Māori. Furthermore, it is important to recognise that some Māori researchers may also have limited experience with Māori communities and Māori research.

Frameworks, models and the ethical review system described in this resource can assist to overcome some of these cross-cultural issues, as can meaningful engagement with Māori. Researchers can also ask themselves the following questions (G Smith 1992).

- Who has helped define the research problem?
- For whom is this study worthy and relevant? Who says so?
- Which cultural group will be the one to gain new knowledge from this study?
- To whom is the research accountable?
- Who will gain most from the study?

Non-Māori researchers are also encouraged to:

- examine their own realities and attitudes that they bring to each research participant
- evaluate the impact of historical, political and social processes on people's attitudes towards their research topic
- demonstrate flexibility in their relationships (Tolich 2001).

Kaupapa Māori research has further implications for non-Māori researchers (L Smith 2005). A common view is that researchers involved in such research must have Māori identity. Others consider that non-Māori researchers can follow a methodology consistent with Kaupapa Māori research, particularly if they are conducting it in relationship with Māori, and the research remains true to the principles and values described in this document, focusing on the purpose and the beneficiaries of the research.

5.8 Meaningful engagement

Māori participation at all levels of Māori research is clearly a critical component of ethical Māori research. This document has described Māori participants, Māori partnerships and collaboration (with Māori individuals and collectives), guidance/mentoring by kaumātua, accountability to Māori, Māori researchers, and Māori as central to Kaupapa Māori research. It is important to recognise the complexity of developing relationships with Māori that are effective, are appropriate, involve a balance of power and are meaningful. A process of 'consultation' with Māori will be inadequate if those consulted play no part in framing the research question or if their opinions are not reflected in the analysis and research outcome. Instead, 'meaningful engagement' with Māori in research implies active participation and the development of significant relationships with Māori in order to incorporate Māori views and values throughout the research process.

It is also important to consider who to engage, and to ensure that those engaged are sufficiently knowledgeable to play a meaningful role. Concepts such as 'kia tūpato' (be cautious) and principles such as 'getting things right from the start' are important here so that Māori are given adequate opportunity and appropriate resources (including time) to become familiar with the processes, prospects, risks and benefits of the research proposal.

5.9 Benefit sharing

Equity and justice are ethical principles underpinning benefit sharing and highlighting its importance. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk vs benefit, short vs long term) and how they will be distributed (researcher vs participant vs community vs society). It is a legitimate outcome for researchers to benefit from their involvement in research but they should also consider the possible benefits for Māori participants and their communities.

5.10 Research areas of specific concern to Māori

5.10.1 The body and its parts

Māori and indigenous people generally consider the body to be tapu (Dansey 1992; Reynolds 2004; Hutchings 2009). Researchers involved in health or medical research that involves the body, or any part of the body such as organs, blood, hair, saliva and/or other tissue, must do so in a respectful manner (Auckland District Health Board 2003). The collection of human tissue is particularly sensitive when it involves the use of a deceased person's tissue (Hudson et al 2008). Where research involves the body and its parts, concerns for Māori have been expressed (Sporle and Koea 2004b; A Mead and Ratuva 2007; Hutchings 2009; Hudson et al 2010) in relation to:

- the nature of consent for such research
- consent for future and undisclosed or unknown use
- ongoing storage in tissue banks
- the establishment of cell lines.

5.10.2 Genetic research

Genetic research is an area of prime sensitivity for Māori because of its association with whakapapa. Early genetic research focused on identifying single genes responsible for specific familial disorders. However, radical technological advancements such as high throughput testing and genome-wide scanning techniques have made it possible to examine complex conditions influenced by multiple genes and environmental factors to determine population susceptibility. The association of genetic susceptibility to disease with ethnicity is problematic for population genetic research, with the potential for community disruption, stigmatisation, stereotyping or undermining either through research processes or outcomes. Care needs to be taken to avoid such harm, which can be inflicted by using incorrect terms, for example 'Māori genes'.

Māori communities are also concerned about new technologies and research in areas such as genetic engineering, the creation of transgenic life-forms, xenotransplantation, and human genome research investigating human variation and diversity in indigenous populations (IRI 2000; Reynolds 2004; Hutchings 2009; Hudson et al 2010; Taupo 2012).

6 Summary

Gains in Māori research ethics are likely to be achieved through the developing Māori research workforce, the growing body (and improved availability) of literature describing the key components of ethical research practice for Māori, Treaty of Waitangi training courses for researchers, engagement of Māori advisors, advisory panels and communities, ongoing attention to the evaluation of the ethical review system, and a stronger focus in academic work and government policy on achieving equity.

Expectations of what constitutes ethical behaviour in Māori research have evolved over time and can be expected to continue to develop in the future, reflecting changing dynamics in our society. This document offers a summary of published information on Māori research ethics, with a focus on health and disability research. It is designed as a resource for those interested in Māori research ethics, to identify the important issues for Māori research ethics, and to assist researchers, ethics committees, and communities to improve relationships and research experiences for Māori. This resource is not intended to prevent or to constrain research endeavours. Rather, its fundamental purpose is to enhance research quality, to improve research outcomes and to maintain robust ethical standards for all New Zealanders.

Central to the discussion of Māori research ethics in this document is the need to:

- incorporate key principles and values, such as tikanga Māori and mātauranga Māori, that are appropriate for Māori and stem from a Māori world view
- understand and address the implications of the Treaty of Waitangi
- consider issues of power and equity, including in research development, methodology, implementation and analysis
- ensure cultural safety, protect knowledge and engage meaningfully with Māori
- align with Māori priorities
- improve outcomes for Māori.

This document has described a number of frameworks and models that those in health and disability and other sectors can use to consider Māori research ethics. These frameworks often present questions for the researcher to consider during the research development phase, to ensure the research is ethical for Māori. The frameworks and models described in this resource all discuss the importance of meaningful engagement with Māori communities. A focus on caution, trust, relationships, respect, consequences and outcomes is commonly described as central to the Māori ethic, and improving Māori ethical understanding will make a valuable contribution to ethical practice in research and society.

Glossary of Māori Terms

Term	Explanation in the context of this document
Aroha	Love, respect, empathy
Aroha ki te tangata	A respect for people
Hau	Wind, vital essence, vitality of life
Hauora	Health, wellbeing
Hapū	Sub-tribe
Hui	Meeting, gathering
Io	Supreme being, source of life
Ira tangata	Human element
Iwi	Tribe
Kaitiaki	Guardian
Kaitiakitanga	Guardianship, preservation, protection and connection with the elements that link the spiritual and physical world
Kanohi ki te kanohi	Face-to-face
Kanohi kitea	The seen face
Kaua e takahia te mana o te tangata	Do not trample over the mana of people
Kaumātua	Elders
Kaupapa Māori	Māori ideology
Kawa	Protocol
Kāwanatanga	Government
Kia āta haere	Proceed with understanding or care
Kia āta kōrero	Conduct robust or considered discussion
Kia āta whakaaro	Conduct precise or robust analysis
Kia āta whiriwhiri	Consciously determine
Kia māhaki	To be humble, modest
Kia tūpato	Be cautious, be careful, be considered
Koha	Gift, offering, contribution
Kōrero	Speak, talk, discussion
Kotahitanga	Solidarity, oneness. This concept also links to the holistic nature of health from a Māori perspective where the physical, spiritual, psychological, environmental and social aspects must be in balance to achieve wellbeing
Māhaki	Respect, humility, modesty

Term	Explanation in the context of this document
Mana	Power, prestige, leadership and authority bestowed, gained or inherited individually and collectively. In Māori research ethics, mana relates to equity and distributive justice in terms of the potential or realised risks, benefits and outcomes of the research. It also acknowledges issues of power and authority in relation to who has rights, roles and responsibilities when considering such risks, benefits and research outcomes
Manaaki ki te tangata	to host people, be generous
Manaakitanga	Caring for others, nurturing relationships and being careful about how others are treated
Mana motuhake	Self-determination, separate identity, autonomy, self-determination
Mana tangata	Dignity, power, authority of the people
Mana whakahaere	Governance
Mātauranga	Knowledge, wisdom, understanding
Matemateāone	Feeling for the land, connection to the land and to all things connected to the land, feeling of connection to your home (a Tuhoe term)
Mauri	The life essence of a person or object
Mihimihi	To greet, thank, acknowledge
Ngākau māhaki	Respect, to be respectful, pleasant
Noa	Restoring balance, removing tapu
Nohotahi	Cooperation
Oritetanga	Fairness and equity
Pono	To be true, valid, honest
Rangatiratanga	Authority, responsibility, ownership, self-determination
Rongoā	Remedy, medicine
Taonga	Treasure or something that is valued
Take-utu-ea	A process of resolution
Tāngata whenua	Literally 'the people of the land'; relates to local iwi, hapū and whānau
Tapu	Sacred values
Te Ao Māori	The Māori world view
Te Ao Wairua	The spiritual realm
Te reo	Language
Te Wheke	The Octopus. This describes a Māori model of health where each of the eight tentacles of the octopus symbolises: whanaungatanga (social), hinengaro (intellectual), whatumanawa (emotional), ao tūroa (physical), wairua (spiritual), mauri (psychological), mana (personal) and taonga tuku iho (cultural)
Tiaki	Guide, help, assist
Tika	What is right and good for any particular situation

Term	Explanation in the context of this document
Tikanga	Customs
Titiro	Look
Tuakana–teina	Older sibling–younger sibling relationship
Tūmanako	hope
Uha	Female, femininity
Utu	Compensation or reciprocity, and the maintenance of harmony and balance
Wairua	Spirit, soul
Wairuatanga	Spirituality
Wakaritenga	Legitimacy
Wānanga	To meet and discuss; a seminar, conference or tertiary institution that caters for Māori learning needs; tribal knowledge, learning; an instructor, expert
Whakaaro	Thoughts, opinion, understanding
Whakapono	To believe
Whakarongo	Listen
Whakatau	Prepare, settle, welcome
Whakaiti	Make small, lessen
Whakamana	Give authority to, empower, enable
Whakapapa	Genealogy, lineage, descent
Whānau	Family, relations, extended family
Whanaungatanga	A concept that recognises the pivotal role of kinship bonds and whānau (family, relations) for Māori research and therefore encompasses whakapapa and includes relationships to non-kin who have become kin-like through shared experience and connection
Whānau ora	The goal of the New Zealand Māori Health Strategy: all whānau members living longer and enjoying a better quality of life
Whāngai	To foster, adopt
Whare Tapa Whā	A model of Māori health based on a four-sided house, consisting of: te taha wairua (spiritual wellbeing); te taha hinengaro (mental emotional wellbeing); te taha tinana (physical wellbeing); and te taha whānau (extended family wellbeing and identity)

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Appendix 1: Selected Timeline of Developments in Māori Research Ethics

Date	Hui/publication	Purpose/outcome
1991	Ngahuia Te Awekotuku publishes <i>He Tikanga Whakaaro</i>	
June 1993	First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples (Whakatane)	Passed the Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples.
December 1993	The Ministry of Health establishes Māori Working Group on Health Sector Ethics	Established to assist the Interim Taskforce on Health and Disability Service Ethics and Interim National Ethics to find ways of reflecting tikanga in the process of ethical review.
March 1994	Te Ara Ahu Whakamua, Māori Health Decade Hui	Called for a Māori research ethics framework.
1994	Te Puni Kōkiri publishes <i>Health Sector Ethics: Nga Tikanga Pono Wahanga Hauora</i>	
1996	First meeting Pū Tai Ora	
September 1996	Hui Whakapiripiri, Wellington (HRC)	Discussed strategic directions for Māori health research, including ethics, mechanisms for guardianship and protection, tikanga/kaupapa Māori as a guiding principle, and commitment to kaitiakitanga. Delegates accepted the Hongoeka Declaration for Māori Health Researchers and endorsed the Mataatua Declaration (1993).
December 1997	Hui Whakatipu/piripiri, Whaiora Marae, Otara, Auckland (HRC)	Endorsed the Hongoeka Declaration 1996. Discussed ethics and intellectual property including training on Māori ethical principles and issues, the need for kaitiakitanga and support for a national Māori health research ethics committee.
July 1998	Te Oru Rangahau Māori Research Conference, Palmerston North	
1998	HRC produces <i>Guidelines for Researchers on Health Research Involving Māori</i>	Purpose to help develop: 1) research partnerships between health researchers and Māori communities or groups on issues important to Māori health; and 2) research practices that ensure biomedical, clinical and public health research effectively contributes to Māori health development.
1998/1999	Pū Tai Ora – tikanga Māori, Māori ethical principles, training/education	

Date	Hui/publication	Purpose/outcome
1999	Te Puni Kōkiri publishes <i>Evaluation for Māori: Guidelines for government agencies</i>	Purpose to assist those involved in evaluation as policy analysts, evaluators, and researchers working in government agencies. The guidelines outline how quality information can be collected from and about Māori (Te Puni Kōkiri 1999, p 7).
1999	Linda Smith publishes <i>Decolonising Methodologies: Research and indigenous peoples</i> (Smith 1999)	Smith calls for the decolonisation of research methods and critically examines the historical and philosophical base of Western research. She explores frustrations with various Western paradigms, academic traditions and methodologies.
28 February – 1 March 2000	Report of the seminar on the draft principles and guidelines for the protection of the heritage of indigenous people (UN Commission on Human Rights, Geneva)	The report calls attention to the need to develop effective principles and modes of legal protection of indigenous people's heritage.
2001	Fiona Cram publishes <i>Rangahau Māori: Tona tika tona pono: The validity and integrity of Māori researchers</i>	
2001	Te Pū Tai Ora Wānanga	Supporting an initiative from Māori members of ethics committees, the HRC asked Tariana Turia, Associate Minister of Health with responsibilities for Māori health, for resources to develop a framework for Māori ethical review of health research. Two wānanga of Māori ethics committee members resulted. Issues discussed include: what ethics are from a Māori perspective, the role of ethics committees, questions that need to be considered when reviewing research proposals, self-determination, Māori ethical principles/models for decision-making, representation within whānau, hapū and iwi, and quality of consultation.
March 2002	Ministry of Health publishes <i>Operational Standard for Ethics Committees</i>	The <i>Operational Standard</i> , later updated in 2006, includes guidance on research involving Māori.
2002	Te Pū Tai Ora Wānanga	Māori researchers and participants attended two wānanga on the development of a framework for Māori ethical review of health research. Topics included kaitiakitanga/tikanga Māori, and a request for resources to develop a Māori framework for ethical review.
2002	Kiri Powick publishes <i>Ngā Take Matatika mō te mahi Rangahau Māori. Māori research ethics: a literature review of the ethical issues and implications of kaupapa Māori research and research involving Māori for researchers, supervisors and ethics committees</i>	

Date	Hui/publication	Purpose/outcome
2002	Minister of Health requests NEAC to take responsibility for developing a Māori framework for ethical review of health and disability research	
2003	Hirini Mead publishes <i>Tikanga Māori: Living by Māori values</i> (Mead 2003a)	
2003	NEAC completes key informant interviews (six individual and two group discussions)	Participants were asked about ethical issues arising for Māori when carrying out Māori health and disability research and how NEAC could be responsive to those issues. NEAC produced a report outlining these initial discussions (Cram 2003).
December 2003	NEAC publishes <i>Review of the Current Processes for Ethical Review of Health and Disability Research in New Zealand</i>	The Minister of Health accepted NEAC's recommendations in May 2004.
June 2004	Mātauranga Tuku Iho Tikanga Rangahau	Ngā Pae o te Māramatanga hosts a Traditional Knowledge and Research Ethics Conference in Wellington. Conference sponsors include NEAC.
2004	NEAC, the HRC and Ngā Pae o te Māramatanga establish a collaborative relationship to facilitate development of a Māori framework for health and disability research ethics	
2004	Maui Hudson publishes <i>He Matatika Māori: Māori and ethical review of health research</i>	
2004	Rachel Robson writes <i>Māori Framework for Ethical Review of Health and Disability Research: Scoping report to the National Advisory Committee on Health and Disability Ethics</i>	
December 2004	NEAC agrees to Māori Health Research Ethics Framework Project Plan	
March – June 2005	Meetings of the three partner organisations' joint working group on Māori framework. A pānui is also drafted outlining the collaboration	
2005	Hui Whakapiripiri	Participants discuss the quality of Māori consultation process, systems for monitoring gene/tissue banking, and ethics application form.

Date	Hui/publication	Purpose/outcome
2005	Pū Tai Ora hui	Themes discussed include Māori members' role, quality of consultation and representation, need for consensus and consistency, frameworks and models for decision-making on Māori ethical issues, and the need for more information in a number of areas.
January 2006	NEAC's contracted stocktake on how the central issues in New Zealand and other countries have so far been addressed is completed (Kennedy and Wehipeihana 2006)	Purpose to undertake a stocktake and analysis of national and international frameworks, policies, guidelines, standards and other public statements for research involving indigenous peoples, with a particular focus on health and disability research.
2006	Hui Whakapiripiri	Participants discuss Ngāi Tahu ethics, Rod Lea effect, ethical issues for Māori, and role of Māori ethics committee members.
2006	NEAC drafts an issues paper	The issues paper compiles work to date to use as a resource to progress the project.
October 2006	Pū Tai Ora hui	Māori and Pacific members of the health and disability ethics committees meet.
June 2007	Meeting of NEAC, HRC and Ngā Pae o te Māramatanga	Participants re-confirm partnership and discuss future project steps.
June 2007	Pū Tai Ora hui	Māori and Pacific members of the health and disability ethics committees meet.
October 2007	Meeting of NEAC, HRC and Ngā Pae o te Māramatanga	Participants agree on new project plan and next steps in project, including producing this resource document.
2008	HRC updates its 1998 <i>Guidelines for Researchers on Health Research Involving Māori</i>	
2008	HRC hosts the 9th Global Forum on Bioethics in Research, with the theme: Ethics of research involving indigenous peoples and vulnerable populations	Mason Durie presents 'Bioethics, Indigeneity and Māori Experience'
2008–2009	Pū Tai Ora Māori Research Ethics Framework Writing Group resourced to workshop and develop draft framework	
2010	HRC updates the 2008 <i>Guidelines for Researchers on Health Research Involving Māori</i> Version 2	
2010	Māori Research Ethics Guideline Writing Group publish <i>Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members</i> . Health Research Council (Hudson et al 2010)	

Date	Hui/publication	Purpose/outcome
2012	A second edition of <i>Decolonising Methodologies: Research and indigenous peoples</i> is published (Smith 2012)	
2012	Changes to health and disability ethics committees come into effect on 1 July 2012, including the new <i>Standard Operating Procedures for Health and Disability Ethics Committees</i> (Ministry of Health 2012)	
2012	NEAC finalises <i>Āhukatanga ū ki te tika me te pono mō te Rangahau Māori</i> <i>Māori Research Ethics: An overview</i>	

Appendix 2: Example of Kaupapa Māori Research

An example of Kaupapa Māori research was presented in 2006 from independent research commissioned by the Families Commission Blue Skies Fund. The purpose of the research was to determine the capabilities of whānau to adapt to their circumstances and maintain their wellbeing when one or more of their members lived with a disability.

Kaupapa Māori principles underpinning this research included:

- **whanaungatanga** – acknowledging the value of existing relationships between participants and other people; approaching participants through the existing relationships that they had; introducing interviewers to participants before the interviews were held
- **whakapapa** – acknowledging the culture, places and hapū/iwi to which participants belonged; explaining interviewers' whakapapa to participants and making whakapapa connections
- **whakamana** – respecting the participants' decisions and opinions
- **tikanga** – respecting cultural customs
- **kawa** – respecting cultural practices in participants' homes
- **mihimihi** – acknowledging each other's whakapapa and the possibility of whānau connections
- **koha** – acknowledging the informants' sharing of knowledge by offering a gift in return and by providing feedback on the project
- **whakaiti** – researchers' humble approach to the possibility that participants may lack confidence in the value of their views and opinions
- **tuakana-teina** – acknowledging participants as the knowledge-holders and researchers as the knowledge-seekers
- **whakatau** – respecting the need to 'settle-in' with each other before engaging in the interviews.

The application of these principles is described in more detail in the final report, *The Role of Whānau in the Lives of Māori with Physical Disabilities* (Collins and Hickey 2006, p 6).

Appendix 3: Health Equity Assessment Tool (Equity Lens) for Tackling Inequalities in Health

Source: Ministry of Health (2004). URL: www.health.govt.nz/publication/health-equity-assessment-tool-equity-lens-tackling-inequalities-health

There is considerable evidence, both internationally and in New Zealand, of significant inequalities in health between socioeconomic groups, ethnic groups, people living in different geographical regions and males and females (Acheson 1998; Howden-Chapman and Tobias 2000). Research indicates that the poorer you are, the worse your health. In some countries with a colonial history, indigenous people have poorer health than others. Reducing inequalities is a priority for government. The New Zealand Health Strategy acknowledges the need to address health inequalities as 'a major priority requiring ongoing commitment across the sector' (Minister of Health 2000).

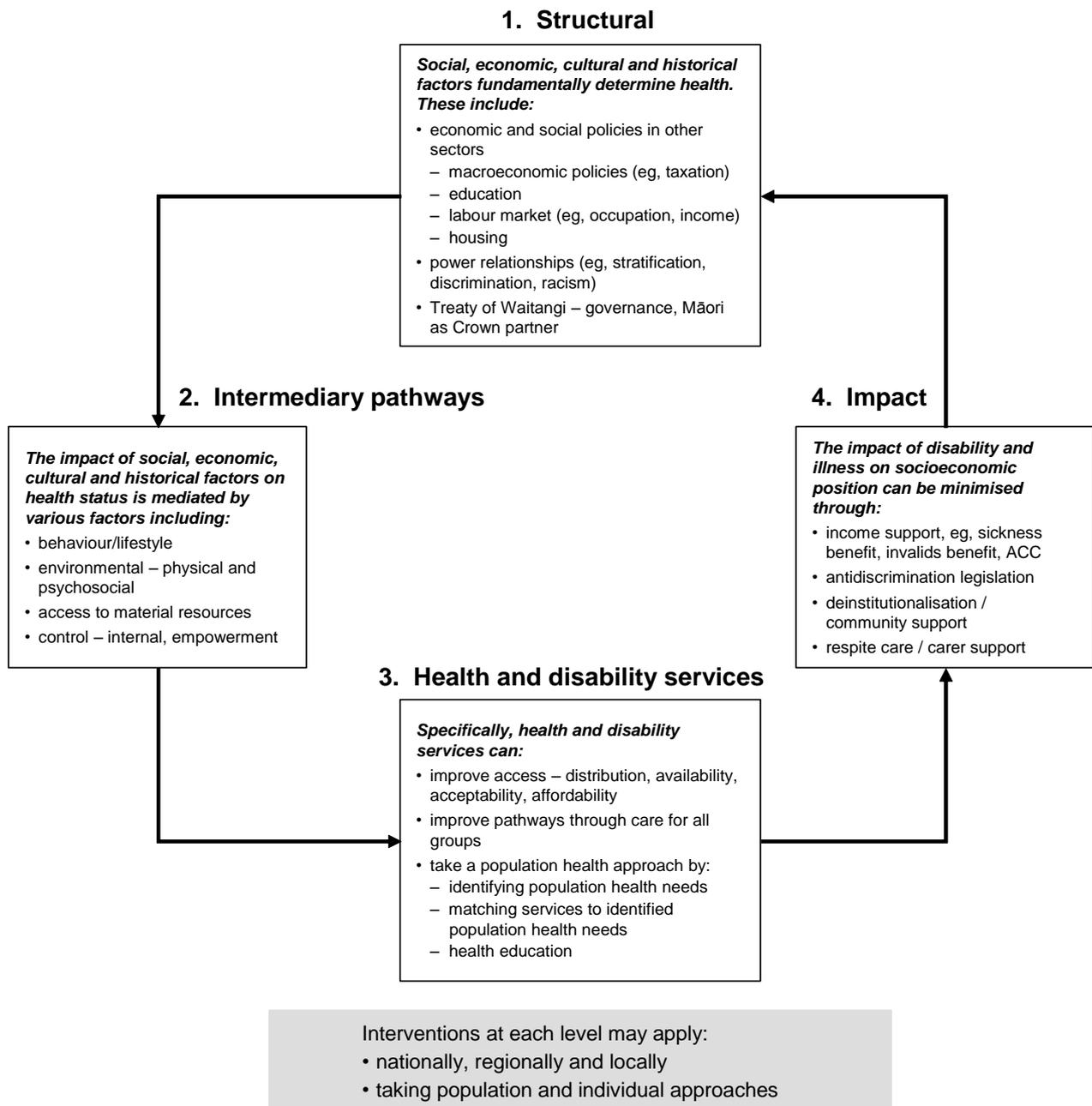
Inequalities in health are unfair and unjust. They are also not natural; they are the result of social and economic policy and practices. Therefore, inequalities in health are avoidable (Woodward and Kawachi 2000).

The following set of questions has been developed to assist you to consider how particular inequalities in health have come about, and where the effective intervention points are to tackle them. They should be used in conjunction with the Ministry of Health's Intervention Framework (Ministry of Health 2002).

1. What health issue is the policy/programme trying to address?
2. What inequalities exist in this health area?
3. Who is most advantaged and how?
4. How did the inequality occur? (What are the mechanisms by which this inequality was created, is maintained or increased?)
5. What are the determinants of this inequality?
6. How will you address the Treaty of Waitangi in the context of the New Zealand Public Health and Disability Act 2000?
7. Where/how will you intervene to tackle this issue? Use the Ministry of Health Intervention Framework to guide your thinking.
8. How could this intervention affect health inequalities?
9. Who will benefit most?
10. What might the unintended consequences be?
11. What will you do to make sure it does reduce/eliminate inequalities?
12. How will you know if inequalities have been reduced/eliminated?

Appendix 4: Intervention Framework to Improve Health and Reduce Inequalities

Source: Ministry of Health (2002)



Appendix 5: The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples

Source: www.wipo.int/export/sites/www/tk/en/folklore/creative_heritage/docs/mataatua.pdf

In recognition that 1993 is the United Nations International Year for the World's Indigenous Peoples; The Nine Tribes of Mataatua in the Bay of Plenty Region of Aotearoa New Zealand convened the First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples (12–18 June 1993, Whakatane).

Over 150 delegates from fourteen countries attended, including indigenous representatives from Ainu (Japan), Australia, Cook Islands, Fiji, India, Panama, Peru, Philippines, Surinam, USA, and Aotearoa.

The conference met over six days to consider a range of significant issues, including; the value of indigenous knowledge, biodiversity and biotechnology, customary environmental management, arts, music, language and other physical and spiritual cultural forms. On the final day, the following Declaration was passed by the Plenary.

Preamble

Recognising that 1993 is the United Nations International Year for the world's indigenous peoples

Reaffirming the undertaking of United Nations member states to –

“Adopt or strengthen appropriate policies and/or legal instruments that will protect indigenous intellectual and cultural property and the right to preserve customary and administrative systems and practices” – United Nations Conference on Environmental Development; UNCED Agenda 21 (26.4b)

Noting the working principles that emerged from the United Nations Technical Conference on Indigenous Peoples and the Environment in Santiago, Chile from 18–22 May 1992 (E/CN.4/Sub.2/1992131)

Endorsing the recommendations on culture and science from the World Conference of Indigenous Peoples on Territory, Environment and Development Kari-Oca, Brazil, 25–30 May 1992

Declare that indigenous peoples of the world have the right to self determination and in exercising that right must be recognised as the exclusive owners of their cultural and intellectual property

Acknowledge that indigenous peoples have a commonality of experiences relating to the exploitation of their cultural and intellectual property

Affirm that the knowledge of the indigenous peoples of the world is of benefit to all humanity

Recognise that indigenous peoples are capable of managing their traditional knowledge themselves, but are willing to offer it to all humanity provided their fundamental rights to define and control this knowledge are protected by the international community

Insist that the first beneficiaries of indigenous knowledge (cultural and intellectual property rights) must be the direct indigenous descendants of such knowledge

Declare that all forms of discrimination and exploitation of indigenous peoples, indigenous knowledge and indigenous cultural and intellectual property rights must cease.

1 Recommendations to indigenous peoples

In the development of policies and practices, indigenous peoples should:

- 1.1 define for themselves their own intellectual and cultural property
- 1.2 note that existing protection mechanisms are insufficient for the protection of indigenous peoples' intellectual and cultural property rights
- 1.3 develop a code of ethics which external users must observe when recording (visual, audio, written) their traditional and customary knowledge
- 1.4 prioritise the establishment of indigenous education, research and training centres to promote their knowledge of customary environmental and cultural practices
- 1.5 reacquire traditional indigenous lands for the purpose of promoting customary agricultural production
- 1.6 develop and maintain their traditional practices and sanctions for the protection, preservation and revitalisation of their traditional intellectual and cultural properties
- 1.7 assess existing legislation with respect to the protection of antiquities
- 1.8 establish an appropriate body with appropriate mechanisms to:
 - a) preserve and monitor the commercialism or otherwise of indigenous cultural properties in the public domain
 - b) generally advise and encourage indigenous peoples to take steps protect their cultural heritage
 - c) allow a mandatory consultative process with respect to any new legislation affecting indigenous peoples' cultural and intellectual property rights
- 1.9 establish international indigenous information centres and networks
- 1.10 convene a Second International Conference (Hui) on the cultural and intellectual property rights of indigenous peoples to be hosted by the Coordinating Body for the Indigenous Peoples Organisations of the Amazon Basin (COICA).

2 Recommendations to states, national and international agencies

In the development of policies and practices, states, national and international agencies must:

- 2.1 recognise that indigenous peoples are the guardians of their customary knowledge and have the right to protect and control dissemination of that knowledge
- 2.2 recognise that indigenous peoples also have the right to create new knowledge based on cultural traditions
- 2.3 note that existing protection mechanisms are insufficient for the protection of indigenous peoples' cultural and intellectual property rights
- 2.4 accept that the cultural and intellectual property rights of indigenous peoples are vested with those who created them
- 2.5 develop in full co-operation with indigenous peoples an additional cultural and intellectual property rights regime incorporating the following:
 - collective (as well as individual) ownership and origin
 - retroactive coverage of historical as well as contemporary works
 - protection against debasement of culturally significant items
 - cooperative rather than competitive framework
 - first beneficiaries to be the direct descendants of the traditional guardians of that knowledge
 - multi-generational coverage span.

Biodiversity and customary environmental management

- 2.6 Indigenous flora and fauna is inextricably bound to the territories of indigenous communities and any property right claims must recognise their traditional guardianship.
- 2.7 Commercialisation of any traditional plants and medicines of indigenous peoples, must be managed by the indigenous peoples who have inherited such knowledge.
- 2.8 A moratorium on any further commercialisation of indigenous medicinal plants and human genetic materials must be declared until indigenous communities have developed appropriate protection mechanisms.
- 2.9 Companies, institutions both governmental and private must not undertake experiments or commercialisation of any biogenetic resources without the consent of the appropriate indigenous peoples.
- 2.10 Prioritise settlement of any outstanding land and natural resources claims of indigenous peoples for the purpose of promoting customary, agricultural and marine production.
- 2.11 Ensure current scientific environmental research is strengthened by increasing the involvement of indigenous communities and of customary environmental knowledge.

Cultural objects

- 2.12 All human remains and burial objects of indigenous peoples held by museums and other institutions must be returned to their traditional areas in a culturally appropriate manner.
- 2.13 Museums and other institutions must provide, to the country and indigenous peoples concerned, an inventory of any indigenous cultural objects still held in their possession.
- 2.14 Indigenous cultural objects held in museums and other institutions must be offered back to their traditional owners.

3 Recommendations to the United Nations

In respect for the rights of indigenous peoples, the United Nations should:

- 3.1 ensure the process of participation of indigenous peoples in United Nations fora is strengthened so their views are fairly represented
- 3.2 incorporate the Mataatua Declaration in its entirety in the United Nations Study on Cultural and Intellectual Property of Indigenous Peoples
- 3.3 monitor and take action against any states whose persistent policies and activities damage the cultural and intellectual property rights of indigenous peoples
- 3.4 ensure that indigenous peoples actively contribute to the way in which indigenous cultures are incorporated into the 1995 United Nations International Year of Culture
- 3.5 call for an immediate halt to the ongoing 'Human Genome Diversity Project' (HUGO) until its moral, ethical, socioeconomic, physical and political implications have been thoroughly discussed, understood and approved by indigenous peoples.

4 Conclusion

- 4.1 The United Nations, international and national agencies and states must provide additional funding to indigenous communities in order to implement these recommendations.

Appendix 6: The Hongoeka Declaration for Māori Health Researchers

He Putorino ka tangi
He kupu whakairi ka puta ki te ao
Korero atu ra mo toku mana motuhake
Tenei te whakapiki koianeī te whakakake
Tihei mauri ora.

Like the flute that sounds
Words suspended taking a message to the world
Speak to them of my mana motuhake
Tis on the rise, tis onward morning
Tihei mauri ora.

As Māori researchers in the area of Māori health we are committed to working for research which contributes towards hapū, iwi, tāngata whenua development. This process means regaining Tino Rangatiratanga and overcoming the negative impacts of colonisation. We acknowledge the Treaty of Waitangi as the basis for partnership between Māori and the Crown and will work to incorporate the values underpinning the Treaty in our work.

As a result of this hui, we declare that:

- we endorse the Mataatua Declaration on the Rights of Indigenous Peoples' over their cultural and intellectual property
- we believe Māori health research should be determined and coordinated by Māori, working with Māori for Māori
- we support Māori determination for our standards of health and wellbeing
- we will work towards Māori control over policies, priorities and funding decisions relevant to Māori research
- as partners to the Treaty, Māori reserve the right to use any approach to health research that will benefit our people
- we will promote and develop kaupapa Māori methodology and methods
- we are committed to promoting te reo Māori and tikanga Māori as appropriate for Māori health research
- we believe that research encompasses the past, the present and the future
- we recognise that there are diverse Māori realities
- we are accountable to whānau, hapū and iwi
- we will monitor, critique, and discuss, including in hui and public forums, all research impacting on Māori health and
- we are committed to strengthening the community of Māori health researchers and urge all relevant supporting organisations to urgently develop this workforce.

Hui Whakapiripiri, Hongoeka Marae, Plimmerton, February 1996