

# The Development of Guidelines for Indigenous Research Ethics in Aotearoa/New Zealand

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## **Abstract**

The development of Indigenous frameworks for research ethics has been a key component of progressing Indigenous aspirations for research around the world. They have provided a focal point for challenging approaches to research that prioritise non-Indigenous methods and values, and allow non-Indigenous researchers to claim expert status over Indigenous peoples, places and knowledges. The theme of self-determination underpins contemporary approaches to Indigenous development and the repositioning of state-Indigenous nation relationships. This paper describes the background, development, and implementation by Māori communities and researchers of an Indigenous ethical framework in Aotearoa/New Zealand.

## **Introduction**

The development of Indigenous frameworks for research ethics has been a key component of progressing Indigenous aspirations for research around the world. They have provided a focal point for challenging approaches to research that prioritise non-Indigenous methods and values, and allow non-Indigenous researchers to claim expert status over Indigenous peoples, places and knowledges. There are tensions with 'outsiders' doing research 'on' Indigenous peoples, and also sometimes tensions within our own Indigenous communities around research methods and values, and what is considered ethical and not ethical. These tensions are particularly apparent when research involves new technologies.

The theme of self-determination underpins contemporary approaches to Indigenous development and the repositioning of state-Indigenous nation relationships. This paper describes the background, development, and implementation by Māori communities and researchers of an Indigenous ethical framework in Aotearoa/New Zealand.

## **Background**

Colonisation of Indigenous communities has been an outcome of the globalisation of Western ideas, values and lifestyles. Through this process the identities of many Indigenous communities have been redefined as they are incorporated into a global network of complex societies comprised of different communities and different cultures (Smith, Burke et al. 2000). The processes of colonisation have had a marked effect on the ability of Indigenous peoples to control their existence within the world. As Smith (1997) writes,

*The whole process of colonisation can be viewed as a stripping away of mana (our standing in our own eyes) and an undermining of rangatira-tanga (our ability and right to determine our destinies). Research is an important part of the colonisation process because it is concerned with defining legitimate knowledge. (Smith 1997, 185)*

The resurgence in discourse around Indigenous knowledges, Indigenous identities and Indigenous rights, culminating in the Declaration on the Rights of Indigenous Peoples (UN General Assembly, 2007), represents a reclaiming of status, an examination of the importance of relationships to a particular area and the special bond between the people and the land (Ratima 2001). In Aotearoa/New Zealand, this is affirmed by the Māori term ‘tangata whenua’ or ‘people of the land’ which is also used to describe indigeniety. Tangata whenua rights have been recognised as Indigenous rights and differ from those bestowed on a minority or those with a marginalised status (ie. socioeconomic deprivation) (Reid et al 2000). In the research context, Robson and Reid (2001) have summarised tangata whenua rights as;

- the right of self-determination,
- the right to equity of values,
- the right to collective well-being,
- the right to equal quality of information, and
- the right to policy based on evidence that is valid for Māori.

The articulation of rights and interests as they relate to research are part of reclaiming control of the research process and definitions of knowledge. Repositioning Māori from being ‘subjects’ of research to active researchers and creators of knowledge challenges the appropriateness of non-Indigenous research approaches and their ability to contribute to Māori development. The development of Māori (and Indigenous) research methodologies provides the foundation for researching

in a more respectful manner. For example, Kaupapa Māori research is a uniquely Māori methodology that is grounded in Māori values and ethics, privileges Māori knowledge and ways of knowing, and reinforces cultural protocols to inform ethically robust research relationships. Common characteristics of Māori research are based on respect for Māori preferences, Māori control of research processes and the need for benefits to be realised in the Māori community. Principles to guide researchers when working with Māori align to qualities valued by the Māori community. These characteristics, principles and qualities begin to describe ethical behaviours required of researchers within Aotearoa/New Zealand.

*Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga' – for tikanga reflects our values, our beliefs and the way we view the world. (Te Puni Kokiri, 1994)*

Some of the key documents and events informing the body of Māori research ethics and which contributed to the subsequent development of 'Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members (2010)' were;

- First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples in Whakatane New Zealand which passed the Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples (1993)
- Māori Working Group on Health Sector Ethics established by the Ministry of Health in 1993 to assist the Interim Taskforce on Health and Disability Service Ethics and Interim National Ethics to find ways of reflecting tikanga (Māori values and ethics) in the process of ethical review
- Te Puni Kokiri, the Ministry of Māori Development, publishes a report on Health sector ethics: Nga tikanga pono wahanga hauora: Mechanisms for Māori into ethical review in 1994
- Health Research Council of New Zealand (HRC) holds inaugural Māori Health Researchers Gathering (Hui Whakapiripiri) which passes the Hongoeka Declaration for Māori Health Researchers (1996). Gatherings continue on a regular basis
- Conference Proceedings of Te Oru Rangahau Māori Research Conference held in 1998 include a number of papers on Māori research ethics
- HRC produces Guidelines for Researchers on Health Research Involving Māori to help develop 1) research partnerships between health researchers and Māori communities or groups on issues important to Māori health, and 2) research

practices which ensure that biomedical, clinical and public health research effectively contributes to Māori health development

- Pūtaiora established as an informal network of Māori members of ethics committees in 1999. Meetings continue on an ad hoc basis
- Ministry of Māori Development publishes Evaluation for Māori: Guidelines for Government agencies (Te Puni Kokiri, 1999) to outline how quality information can be collected from and about Māori
- Dr Linda Tuhiwai Smith publishes Decolonising Methodologies: Research and Indigenous Peoples (Smith, 1999) which becomes a seminal text in the area of Indigenous research
- Supporting an initiative from Māori members of ethics committees, the HRC ask Tariana Turia, Associate Minister of Health with responsibilities for Māori health, for resources to enable work to take place on the development of a framework for Māori ethical review of health research (2001)
- Ministry of Health publishes Operational Standard for Ethics Committees which includes guidance on research involving Māori (appendix 8) (MoH, 2002; updated 2006)
- Minister of Health requests the National Ethics Advisory Committee (NEAC) to take responsibility for developing a Māori framework for ethical review of health and disability research (2002)
- NEAC completes key informant interviews about ethical issues arising for Māori when carrying out Māori health and disability research and how NEAC could be responsive to those issues (Cram, 2003)
- NEAC contract a scoping report on Māori Framework for Ethics Review of Health and Disability Research (Robson, 2004)
- Nga Pae o te Maramatanga (NPM), Māori Centre of Research Excellence, hosts a Traditional Knowledge and Research Ethics Conference. Conference proceedings include a number of papers on Māori and Indigenous research ethics (Nga Pae o te Maramatanga, 2004)
- Thesis completed on He Matatika Māori: Māori and Ethical Review of Health Research (Hudson, 2004)
- NEAC, the HRC and NPM establish a collaborative relationship to facilitate development of a Māori Framework for health and disability research ethics (2005)
- NEAC conduct a stock take 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 (Kennedy & Wehipeihana, 2006)

- NEAC drafts an Overview of Māori Research Ethics paper for discussion with Māori researchers and ethics committee members (2007)
- HRC updates its 1998 Guidelines for Researchers on Health Research Involving Māori (Health Research Council, 2008)
- Pūtaiora nominates members to a writing group to assist the NEAC/HRC/NPM collaboration to develop a Māori ethical framework (2008)
- Te Ara Tika Guidelines on Māori Research Ethics: A framework for researchers and ethics committee members (2010) is published by the HRC and appended to the HRC Guidelines for Researchers on Health Research Involving Māori

A significant amount of time has been required to encourage the key stakeholders in government, including the ethics and health research sectors, to commit resources towards the development of a framework for Māori ethical review of health research as well as to determine the level of ‘cultural mandate’ within relevant agencies to undertake the task. While the agencies were generally comfortable with conducting interviews and developing scoping reports and discussion documents, the responsibility to develop a framework which all the stakeholders indicated should be grounded in tikanga Māori was seen to be outside their sphere of expertise. The development of the framework only began in earnest once the Māori members of ethics committees themselves (Pūtaiora) established a writing group to workshop the guidelines. The importance of Indigenous leadership and scholarship in the writing of the guidelines should not be underestimated.

### **Te Ara Tika Guidelines on Māori Research Ethics**

As authors of these guidelines the task has been to weave together the various strands of work that connected tikanga Māori (traditional values and ethics), Māori research ethics, and the health research context in a way that could be understood and applied in a practical manner within the deliberations of ethics committees. The purpose of the guidelines was defined as: (1) to explain key ethical concepts for Māori; (2) to support decision-making around Māori ethical issues; (3) to identify ways to address Māori ethical concerns; and (4) to clarify the roles of Māori ethics committee members.

Conceptualising a framework that deals with issues arising from the interface of different values, ethics and knowledges is a challenging exercise particularly as research has become a politically contested space for Indigenous peoples. Our writing process began by affirming key principles that needed to be reflected in the

framework. First, engagement with research(ers) should be an empowering exercise for Indigenous communities and that it should lead to improved outcomes or relationships. Second, the framework must affirm traditional values and ethics (tikanga Māori) in the context of research and the Treaty of Waitangi, which acts as the primary foundation for State-Indigenous Nation relationships in New Zealand. Third, that relevant concepts arising from Indigenous ethics and Western ethics be included. Fourth, that we recognise the different expectations arising from different types of research and create a progressive framework that links directly to regulatory documents (e.g. The Operational Standard for Ethics Committees). These principles guided the direction of the development process. While there was a preference for developing a uniquely Māori ethical framework reflecting Indigenous values this had to be tempered with the need to ensure practical utility of the framework for both Māori and non-Māori members of the ethics committees, and for Māori and non-Māori researchers. We were fortunate to be able to draw on a number of existing models of Māori health (Te Whare Tapa Wha, Te Wheke, Nga Pou Mana, Te Pae Mahutonga), Māori research (Kaupapa Māori principles, Smith, Bishop & Glynn) Māori ethics (Durie, Smith & Cram, Henare), and tikanga (Mead) to provide a strong philosophy foundation for the framework.

### **Structure of the Framework**

We considered the dynamics of the engagement space between researchers and the community and oriented the framework around four key questions that we thought a Māori community would ask of researchers.

- He aha te whakapapa o tēnei kaupapa? / How did this project come about?
- Kei a wai te mana mō tēnei kaupapa? / Who is in charge of the project?
- Me pehea e tika ai tēnei kaupapa? / Will it produce the intended outcomes?
- Mā wai e manaaki tēnei kaupapa? Who looks out for the peoples interests?

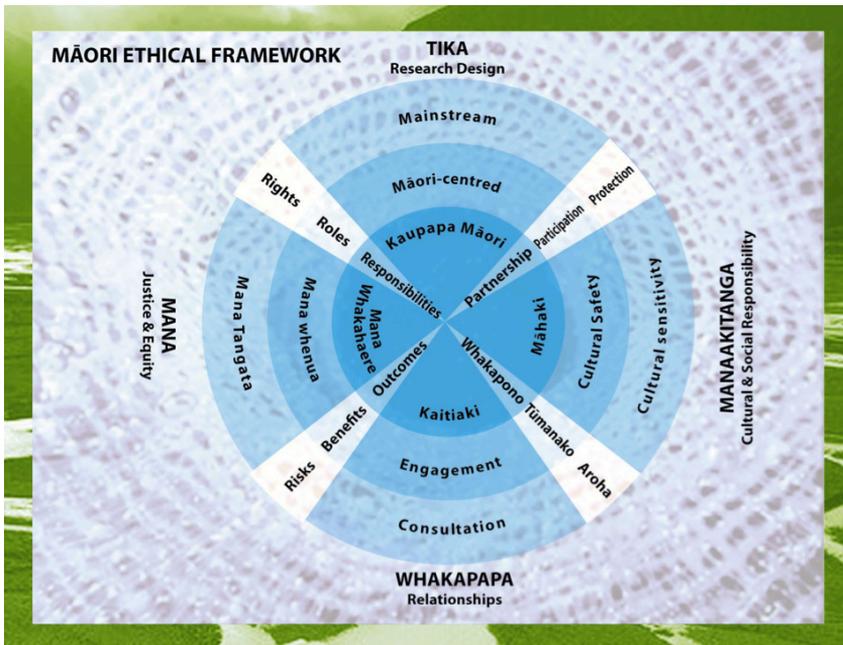


Figure 1: Māori ethical framework

The concepts of whakapapa, mana, tika and manaaki ground the framework in traditional Māori values. In giving Māori concepts a central place within a framework for research ethics it was important that we also defined the context for our interpretation of these concepts, particularly as our interpretation in no way represents the fullness of meaning associated with their traditional use. Whakapapa, in a traditional context refers to relationships between people, places, objects, and phenomena (Roberts et al, 2004), but in this context is used to explain both the genesis and purpose of any particular research and provides a mechanism for describing and understanding how relationships are formed and how they progress. Processes of consultation, engagement and kaitiaki (guardianship) are encompassed within this segment. Mana in a Māori context refers to power and authority (Mead, 2003) and this is related in the framework to concepts of equity and justice. Mana tangata (individual decision-making), mana whenua (collective decision-making) and mana whakahaere (governance) are the key components of this segment. Tika, meaning right or correct (Barlow, 1991), is the foundation for tikanga (values, ethics, protocols) and in the context of the framework relates to the validity of the research proposal in terms of whether its design and methods are likely to produce the intended outcome. Manaaki encompasses a range of meanings relating to car-

ing for others (Mead, 2003) and in this context is associated with notions of cultural and social responsibility and respect for persons (Hudson et al 2010). Cultural sensitivity, cultural safety and mahaki (cultural practice) are represented within this segment.

We have differentiated research that involves Māori as part of a general population sample (mainstream), research that focuses specifically on Māori using Western methodologies (Māori-centred) and research focusing on Māori that uses Māori methodologies (Kaupapa Māori).

The framework has layers based on a progressive expectations of ethical behaviour recognising a minimum standard, good practice and best practice approach to research with Māori as it relates to the type of research being conducted. The axis provides space for cross-cutting concepts that relate to;

- a) Principles of the Treaty of Waitangi (Partnership, Participation, Protection)
- b) Actions implied by the Treaty of Waitangi (Rights, Roles and Responsibilities)
- c) Risk, benefits and outcomes of research
- d) Māori values of whakapono (faith), tumanako (aspirations), aroha (awareness)

Each layer encircles the framework and the values and ethics represented within them to articulate the expected level of ethical behaviour. The framework is progressive so that each successive layer is expected to address the issues in the level below. For mainstream research projects it is important to acknowledge the rights of individuals to consider participation and that in most cases the primary concern will be the level of risk that they are exposed to. Consultation processes create awareness of the expected levels of cultural sensitivity that will be provided to protect the interests of the participants. For Māori centred research projects it is important to consider the roles that Māori collectives (tribes, trusts) have in decision-making as it relates to the benefits of the project. Engagement with Māori collectives also allows the researchers to understand how the project can support Māori aspirations and ensure that cultural safety protocols are in place to support Māori participation in the project. For Kaupapa Māori projects governance responsibilities are shared between the researchers and Māori collectives to improve the outcome benefits. Māori collectives take an active guardianship role and ensure that the partnership approach embeds cultural respect within all the research processes.

A range of ethical issues for Māori, summarised from regulatory documents (The Operational Standard for Ethics Committees) and published articles/guidelines (Cram, 2001; Powick, 2002; Hudson, 2004; Robson, 2004; Sporle & Koea,

2004; Kennedy and Wehipeihana, 2006) were then located within the framework. Existing ethical principles enshrined within the Operational Standard (Respect for persons; Informed consent; Privacy and confidentiality; Validity of the research proposal; Minimisation of harm; Justice; Cultural and Social responsibility; Compensation for research participants) were also positioned within the framework. The writing group was conscious of not developing a separate ethical framework but one that incorporated both non-Indigenous and Māori ethical principles and clarified the connection between them. The principles of Justice, Research Design, Cultural and Social responsibility were aligned directly to core Māori values (Mana, Tika and Manaakitanga) while the other principles were incorporated within the framework.

### **Implementation of the framework**

The process of testing and validating the framework with stakeholders involved a series of consultation exercises. This included the Māori Research Ethics collaboration working members (NEAC/HRC/NPM), the Māori members of ethics committees (Pūtaiora), Chairs of Health and Disability Ethics Committees, presentations to Māori research community and Public Health community, as well as the Bioethics community. Once feedback had been incorporated the 'Te Ara Tika Guidelines on Māori Research Ethics' document was presented to the Māori Health Committee of the HRC for inclusion as an appendix to the Guidelines for Researchers on Health Research involving Māori (HRC). This was a strategic decision to ensure that the framework would be utilised by researchers and ethics committee members and incorporated into existing ethical review processes. The Guidelines for Researchers on Health Research involving Māori (HRC) are required reading for HRC funding proposals and ethics applications through the Health and Disability Ethics Committees. Copies of the documents were provided to members of institutional and Health and Disability ethics committees, and the document and an accompanying presentation is available on the HRC website (<http://www.hrc.govt.nz/news-and-publications/publications/Māori>). The framework has been presented in a range of national and international forum and is now gaining attention from outside the health research. The framework has been adopted by researchers to inform their research activities (Came, 2013) and has provided the foundation for further research on subjects related to Māori and Indigenous ethics (*Health Research Council funded Te Mata Ira: Cultural Guidelines for Biobanking and Genomic Research; Marsden funded Ethics review project: Tensions around ethics review and Māori Consultation*).

### **Discussion - Developing Indigenous Ethical Frameworks**

The development of an Indigenous ethical framework is a step towards recognising Indigenous sovereignty. The inability to recognise cultural difference and its influence on the formation of knowledge is at the centre of Indigenous peoples concerns with universalism in research and ethics.

*In a research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development. (NHMRC, 2003) Pg 3*

A key struggle for Indigenous peoples is gaining recognition for Indigenous knowledges, proving the authenticity and control over their forms of knowledge, and right to govern participation in research (Smith 1999). The development of Indigenous ethical frameworks has been one component of the empowerment approach for Indigenous communities and has occurred in other Indigenous jurisdictions such as the Aboriginal and Torres Strait Islanders in Australia (i.e. The Australian Institute of Aboriginal and Torres Strait Islander Studies 2000; Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (National Health and Medical Research Council 2003); First Nations in Canada (i.e. Mi'kmaq Ethics Watch, Grand Council 2000; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010); American Indians Tribes in the USA (Navajo Nation Human Research Review Board Procedural Guidelines for Principal Investigators); and, Māori in New Zealand (Koru of Māori Ethics, Manuka Henare; Rangahau Painga, Mason Durie; Te Noho Kotahitanga, Hugh Kawharu). Indigenous ethical frameworks shift the focus from rule based consultation towards value based engagement (Anderson et al, 2003; Ruttan, 2004; Castellano, 2004).

*The emphasis of the Guidelines is on value-based engagement rather than rule-based consultation to promote consistency with Indigenous communities and their values (Anderson et al. 2003).*

Values influence expectations of the process of ethical review and the way in which 'ethical issues' are identified and 'ethical principles' are applied. A non-Indigenous cultural bias present in research and ethics is found in the assumptions that

knowledge in itself is a good thing; research is a means to get knowledge; individual rights are paramount; and, to be valid, research must follow the rules of research (Brew 2001). These values are commonly inconsistent with the views of Indigenous cultures and communities which therefore challenges the ethical soundness of research that marginalises their values and beliefs. It is in the application of a given principle or the preference for one principle over another that the underlying value base is revealed. Cultural values for example have been shown to have a marked influence on the decision to give primacy to beneficence over autonomy (Tsai, 1999; Oguz, 2003). This bias towards autonomy-based interpretations that encourage individually mediated principles rather than beneficence oriented interpretations, which promote community-oriented principles, also influences what constitutes an ethical issue for an Indigenous community (Hudson, 2004). A distinction can be drawn between the internal ethicality of a project (ethics in relation to participants) and external ethicality of the project (ethics in relation to the community) as part of the Indigenous ethical review (Hudson, 2009). Both aspects of a project should be part of the research consultation process with Indigenous communities.

*So whilst a guideline might focus the thinking of researchers on critical issues such as the potential benefit of the research, in itself, the guideline does not resolve potential conflict. It identifies an issue that must be negotiated. (Anderson, Griew et al. 2003) pg 25*

The utility of any Indigenous ethical framework will be determined to some extent by the ability of both Indigenous communities and research communities to understand the concepts that they use and apply them to the range of research methodologies. Creating opportunities for non-Indigenous understanding, and for Indigenous participation in ethical debates will contribute to the development and understanding of Indigenous “ethical” issues, concepts, values and their application to contemporary ethical challenges including those involving the collection and use of tissue for future research and/or genetic technologies (Schnarch, 2004; Tupara, 2012; Harding et al 2012; Hiratsuka et al, 2012; Tallbear, 2013; Taualii et al 2013).

*Ethics as a concept and as a science of a body of knowledge is constantly being tested and changed. Similarly, ethical values are changing and we live in a dynamic world in which our past guides the present and the future (Te Puni Kokiri 1994). Pg 13*

As Māori communities construct new ethical boundaries to address emerging issues they look internally and externally to assist their deliberations. The broader Indigenous community are a rich source of knowledge and experience to inform the construction of local guidelines. Comparative analyses identify the relative strengths of the various Indigenous approaches to ethical review (Powick, 2002; Ermine et al, 2004; Stewart, 2008; Taniguchi et al 2012). A key feature of all Indigenous ethical frameworks is the robustness of the cultural mandate. Indigenous leadership is an important aspect even if national agencies provide resources and support to the process. Maintaining the integrity of cultural values and beliefs even as they are integrated and aligned with western ethical concepts is a significant responsibility and one that requires the involvement of people who can traverse the interface between traditional values and research ethics.

*It is important that, as Māori researchers, we claim these ways of doing research as based in Māori philosophy. Otherwise there is a risk that such practices will be misappropriated by non-Māori researchers and reframed in ways that remove or invalidate the cultural context from which they derive their meaning and effectiveness. (Jones, Crengle & McCreanor, 2006)*

The recognition and application of Indigenous rights are also subject to changing political contexts. The recent restructuring the Health and Disability Ethics Committees in New Zealand follows similar modifications made to the system of ethical review in the UK (Report of the Health Committee, 2011; New Zealand Ministry of Health, 2012a; Department of Health, 2011; Rawlins 2011). The report made a number of recommendations including changes to Māori consultation where they proposed that the National Ethics Advisory Committee or the Ministry of Health be instructed to:

*...make clear guidelines for ethics and Māori consultation within nine months of this report being presented. The guidelines should be clearly aimed at maximizing protection, expertise, and efficiency, and should clarify the purpose of Māori consultation.*

Clarifying guidelines is a valuable exercise and addresses a concern expressed by Tolich in 2002 that the absence of guidelines on Indigenous consultation effectively paralyzes research activities. However, Gillett & Douglass (2012) suggest the reforms “seem driven by an obsession with removing obstacles to biomedical research (especially that with commercial benefits)” and weaken existing safeguards.

New Standard Operating Procedures (New Zealand Ministry of Health, 2012b p.7) reduce the number of committees from seven to four, reduce the number of committee members from twelve to eight, introduce a 35-day turnaround for approval, require researchers to organise their own peer review, and allow Māori Consultation to run concurrently with the ethics review process. Each of these changes reduce the level of meaningful Māori participation in processes of ethical review and undermine the potential impact of Te Ara Tika on improving the ethical behaviour of researchers working with Indigenous communities. Fortunately, many institutions (Universities, District Health Boards) have adopted Te Ara Tika and are developing their own review processes to fill the gap created by changes to the National system and ensure Māori ethical issues are addressed appropriately (Capital & Coast District Health Board, 2013).

### **Conclusion**

While Māori have a history of continual use of their own ethical principles in their own society, its application within the wider mainstream society, and the area of research in particular, has only emerged in recent years. In this sense, issues of ethicality for Māori have always been closely linked with Māori development and the integration of Māori values into mainstream structures. Respectful and appropriate engagement with Māori is expected of the research community, which includes growing the research capacity of Māori in order to undertake research that is relevant and seeks to improve the health and wellbeing of Māori and the environment we all live in. The challenge for non-Māori and Māori researchers in New Zealand is to affirm Māori rights to participate in a manner that enhances Māori protocols (tikanga) and Indigenous Māori knowledge (mātauranga) and leads to improved outcomes for Māori. This challenge is shared by other Indigenous communities and is facilitated by maintaining control of the nature and level of involvement at the cross-cultural interface. In the context of a fast changing world increasingly impacted by globalisation, integrating new perspectives within an Indigenous worldview, while retaining our cultural integrity is the reality of modern life. A robust system of ethical review should not only accommodate but also reinforce the cultural values and ethics of Indigenous communities as the decisions we make today impact on our families and generations to come.

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