



Maori responsiveness in health and medical research: clarifying the roles of the researcher and the institution (part 2)

Andrew Sporle, Jonathan Koea

Abstract

Introduction The combination of the Health Research Council's *Guidelines for researchers on health research involving Maori* and the 1998 revision of the *National application form for ethical approval* generated an expectation that all research development required consultation with Maori.

Methods and Results This paper clarifies issues of consultation for health researchers in two ways. Firstly, the historical development of the focus on the Maori research responsiveness is outlined. Secondly, we argue that research institutions, rather than researchers, need to take a lead role in consulting on research issues with Maori organisations.

Conclusions Consultation with Maori at the institutional level could help clarify and address key ethical issues in research—while reducing the workload for researchers, Maori organisations, and host institutions alike.

This paper attempts to clarify the issues regarding consultation with Maori (in the development of biomedical and clinical research), and follows an earlier paper reviewing nine key areas relevant to Maori responsiveness that can be readily addressed by researchers in their proposals.¹

In this paper, the development of the requirement for Maori responsiveness for health research is briefly outlined—to show that the Maori consultation process follows similar requirements to the rest of the health sector, and is unlikely to change in the foreseeable future.

Some institutional initiatives have been established to assist researchers developing proposals. However, research-focused consultation currently has not been developed at the institutional level, which (if implemented) would be an effective means of minimising the work of researchers and Maori communities/organisations alike, while generating a proactive set of clear research guidelines.

The development of the consideration of Maori responsiveness in Crown-funded health research

The consideration of Maori responsiveness in research is not new and has been driven by policy and legislative activities of successive governments for over a decade. The need to increase the contribution of health research to improving Maori health and accommodating specific cultural issues in the research process were raised by the official review of health research that recommended the creation of the Health Research Council (HRC).²

The Health Research Council Act (1990) sought to address these issues via the creation of a Maori Health Committee as a standing committee of the HRC responsible for advising on research 'into issues that affect Maori people, with particular reference to research impinging on cultural factors affecting Maori people'.³

In addition, the Health Research Council Act required that the HRC Ethics Committee included membership with knowledge of tikanga Maori (Maori lore). These functions of the HRC were further reinforced by the *1996 Policy Guidelines* from the Minister of Health to the HRC.⁴ These guidelines were intended to ensure that the HRC's activities meshed with the current priorities of the rest of the health sector. In 1999, the Ministry of Research Science and Technology published its *Blueprint for Change*—a statement of policies and procedures for the whole of the Crown investment in research science and technology.⁵ This document set out ten key stewardship expectations for all Crown purchase agents against which their performance would be assessed. Responsiveness to the needs and diversity of Maori was one of these expectations.

The recent structural changes effected by the New Zealand Public Health and Disability Act 2000⁶ have reinforced the need for all aspects of the health and disability sector to be responsive to the health needs of the Maori population. As outlined in the New Zealand Health Strategy, the Ministry of Health wants information that will improve Maori Health, and the community wants research of relevance,⁷ thus making the Maori responsiveness requirement relevant to health research for the foreseeable future.

Researchers and Maori responsiveness

In seeking to determine the Maori responsiveness of their intended project, some researchers choose to consult directly with Maori researchers and/or organisations. Unfortunately, this creates an additional and un-remunerated workload for Maori researchers and organisations, distracting them from their own activities and (in the case of Maori researchers) contestable funding applications. The consideration of the Maori responsiveness of an intended research project involves several key steps, most of which are simple extensions of the usual processes in developing a research idea.

The first step is to consider the importance of the health issue for Maori. This can be included in the literature search and review—with *Hauora*⁸ and *Our Health, Our Future*⁹ being excellent starting points. Where published information is not available, anecdotal evidence may be available from clinical colleagues, or some information may be available from the New Zealand Health Information Service (NZHIS) or the local district health board (DHB).

If the topic is relevant to Maori health, then determining how to ensure the project can realise any potential contribution to Maori health involves learning from approaches used in prior or current projects in their own or similar fields. There is a rapidly developing experience in a range of Maori responsiveness strategies amongst mainstream researchers in the biomedical, clinical, and public health fields. A combination of consulting the literature and talking with peers is an efficient means of determining possible effective strategies for new projects. It also enables the possible use of other researcher's pre-existing networks with Maori organisations.

The third step involves the identification of end-user organisations related to the research topic. Within the identified organisations, there may be Maori-focused sections or staff, or there may be specific Maori organisations with a dedicated interest in the proposed topic. As with any end-user relationship, working with Maori in such organisations (or Maori-specific organisations) benefits researchers by the application of their work, and by the possibility of a relationship that reaches across a range of projects. The relationship may also be useful in the development of research ideas, recruitment of participants, and dissemination of results. The benefit for Maori in these organisations is that they get to help develop research that is relevant and addresses their needs as a service or policy provider. The resulting research also has possibilities for the development of their workforce or even new services.

A fourth step involves the researcher referring to any institutional codes of practice on the Treaty of Waitangi or Maori responsiveness issues in research, especially if their project involves Maori as participants. Some host institutions for researchers have developed (or are developing) such codes of practice. If no guidelines exist, then researchers should consider lobbying their institution to develop locally relevant policies and procedures in line with the requirements of the HRC.

If significant research-related issues have not been clarified and resolved (by these processes), then researchers should consult with institutional-resource people. For researchers in DHB settings, this involves working through the issues with the research manager and/or Maori management staff in the relevant sections of the organisation. Some universities (eg, University of Otago) already have staff to work with researchers on Maori responsiveness activities—while others, such as Auckland University, have developed processes for pre-submission review of applications.

A Maori consultation framework for research

The stated intent of the HRC in publishing the *Guidelines*¹⁰ was to assist in the development of:

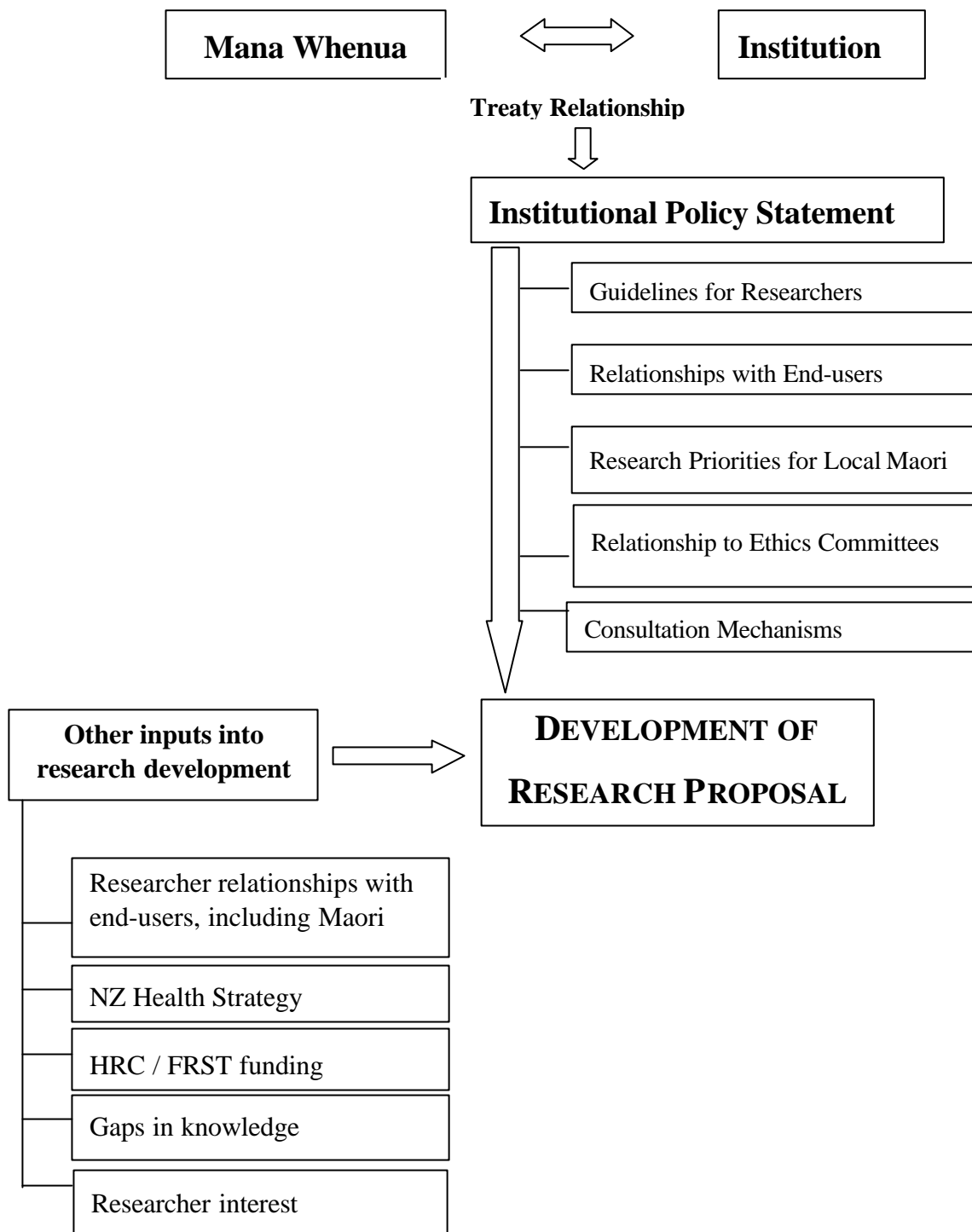
- Research partnerships between health researchers and Maori communities/groups on issues important to Maori health.
- Research practices, which ensure that biomedical, clinical and public health research effectively contributes to Maori-health development (whenever possible).
- Research practices that ensure, maintain, or enhance mana Maori.

The HRC guidelines were intended to provide advice to individual researchers rather than all persons involved in the research process. Efficiency and Treaty of Waitangi arguments indicate that much of the consultation should take place at the institutional level.¹¹ Consultation with Maori is already a requirement of DHBs¹² via the New Zealand Public Health and Disability Act—and Treaty of Waitangi issues feature in most University charters.

Currently, most of the consideration of Maori responsiveness issues occurs late in the research development process (once the research idea or even the design has been formulated). As a result, opportunities are missed, or researchers are faced with the prospect of additional work-amending research proposals late in development.

A possible alternative process is outlined in Figure 1, where the host institution is responsible for the consultation and for ensuring the Maori responsiveness of research activities.

Figure 1. A framework outlining the interrelationships between host institutions, researchers, Maori end-users, ethics committees, and mana whenua.
(HRC=Health Research Council; FRST=The Foundation for Research, Science and Technology.)



Locating the responsibility for consultation with host institutions ensures that the universities and DHBs operate as Crown agents, and negotiate research policies and practices as part of their consultation and partnership activities with mana whenua (people with authority over the region).

In this model, the formulation of Maori responsive research policies and practices are a specific outcome of the operation of the Treaty of Waitangi relationship between the host institution and mana whenua. Such policies would then be available to all institutional researchers, and be able to guide research proposal development from its inception in a similar manner to other institutional policies.

These policies would involve institutional guidelines for researchers that could clarify acceptable practices regarding involvement of Maori participants, use of tissue samples, use of Maori genetic material in research, intellectual property issues with regard to indigenous flora and fauna, and when consent is required and how procedures for obtaining it.

The document could also outline unacceptable practices as well as practices that would require further consultation and negotiation to resolve. In the case of procedures for obtaining consent, it would also clarify the consultation mechanisms and points of contact that the institution or researcher would engage with. The policies could also include local research priorities for Maori wellbeing, relationships of mana whenua with any institutional ethics committees, and possibly even a co-ordinated approach to relationships with mainstream and Maori end-users for research on specific topics (eg, National Heart Foundation and Te Hotu Manawa Maori for research on cardiovascular health and health services).

This approach would provide the institutions, ethics committees, and funding bodies with clear mechanisms for assessing the Maori responsiveness of an intended research project. It would also provide a way for Maori responsiveness practices to be developed via a combination of precedent and ongoing consultation. Where there is more than one research institution (eg, a DHB and a university) within a region, this approach would enable to common local research policies to develop.

The researchers would benefit by having clear guidelines to follow that could be referenced in any funding or ethical application. Furthermore, researchers could then focus on the other determinants of their research interest, including their relationship to the endusers of their work. Consultation would be limited to those circumstances defined by institutional guidelines (which would be signalled well in advance), and institutional consultation mechanisms would be provided. This would also remove (from mana whenua and Maori organisations) the burden of multiple consultations from individual research proposals.

Conclusions

The introduction of Treaty of Waitangi considerations and Maori responsiveness requirements has been undertaken to ensure that the Crown's investment in research science and technology contributes to Maori development whenever possible. Unfortunately, however, it introduced a further degree of uncertainty into the funding- and ethical-review application processes.

This uncertainty could be removed altogether by the provision of institutional policies on Maori responsiveness in research, especially if those policies were the result of institution-led consultation and negotiation with local Maori representative organisations. Such policies would also serve to guide the activities of ethics committees and funding bodies in their assessment of research proposals.

Author information: Andrew Sporle, Lecturer/Research Fellow; Jonathan Koea, Hepatobiliary Surgeon, Department of Surgery, Auckland Hospital, Auckland

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Correspondence: Jonathan Koea, Clinical Associate Professor, Clinical Advisor Maori Health, Department of Surgery, Auckland Hospital, Private Bag 92024, Auckland. Fax: (09) 375 4334; email: jonathank@adhb.govt.nz

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