# A CULTURAL TURN

# The trivialisation of indigenous research ethics in New Zealand post-2012 health and disability ethics committees

Barry Smith\*
Martin Tolich<sup>†</sup>

## **Abstract**

Recent changes to health ethics oversight in New Zealand has presented a number of challenges for the way in which health and disability ethics committee (HDEC) members handle Treaty of Waitangi responsibilities. Informants suggest that indigenous research ethics has either virtually dropped off the table or taken a "cultural turn" in the sense that the meaning of consultation has been "trivialised"; however, this fate is not indicated uniformly across all HDECs. This paper discusses the new ethics review environment for health oriented research in terms of the containment of indigenous research ethics processes with the present "cultural turn", meaning that any deliberate focus on the research question or on a project's possible impact on reducing health disparities is rare.

# Keywords

Māori, New Zealand, health and disability ethics committees, institutional review boards, health disparity

<sup>\*</sup> Population Health Analyst, and Chair Research and Ethics Committee, Lakes District Health Board, Rotorua, New Zealand. Email: barry.smith@lakesdhb.govt.nz

<sup>&</sup>lt;sup>†</sup> Associate Professor, Department of Sociology Gender and Social Work, University of Otago, Dunedin, New Zealand.

#### Introduction

The recent 2012 decision by the New Zealand Government (Ministry of Health, 2012a) to restructure the health and disability ethics committees (HDECs) provides an opportunity to examine how organisations like ethics committees adapt to major changes. The 2011 report of the Health Committee was entitled *Inquiry into Improving New Zealand's Environment to Support Innovation through Clinical Trials* (Health Committee, 2011). The resulting "improvements" were manifest across a number of areas. The new standard operating procedures now place prohibitions on HDECs—they are no longer permitted to consider the quality of the science in an application.

HDECs are not themselves directly responsible for assessing the scientific validity of proposed studies. Researchers and sponsors must ensure that the scientific validity of proposed research has been peer-reviewed before an application is made to an HDEC. While HDECs are responsible for checking that appropriate peer review has been carried out, they do not conduct it themselves. (Ministry of Health, 2012b, p. 7)

New Zealand is only one of a number of countries that have relatively recently made these sorts of changes in an attempt to simplify their ethics review systems. The United Kingdom made similar modifications in 2012 with a revamped UK-wide system of "Governance Arrangements for Research Ethics Committees" (Department of Health, 2011; Rawlins, 2011) covering all health and social care research.

The New Zealand Government's restructuring of ethics committees was economically motivated. Gillett and Douglass (2012) claim the reforms are driven by a desire to open up the way for more biomedical research, particularly if it is accompanied by commercial benefit, and seriously undermined some of the existing safeguards. In 2010, when the Health Committee

initiated its inquiry, the media release highlighted and emphasised the significant economic benefits of clinical trials to New Zealand:

Currently Phase I–IV trials have been estimated to be worth between \$12 million to \$30 million per year in New Zealand, compared with Australia where they are worth \$450 million per year. (Health Committee, 2011, p. 11)

The tenor of the New Zealand Government's response to this 2011 report led to a number of specific changes that were largely predicated on the view that the system of ethics review in New Zealand was too slow and, by implication, impeded innovation in health research, particularly innovation generated from the activity of the pharmaceutical industry. The consequential changes to the way HDECs operate include a reduction in the number of committees from seven to four, a reduction in the number of members from twelve to eight, the introduction of a 35-day turnaround clock, the requirement for researchers to organise their own peer review and a related feature (noted earlier) that ethics committees were no longer responsible for assessing the quality of the science. While some observers might see the changes around responsibility for the science as being a good thing, it is, nonetheless, the case that the ethical issues very frequently have their origin in the operationalisation of the research design. There were also specific changes to the ways indigenous research ethics was to be practised. Rather than being a requirement ahead of time, consultation could run concurrently with the ethics review even though such engagement has the potential to improve both science and the ethics of a project. Much of the stance on consultation was driven by two recommendations in the Health Committee's (2011) report. In Recommendation 14, it states that the revamping of the ethics review system must "remove duplication in the processes carried out by the Health and Disability Ethics Committees, the Standing Committee on Therapeutic Trials, and district health boards in consulting with Māori" (p. 32).

In Recommendation 15, the report proposes that the National Ethics Advisory Committee or the Ministry of Health be instructed to "make clear guidelines for ethnic and Māori consultation within nine months of this report being presented. The guidelines should be clearly aimed at maximising protection, expertise, and efficiency, and should clarify the purpose of Māori consultation" (p. 32). This, on the surface, might seem good news, for according to Tolich (2002), the absence of guidelines on how to carry out indigenous consultation effectively paralyses research—especially for Pākehā. These intended guidelines, however, have not been forthcoming and, in lieu of these guidelines, the four HDECs have operated in a vacuum generating their own unique interpretations of what constitutes indigenous research ethics, largely because various statements on Māori ethics have never been formally ratified by those managing the HDEC system. These interpretations can be characterised in terms of three themes, each of which we present below following an overview of the persistent resistance to indigenous research ethics. The three themes focus on the degree of uniformity in the review process across the four HDECs, the cultural turn away from consideration of the nature of the research itself and the outsourcing of indigenous research ethics.

# Methodology and ethical considerations

Ethical approval to observe all New Zealand ethics committees was granted (#12/248) by both the University of Otago Human Ethics Committee in 2012 and the Ngāi Tahu Research Consultation Committee with the Māori author of this paper leading this process. In due course, permission to interview the Māori HDEC members and the Māori advisors was sought from

and granted (#13/121) by University of Otago ethics and consultation committees. We note that HDEC approval was not required for this research, as it did not fall within the gamut of being health research.

The following analysis on the new HDECs is based on four key sources of information. The first source was the publicly available HDEC minutes, which were thematically coded, identifying HDEC discussions that focused on cultural requirements, made mention of health inequalities or failed to discuss either. Second, we conducted three interviews with the four HDEC members who have the role of introducing Māori perspectives into committee discussions. Third, four interviews were conducted with senior academics and health researchers who have been acting as key advisors to non-Māori health researchers about how to effectively and "appropriately" carry out research in Māori contexts. Fourth, and most importantly, the two authors conducted direct observation of the new HDECs during meetings as part of a larger funded study to examine tensions generated in ethics committees when dealing with Māori consultation.

Between February and June 2013 the second author observed all four HDECs. Two committees were observed twice, one once, and one three times. The meetings lasted between four and six hours. Immediately after the meetings, the jotted field notes were verbally recorded onto a digital voice recorder as expanded field notes, professionally transcribed and thematically analysed in accordance with standard qualitative methodologies. These observations identified one HDEC as an outlier. Unlike the other HDECs, the Central HDEC mentioned indigenous research ethics when reviewing most applications. The first author observed consecutive meetings confirming that, in contrast to other observations and the minutes of the HDECs, the Central HDEC was different.

#### Resistance to consultation

Waiting for proposed indigenous research ethics guidelines that concern studies requiring engagement with indigenous peoples in the New Zealand context is not a new experience. Over the past 25 years, ethics committees, and especially Māori members on HDECs, have waited for workable solutions on indigenous research ethics that have wide and formal acceptance. Despite these having been hinted at in the work programmes of a number of agencies, including the National Ethics Advisory Committee, no "formally sanctioned" guidance document for use by HDECs has appeared in the past 25 years, and certainly not in the past 14 months. This has led current Māori representatives and institutional Māori advisors to share a concern that issues regarding Treaty responsibilities are "falling off the table" and that there is resistance to, in the sense of an unwillingness to accept, mechanisms that would enable and embrace a fuller discussion about how researchers should engage with indigenous contexts.

The perspective held by many Māori, especially those involved in health research, and including those who sit as Māori members on ethics committees, is that engagement with Māori should be a requirement except in very specifically defined and rare circumstances (Smith, 2011). The argument is simply that, under the auspices of the Treaty of Waitangi, Māori are defined as partners of research and thus should benefit from any participation. However, it is the view of Hudson (2009) that the reality is fundamentally different, especially at the stage of ethical review, in that "while Māori values are acknowledged, they are not yet considered to have equal weight in ethical deliberations" (p. 125).

This is notwithstanding the fact that various Māori consultation guidelines do exist; although we reiterate that none have been formally sanctioned by the HDEC system. The 2010 Health Research Council publication

Te Ara Tika—Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members (Hudson, Milne, Reynolds, Russell, & Smith, 2010), which interestingly did not earn a mention in the Health Committee report, refines perspectives on Māori consultation by stating that while all research is of interest to Māori, and all researchers should consult, the form this engagement should take will be determined by whether the research is "mainstream" or "Māori centred". These two categories are defined in terms of whether a data sample is drawn from the whole population or, alternatively, in a way that maximises the number of Māori in order to illuminate a health issue of particular relevance to Māori; for example, diabetes.

The idea that instances of non-engagement should be rare is one that provokes a range of reactions within the health research community at large. Here the negative reaction to the tenet that all research is of interest to Māori is generally couched in critical terms of added cost and time arising from the supposed difficulty of finding suitable parties with whom to consult and then having to wait for responses that are said to be slow moving. In fact, a notable finding of the submissions made to the Health Committee is that there was a consensus among submitters that although the HDEC review is robust it is too slow (Health Committee, 2011). Māori consultation was deemed integral to this tardiness. A select committee submission from Associate Professor Richard Robson from the Christchurch Clinical Studies Trust targets Māori consultation as a primary cause of duplications in the process of gaining ethical approval, which created more bureaucracy, financial costs and delays, thus:

Initially Māori engagement was only required for protocols that were developed in New Zealand which involved a significant Māori population. Protocols that were developed overseas did not generally require separate Māori consultation or engagement. Potential

Māori issues in protocols were reviewed by the two Māori representatives on each Ethics Committee who could, if required, ask for further Māori engagement. In 2003 the [Health Research Council] Ethics Committee issued an edict saying that all studies would now require Māori consultation. (Robson, 2010, pp. 3–4)

A similar theme is found in the Christchurchbased Primorus Clinical Trials Ltd submission to the Health Committee:

There are repeated instances where Māori consultation results in contradictory requests and for sites which are not associated with university or hospital Māori committees. [T]here is often a difficulty with locating a suitable Māori representative who is knowledgeable about clinical research and the implications for Māori therein. We believe this rests with the need for a more robust and extensive training programme for new and existing committee members. It also raises the question as to whether the need for Māori consultation is appropriate for all applications. (Primorus Clinical Trials, 2010, pp. 4–5)

These views are of course not novel. The annual reports from the previous iterations of HDECs from 2004 to 2011 contain expressions of concern about the way researchers react to and deal with Māori consultation and cultural matters generally, which suggests that these pre-2012 HDECs tended to favour a more broadly defined consultation requirement. Comments such as "Some researchers pay no more than lip service to the cultural requirements" (Ministry of Health, 2009, p. 11) confirm a degree of dissatisfaction with the status quo. In 2011, the Northern X HDEC Chair also claimed researchers were not taking Māori consultation seriously:

We are concerned about Māori consultation on two fronts. That the researchers don't regard consultation as a chore that "has to be done" rather than "want to be done". Hence we like to see the researchers engage properly beforehand where it is appropriate. (Ministry of Health, 2009, p. 5)

There is no evidence to suggest that the concerns regarding Māori consultation expressed within these annual reports were ever responded to by those that administered the HDECs. Moreover, a related proposition is that that any relaxation of the requirement to consult with Māori could potentially reduce the amount of research activity focused on Māori issues, especially in respect of research in the areas of personal and population health.

Notwithstanding these manifestations of resistance in the literal sense noted above, our observations and interviews show that, in the latest iteration of the HDECs, issues around Māori are being conceptualised differently. This may be partly because the matter of Māori membership is not explicitly defined, even though the informally stated Ministry of Health's view (see below) is that Māori membership is still considered an important dimension in the composition of ethics committees and that current arrangements function well. Hence, at a meeting of district health board research managers and advisors held in May 2013 about the new ethics system, a Ministry of Health spokesperson is recorded in the meeting notes (V.Gibbons, personal communication, 25 October 2013) as having said:

We have [Māori] members in each committee and some have more than one [with] quite a good balance of expertise. If you look back through the minutes of meetings you will notice the issue of Māori consultation is raised often and they want to know things like what the process is, what the feedback is and whom they consulted. They go back to check who they are. They are always there for Māori people. As far as I am concerned, it does seem something that [members] are careful about. Because the Māori consultation process is not

necessarily coming before the submission, they are focusing quite a lot on what the process is and whom they are getting [advice] from and, if they have already had it, what is the feedback.

Despite this positive claim, the evidence below demonstrates that Māori interests are not equally advocated for across the four HDECs. Māori have been appointed to only three of the four HDECs. The implication of this variability is compounded by the lack of clarity around the legitimation of a Māori presence in the ethics review process; formal guidelines on the process of indigenous research ethics that could provide clarity for all members of HDECs remain absent. The impact of these factors is an observed absence of uniformity.

# Uniformity

The direct observation of HDEC meetings and an analysis of the meeting minutes clearly show that the committees do not take an equal or consistent stance on indigenous research ethics or issues pertaining to Treaty responsibilities. One committee, the Central HDEC, was an "outlier" in terms of its persistence in covering issues pertaining to Māori. Queries in this regard were explored in respect of every application submitted to the committee. By comparison, the other three committees were much less vigorous in pursuing these matters or employing this approach. For example, the minutes of the Northern A HDEC from February 2013 show that the committee dealt with a study where the principal investigator informed the committee that very few Māori were expected to be recruited into the study—a position that the committee appears to have been happy with given there was no call for any requirements of the researcher to engage with Māori. The committee discussed the rationale for Māori consultation stating, "[The researcher] noted that ethnicity was not a focus of the study, and that very few Māori were expected to be

recruited to the study" (Northern A HDEC, 2013, p. 5). The committee was satisfied with this response.

The minutes of the Northern B HDEC rarely contain a mention of Māori consultation either as a cultural concern or as a backdrop to discussing issues around the research. Māori consultation does not appear to be a core concern in their approach to ethics review. In March 2013, the Northern B HDEC minutes record the committee having no problems with a study not addressing health inequalities:

The Committee queried the answer provided to f.1.1 in the application form. [Researcher] clarified that this study will not actively contribute to the reduction of inequalities, and no ethnicity data will be collected. (p. 9)

These two exemplars, among many, demonstrate that, under the post-2012 HDEC regime, and in the absence of any specific guidance on indigenous research ethics, the HDECs were instituting a policy that actually changed the nature of Māori consultation regarding the assumption that given all research is of relevance to Māori, all research will require consultation.

Clearly, the individual HDECs' processes lead to different levels of prioritisation and commitment around Treaty of Waitangi matters, which in turn promotes variation in the way these matters are handled. On occasions, however, energetic advocacy was seen to overcome the influence of this cultural dimension. An example of this was witnessed when a "Māori representative" from the Central HDEC was asked to sit on the Southern HDEC in January 2013. The minutes of this meeting show that, of the 12 applications looked at, 10 received comment from a Māori perspective, with two of these being declined because of a lack of response around Māori amongst cultural issues, rather than queries focusing on variation in health status.

By contrast, minutes from other meetings of the Southern HDEC, including the following meeting in February 2013 that the second author attended, show much less concern for indigenous research ethics. In February, only two of the six applications were mentioned:

- The Committee agreed that as the study (#2) looks at prevalence in Māori they would have an interest in being consulted regarding this study.... Please confirm that Māori consultation will be sought for this study. (p. 5)
- In application #6, the Committee noted that the evidence of Māori consultation provided appeared to be for a different study. (p. 10)

Three of the four Māori HDEC members who were interviewed recognised the presence of this variability across committees. One Māori HDEC member commented:

It seems that when it comes to reasons for provisional approval, it may have been that our particular committee is particularly high on the need for evidence of consultation with Māori, which does not surprise me so I think we are a bit of an anomaly.

The member elaborated on this stating that researchers are becoming aware of this inconsistency:

Actually that guy [a researcher] also raised an issue that has come up many times in that you go to a different HDEC they do process things differently so his frustration obviously because he didn't get the need to engage with Māori, was "Oh if I go here they will tell me one thing, if I go here they are going to tell me another." We have never as a collective had any collective training or had any contact collectively. I think it would be worthwhile.

Variability across the HDECs was evident, but so too was the move away from a focus on how research was to benefit Māori.

#### The cultural turn

Eight years ago, the first author of this paper expressed the concern about an emerging cultural turn in the first annual report of the Multi-region Ethics Committee published in October 2007 as follows:

More often than not where consultation has occurred, it is framed around the need for cultural sensitivity and understanding with much less energy given to exploring the possible paradigmatic and research issues relating to Māori that may be implicated in the project. While matters of culture are important in the research process, there is a need for greater thought to be given to conceptual issues and questions, along with the shape of research outputs, if the results from health research are to contribute more positively to the health status of Māori. (Ministry of Health, 2007, p. 8)

The turn away from dealing with matters such as potential benefits of research toward the more superficial issues of culture is not just a by-product of the post-2012 changes. What is different now is how endemic the cultural turn has become. Collectively, the minutes of all four HDECs and observing the new ethics committees in action suggest that the tendency to overwhelmingly focus on cultural dimensions is now a well-embedded norm. Topics discussed are apt to cover things such as the need for karakia when blood specimens are destroyed and the fact that the head is tapu, which, in the opinion of one experienced advisor interviewed, totally misses the point. This advisor's observation is that:

Pākehā will tick—oh, they are going to have a koha ... there [is] like an 8 point thing they can do and it's like you can have a karakia, have a mihi, take a biscuit, oh it's such crap ... hopefully you are going to be respectful but you're not going to be doing Māori methodology.

In this person's view the ethics committees are merely "focusing on the process because that is their fall-back position ... instead of grappling with the big issues."

One important factor that shapes the nature of dialogue between the committee and applicants is the perception researchers and ethics committee members have about the function and utility of indigenous research ethics. Here, it seems that much of what passes for acceptable engagement with Māori is largely ritualistic and of the tick-box variety, or else undertaken in order to facilitate access to data. From our observations, entertaining the idea that consultation might serve to impact health status, reduce health inequality or develop more appropriate paradigms and methodologies to explore questions of importance to Māori appears to be little thought about even though the question is directly prompted in the online ethics application form. This situation suggests that a good proportion of health-related research has ethical shortcomings because it does not optimally contribute to health outcomes that are of particular pertinence to Māori. Not surprisingly, some "Māori" members of the HDECs find this lack of focus conceptually puzzling. As one stated:

They [other members of the committee] see the science and reciprocity or the science within engagement or the science and consultation as quite separate things ... whereas I would see them as one in the same. I would see it as holistic.

Logistical features of the post-2012 HDEC arrangement encourage this relegation of the bigger questions around health research to a second tier of concern. Even the ethics application form itself separates culture and health disparity. While Question f.1.1 does look at how a study might contribute to reducing inequalities, this question comes late in the form and is spatially separated from the question on culture (Health and Disability Ethics

Committees, 2013, Question p.4.2). This supports the view that the former queries are seen as an unrelated afterthought. Obviously, such a separation does not assist in broadening the discussion within ethics committees accepting that answering issues around culture will very likely present fewer challenges.

Supporting the question on benefit to Māori (Question p.4.1), which immediately precedes the "culture" question, is a reference to the Health Research Council's (2010) *Guidelines for Researchers on Health Research Involving Māori*, which looks at whether or not Māori consultation is required. These guidelines state that:

Consultation is a vital step in the development of a research project either that involves Māori as participants or when the topic is of particular relevance to Māori health. The consultation process can lead to the development of research partnerships, the identification of the most useful research design methods, the resolution of contentious issues, and the maximisation of the potential health outcomes. (p. 9)

The above guideline clearly emphasises a research rather than a cultural dimension with the implied position that a consideration of culture is a necessary but not sufficient focus in the health research context. The document goes on to say that:

As a rule, consultation should take place if Māori are to be involved as participants in a project or the project relates to a health issue of importance to Māori. You may need advice on whether the health issue is of importance. The extent of any consultation should always be appropriate to the scale of the intended project, its relevance and significance to Māori health and the potential for application of the research results. (p. 13)

However, this advice is in itself ambiguous. One possible interpretation of the statement might

be that consultation would only be required as a part of the ethics approval process when research is clearly "Māori-centred". Alternatively, if research participants are recruited from the general population, then an ethics committee could be asked to deal with the issue of Māori consultation on paper much as is the practice now. As one Māori advisor explained:

If ethnicity is a variable of interest in your hypothesis then you have got to put that into your sampling framework and in your analytical framework and it has to be powered appropriately to do that .... What's your hypothesis, is there evidence of ethnicity as a variable?

The advisor's proposition pulls us away from the opinion regarding Treaty responsibilities that softening the requirements for Māori consultation should be the exception and never the rule. We remind ourselves again that this position is derived from the view that, in terms of the Treaty of Waitangi and its primary principles of partnership, participation and protection, all health research will be of relevance to Māori. Added to this, the complexity of research is also seen to alienate a Māori perspective. In commenting on the ability to make a relevant contribution, a Māori HDEC member felt that given "the vast majority of applications before us now are bio-medical; I cannot give input at that level at all."

This complexity can further enhance the cultural turn. These members are then left with commenting on cultural imperatives that merely serve to reduce the scope of contribution thus exacerbating the impression that issues around Māori are being trivialised. The new post-2012 application form is seen by Māori members to support this cultural trivialisation. As one member observed:

In the old ethics form at the beginning of the section that is the Māori section there was a paragraph or two that was taken from the [Health Research Council] research with Māori document ... [which] explained why it was important to understand why all research needed to be both inclusive and understood about the place of Māori. That has gone in the new application form and I think that was a mistake because it gave context, I think it provided a base for researchers to "get it" and now often, more often than not, we just see the throw-away comments about the Treaty, the one line about the Treaty and a response to the question that is asking nothing about the Treaty.

Recent changes to the application form encourage the "easy way out" for those in the research community inclined to seek a soft option. One Māori HDEC member observed the resulting trivialisation in this way:

It is more common to get the other extreme where the answers to the questions, in particularly the Māori section are just very clearly, "Oh I'll just write a line. Oh someone give me a sentence" it's that kind of response—if they are researching a particular health issue for example sometimes—it makes sense to me when they are considering the place of Māori they would at least know the prevalence of that particular issue in the Māori population and some don't even bother to [find out].

Within this scenario, the pathway to the trivialisation of the Māori consultation process is complete.

## **Outsourcing consultation**

Our observations show that HDECs will frequently refer a researcher to someone outside the ethics review process—that is, a Māori advisor or organisation such as a member of a Māori health team within a district health board. For example, the minutes of the Central HDEC reveal two applications where the Māori

issues section was incomplete that apparently required additional advice from a prominent Māori advisor in one case and the Ngāi Tahu Research Centre in the other. Similar recommendations were evident in observations of the Northern A HDEC in February and March 2013. There, researchers whose Māori consultation was deemed incomplete were referred to either a Māori researcher or the Auckland District Health Board. The latter went as far as the Māori representative writing down the relevant email address and giving it to the researcher who was present.

Given that much of the advice being sought revolves around "culture", it may appear that the HDECs do not have much faith in the skills and expertise of their Māori members in respect of their expertise in tikanga and te ao Māori. This all takes place in the absence of any discussion that a move to such an arrangement may transform into a commercial transaction, which potentially could especially undermine research consortia who are community-based as opposed to those that are fully funded university-based researchers. The irony here is that the justification for advice to be given as a part of an economic transaction may remove the potential for community-generated action research to play a part in enlivening and rejuvenating communities suffering social disadvantage.

A further problem associated with the outsourcing of advice on how to consult with Māori stems from the fact that different types of advice are being given by Māori advisors depending on their institutional affiliation. As a Māori HDEC member commented: "Given that many of these advisors seem to have varying levels of traditional knowledge, training should be a requirement for this cohort and not just ethics committee members."

This form of variability was also mentioned by a university-based advisor who suggested that there were major differences in the nature of this advice depending upon whether the advisor was located in a university or in a district health board with the former opting to talk more about methodology while the latter tended to concentrate on issues surrounding the contextual elements of the research. An example given was while a university-based advisor may discuss in detail the merits or otherwise of a questionnaire on mental health services, a district health board advisor might well focus on the current state and structure of mental health services and what implications that might have for the design of the research.

Of course, part of the problem with diverse opinion stems from the researchers themselves, with one university-based Māori advisor emphasising that many researchers actually seek the easy cultural turn: "The cultural gateway is definitely the thing—a lot of them [ask] 'Are there any easy gateways?' .... They [only] want one that will not be too challenging for them." What now follows distils the cultural turn describing how Pākehā and Māori HDEC members deal with it.

# Absorbing the cultural turn in indigenous research ethics

This paper has analysed the four new HDECs' Treaty considerations. There is a lack of uniformity and divergence in what the committees expect from researchers. One committee responds to Māori consultation in every application. The other three committees mention Māori consultation only sporadically. This inconsistency is marked and historically odd in that under previous ethics committee arrangements, the former 15 regional committees were criticised for their inconsistency, which was the prime reason for their demise at the end of 2004. In contemporary HDECs the terms defining the composition of the committees is not specific around the role or contribution of Māori members—a matter that was defined in some detail in past iterations of the ethics review process. Hence, these members, if they exist, will not surprisingly bring a variety of foci to the review process.

Emphasis on the cultural turn highlights the nature of what the post-2012 HDECs focus on. Our observations, which are supported by the online committee meeting minutes, is that, invariably, they focus on cultural issues such as having karakia before the destruction of blood samples and the need for kanohi ki te kanohi and not the query in the online application form, which asks about how research will affect health inequalities. Moreover, the impact of this factor, along with the lack of standardisation around the nature of the advice given, means there will be a predilection for Māori issues to be seen in terms of "soft" elements such as karakia and speaking with kaumātua rather than in terms of a searching exploration of potential impact of research on health outcomes for Māori.

Our position is that talking about cultural matters constitutes a necessary but not sufficient scope for a full and appropriate discussion of these matters. The combination of the aspects mentioned above means the potential for there to be dialogue around the paradigmatic context of health research is remote. In its place parades the "trivialisation" of Māori issues that is exacerbated by the disempowerment of ethics committees in general and the absence of the formalised significance of Māori membership in particular. The HDECs can take a handsoff approach and allow Treaty responsibilities to fall completely off the table. One Māori HDEC member informant disclosed that they were finding supporting Treaty responsibilities to be an uphill battle on their committee and was tending to raise the issues only when they were the primary reviewer for a project. For other projects, other members appear to dominate the discussion. Noteworthy was the outlier Central HDEC, which addressed Māori on every application.

In sum, HDECs appear to have lost their central role in indigenous research ethics. Committees appear to be outsourcing Māori consultation to the extent of recommending Māori advisors by name. Such support for

outsourcing implies that the HDECs simply do not trust their Māori members nor do they appear to value these members' special knowledge base. In addition, HDECs are expressing only limited concern with promoting the need for quality advice around Māori contexts, which seems ironic given that the HDEC application form makes specific mention of the positive value of research contributing to the reduction in health and social inequalities.

## Conclusion

The analysis of the recent changes to the HDECs shows that indigenous research ethics, as viewed under the new HDEC system, is characterised by lack of uniformity, a focus on cultural factors, and the outsourcing of advice for researchers. Thus, the practice of indigenous research ethics continues to be further trivialised under the new ethics review process. This being the case, it may be that progress around improving practice, in terms of consultation and engagement with Māori, will require careful discussion. Elsewhere (forthcoming) we make a bold suggestion that progress around improving the practice of consultation and engagement with Māori could be made if the consultation requirements for mainstream research were to be paper based, and reviewed by an ethics committee without actual expectation of mandatory external consultation conditions. On the other hand, Māori-centred research should require actual and detailed evidence of consultation that would be tied to an explicit articulation of the mutual understanding of the benefits accruing from this relationship. This revision of the consultation process would enhance meaningful engagement with Māori.

## Glossary

kanohi ki te face-to-face interaction

kanohi

karakia a prayer kaumātua an elder

koha a gift or donation

mihi a speech of greeting and

acknowledgement

Pākehā term for New Zealanders of

European descent

tapu sacred

te ao Māori the Māori world

tikanga protocols, correct procedures

#### References

- Department of Health. (2011). Governance arrangements for research ethics committees: A harmonised edition. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213753/dh\_133993.pdf
- Gillett, G., & Douglass, A. (2012). Ethics committees in New Zealand. *Journal of Law and Medicine*, 20(2), 266–272.
- Health and Disability Ethics Committees. (2013). Health and Disability Ethics Committees application form. Retrieved from http://ethics.health.govt.nz/system/files/documents/pages/HDECform.doc
- Health Committee. (2011). Inquiry into improving New Zealand's environment to support innovation through clinical trials. Report of the Health Committee. Retrieved from http://www.parliament.nz/resource/en-nz/49DBSCH\_SCR5154\_1/19f143ece9bbafc1f5970397e5d92a582e003faa
- Health Research Council of New Zealand. (2010). Guidelines for researchers on health research involving Māori. Retrieved from http://www.hrc.govt.nz/sites/default/files/Guidelines%20 for%20HR%20on%20Maori%20Jul10%20 revised%20for%20Te%20Ara%20Tika%20 v2%20FINAL[1].pdf
- Hudson, M. (2009). Think globally, act locally: Collective consent and the ethics of knowledge production. *International Social Science Journal*, 60, 125–133.
- Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). Te ara tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members. Auckland, New Zealand: Health Research Council of New Zealand.
- Ministry of Health. (2007). Multi-region Ethics Committee annual report January 2006 to December 2006. Wellington, New Zealand. Retrieved from http://ethics.health.govt.nz/ about-committees/archived-minutes-andreports-pre-2012/multi-region-committee
- Ministry of Health. (2009). Northern Y Ethics Committee annual report January 2008 to December 2008. Wellington. Retrieved from http://ethics.health.govt.nz/about-committees/ archived-minutes-and-reports-pre-2012/ northern-y-committee
- Ministry of Health. (2012a). Summary of submissions on the draft standard operating procedures for health and disability ethics

- committees, and the draft HDEC application form. Retrieved from https://ethics.health.govt.nz/system/files/documents/pages/SOPs-for-HDECs-submissions-summary.docx
- Ministry of Health. (2012b). Standard operating procedures for health and disability ethics committees. Retrieved from http://ethics.health.govt.nz/operating-procedures
- Northern A Health and Disability Ethics Committee. (2013, 12 February). Northern A Health and Disability Ethics Committee meeting minutes. Retrieved from http://ethics.health.govt.nz/system/files/documents/pages/NTA%20minutes-12%20Mar%202013.doc
- Northern B Health and Disability Ethics Committee. (2013, 5 March). Northern B Health and Disability Ethics Committee meeting minutes. Retrieved from http://ethics.health.govt.nz/system/files/documents/pages/ntb-minutes-5-march-2013.doc
- Primorus Clinical Trials. (2010). Improving New Zealand's environment to support innovation through clinical trials. Submission from Primorus Clinical Trials Ltd. Retrieved from http://www.parliament.nz/resource/0000109739

- Rawlins, M. (2011). A new era for UK clinical research? *The Lancet*, 377(9761), 190–192.
- Robson, R. (2010). Submission on improving New Zealand environment to support innovation through clinical trials. Retrieved from http://www.parliament.nz/resource/en-nz/49SCHE\_EVI\_00DBSCH\_INQ\_9752\_1\_A45690/8849f7b5e6ac61c8bdd403e4485db8793ab0f561
- Smith, B. (2011). Māori consultation. *Ethics Notes*, (*May*). Retrieved from http://www.hrc.govt.nz/sites/default/files/Ethics-May2011.pdf
- Southern Health and Disability Ethics Committee. (2013, 22 January). Southern Health and Disability Ethics Committee meeting minutes. Retrieved from http://ethics.health.govt.nz/system/files/documents/pages/sth-22-jan-2013.doc
- Southern Health and Disability Ethics Committee. (2013, 19 February). Northern B Health and Disability Ethics Committee meeting minutes. Retrieved from http://ethics.health.govt.nz/system/files/documents/pages/sth-19-february-2013.doc
- Tolich, M. (2002). Pākehā "paralysis": Cultural safety for those researching the general population of Aotearoa. *Social Policy Journal of New Zealand*, 19, 164–178.