article

Ethics Guidelines, Health Research and Indigenous Australians

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Abstract

In this paper we overview the findings of a literature review that was undertaken to guide the revision of the Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (NH&MRC, 1991). The literature reviewed, in general, supported the development of specific research guidelines for Aboriginal and Torres Strait Islander contexts. The findings of this review were analysed thematically, and a number of key issues were identified for consideration in the review process. We present a summary of these key issues. In the final section of the paper we consider in more detail two of the key issues raised in the review process (the assessment of relevance or benefit of proposed research; and the process of consultation and negotiation of collective consent) in order to critically consider how these issues should be engaged in revised guidelines. On the basis of this analysis, it is our contention that specific guidelines on key issues are limited to the extent to which they can anticipate all possible research contexts. In order to address this problem, and guide researchers, guidelines should also explicitly outline the values, from an Aboriginal and Torres Strait Islander perspective that are foundational to an ethical research process.

The paper is based upon a literature review that we undertook for the National Health and Medical Research Council in Australia (NH&MRC). During the 2000–2003 triennium, the Australian Health Ethics Committee (AHEC), a principal committee of the NH&MRC, initiated the review of the 1991 Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (hereafter: the Guidelines). AHEC engaged Robert Griew (a member of AHEC) and Daniel McAullay (an independent consultant) to consult with relevant stakeholders about the issues that should be considered in the review of these guidelines (AHEC, 2001). Concurrently, McAullay, Griew and Anderson reviewed the published

literature to ascertain the range of issues that had been canvassed concerning Aboriginal and Torres Strait Islander health research, ethics and guidelines (McAullay et al., 2001). The NH&MRC is a statutory entity created under Commonwealth legislation (the most recent iteration being the National Health and Medical Research Council Act, 1992). The Act provides for the creation of 'a national body to pursue activities designed to foster medical and public health research and the consideration of ethical issues relating to health' (NH&MRC, 1999, p.3). NH&MRC is legislatively required 'to inquire into, issue guidelines on and advise the community on ethical issues relating to health' and specifically to issue

guidelines on the conduct of medical research involving humans (NH&MRC, 1999, p.3). To this end, it has been a requirement since 1985 that institutions, in order to continue to receive NH&MRC funding, observe the standards and procedures set out in these guidelines (otherwise known as the *National Statement on Ethical Conduct in Research Involving Humans*, (NH&MRC, 1999) hereafter referred to as the *Statement*).

Since its original publication in 1966, the *Statement* has been through several revisions, and supplementary notes have been developed which provide ethical guidance on a range of specialist subjects. Specific guidelines for health research in Aboriginal and Torres Strait Islander contexts were first endorsed by the NH&MRC in 1991. These *Guidelines*, as they have remained, were developed in response to political activists in the Aboriginal health movement who, in alliance with a number of sympathetic non-Aboriginal researchers, pressed for protection from exploitative research practices and greater Aboriginal and Torres Strait Islander control of the research process (see Humphery, 2003, this volume).

The *Guidelines* are divided into three sections: consultation; community involvement; and ownership and publication of data. The guidelines document is framed as a set of standards, rules and principles. As such the *Guidelines* address Aboriginal and Torres Strait Islander concerns about specific elements of research practice by delineating the minimum requirements of ethical research practice. Consequently, clauses are contained in the *Guidelines* such as the following:

- 1. In the preparation of the research proposal, the researcher has sought advice not only from State, Territory and Federal Aboriginal and Torres Strait Islander Health agencies, but also from local community health services and agencies ...
- 4. Members of the Aboriginal and Torres Strait Islander community being studied will be offered the opportunity to assist in the research and will be paid for the assistance, and the funds to support that assistance are included in the research budget proposal ...
- 8. Following completion of data collection and analysis, and before any publication or presentation of this data, a summary of the findings will be reported to the community as a whole ...

Whilst the guidelines are specific in the standards they set and in the principles they describe, the rationale or underlying philosophy is not made explicit. Nevertheless, some of these statements appear to be aligned with values such as self-determination and community control. These foundational values have underlined Aboriginal political action in health and other arenas for nearly three decades (Burgmann, 1993; Anderson, 1994; Nathan, 1980; Nathan and Japanangka, 1983) and have influenced activism in this field of research (Humphery, 2003). Consequently, there are clauses in the *Guidelines* that promote Aboriginal and Torres Strait Islander community control of the research process, such as the consultation clauses or specific statements to the effect that:

14 The return of identifiable raw data, its destruction, or secure storage on completion of the research, should be negotiated with the community, or its nominated representative or agency, prior to the commencement of the research.

While others are framed to protect against exploitative research practice:

5. The researcher has accounted for any resources which may be made use of in the conduct of the research, has costed these in the research proposal, and has demonstrated a process for reimbursing the community and/or individuals for any such costs.

In this paper we intend to summarise the findings of our literature review. The literature we identified, in general, supported the development of specific research guidelines for Aboriginal and Torres Strait Islander contexts. Further, there were thematically identifiable sets of issues that need to be considered in the review of the existing guidelines. However, it is our contention that some of these issues cannot be properly engaged in guidelines that only focus on the regulation of specific aspects of research practice by clarifying or benchmarking acceptable practice. In order to demonstrate this we consider in further detail two sets of issues identified in the review: the assessment of relevance or benefit of proposed research; and the process of consultation and negotiation of collective consent. For both sets of issues we argue that specific rules or standards are limited by the extent to which they can be framed to anticipate all possible contexts. Sustained ethical relationships require the development of a mutual understanding (between researcher and researched)

concerning the ethical foundations for research in Aboriginal and Torres Strait Islander contexts. On this basis we propose that guidelines should be more explicitly framed in terms of the Aboriginal and Torres Strait Islander values that provide a foundation for ethical and moral relationships in contemporary contexts.

Review Method

We undertook to review the published literature of Aboriginal and Torres Strait Islander health research, ethics and guidelines for the specific purpose of informing the review of the Australian guidelines. Consequently, our search strategy was focussed on achieving as comprehensive coverage of the Australian literature as possible, and secondarily to place this literature in its international context. The findings of this review were published as an annotated bibliography (McAullay *et al.*, 2001).

The literature was identified by searching the Australian Public Affairs Information Service (APAIS) database (from 1981 to 2000), the health database Austhealth (involving various start dates from 1900 to 2000), and Medline (with a start date of 1966). These databases provide some coverage of the Australian 'grey' or unpublished literature. A number of search keywords were used in locating material, including 'Aboriginal', 'Torres Strait Islander', 'research', 'ethics', 'indigenous', and 'cross-cultural'. In addition, a manual search of bibliographic information contained in the literature itself yielded a further body of previously unidentified material. There have not been previous reviews in the Australian context against which the comprehensiveness of this review can be benchmarked. A comprehensive review of the international literature would require a further elaboration of this search strategy (using local databases and keywords) and collaborating with local experts who could assist in identifying the unpublished grey literature.

Guidelines for Aboriginal Health Research Ethics

In our review of the literature we identified ten broad themes (historical overviews and key issues; examples of Indigenous health research guidelines; the benefit and/or relevance of research; community consultation and consent; Aboriginal and Torres Strait Islander participation in research; the dissemination of research findings; the compliance and monitoring of approved research; collaborative research models; controversial fields of health research, and the scope

of health research guidelines). There was, of course, a significant degree of overlap between these themes, and a number of publications were also classified into more than one category. In the section that follows we will overview the issues raised. The content themes included articles which:

- Provide a historical overview of Indigenous health research and related ethical issues. Several articles in this group gave examples of research conducted with little consultation, co-operation or involvement with those being researched. Many of the articles in this cluster support the use of specific ethical guidelines as a strategy for dealing with the ethical problems in Indigenous health research (for example: Eades and Read *et al.*, 1999; Donovan and Spark, 1997; Hunter, 1991; Kaufert *et al.*, 1999; Wax, 1991)
- Report other examples of Indigenous research guidelines in Australia and internationally (particularly North America). The guidelines described commonly covered issues of consultation, community involvement, cultural appropriateness, and the management of data and information. Some articles raised issues about the jurisdiction of guidelines, for example, the extent to which epidemiological studies such as the analysis of administrative data sets or outbreak investigations should be covered by guidelines (for example Achanfuo-Yeboah, 1995; Glover, 1996; Kaufet et al., 1999; Mahoney and Nichalek, 1998; Savage and Stuart, 1995; Weijer et al., 1999);

In the literature that we reviewed no one advanced an argument against the use of specific guidelines for Indigenous health research. On the contrary the use of specific guidelines was generally supported, even though there were a number of particular issues that attracted critical discussion. In the majority of contexts ethical issues in research were raised as general concerns – without the *Guidelines* being specifically discussed. Articles included in this review also thematically canvassed the following issues:

- the principle of relevance or benefit, and how this might be dealt within research guidelines (this is considered in more detail below);
- community consultation and collective consent, and the

role of guidelines in the ethical assessment of these research processes (this is considered in more detail below).

- the appropriate involvement of Aboriginal and Torres Strait Islander people in health research. The only specific role for Aboriginal people, other than as research subjects, that is identified in the *Guidelines* is as research assistants. The arguments presented in the literature in general press for a review of the guidelines to promote the more comprehensive involvement of Indigenous people in all stages of the research progress (Grootjans and Spiers, 1996; Hecker, 1997; McMasters, 1996; Sibthorpe, 1995; Wax, 1991; Willmot, 1977);
- the effective dissemination of research findings. In this cluster of articles, poor dissemination of research findings, particularly with respect to the feedback of findings to the researched communities, is identified as a key ethical issue in Indigenous health research. The *Guidelines* have a specific clause requiring researchers to provide a summary of findings to the researched community. Some articles report on feedback strategies. (Davidson, 1976; Hunter, 1992; Kimberly Aboriginal Health Workers, 1992; National Aboriginal Community Controlled Health Organisation, 1998);
- the compliance and monitoring of approved research. This issue is not dealt with in the *Guidelines*. The *Guidelines* require researchers and institutional ethics committees to comply with surveillance requirements set out in the *Statement*. In a few articles it was argued that these processes needed review in order to ensure that, once approved, research processes continue to adhere to the agreed processes (Atkinson, 1999; National Aboriginal Community Controlled Health Organisation, 1998);
- collaborative research models in Aboriginal and Torres Strait Islander health that enhance the development of research partnerships and compliance with existing ethical guidelines were described in a few articles (Eades and Read et al., 1999; Mathews, 1998);
- some articles also had a more detailed discussion on the research ethics in fields of research, such as genetic research, which had provoked particular controversy in

- Indigenous contexts (for example: Despoja, 2000; Dodson, 2000; Van Holst, 2000);
- there were a few papers that considered the scope of research guidelines, and the extent to which they should also have jurisdiction over research related activities such as government program evaluation or the epidemiological analysis of public data sets (Watene-Haydon et al., 1995; Guerin, 1997).

A detailed discussion on all these issues is beyond the scope of the paper. In general this literature supports the development of ethical guidelines for Indigenous health research. There is some agreement about the core ethical issues that should be included in revised guidelines, taking into account both the ethical concerns raised and the reported examples of guidelines. Further consideration should be given to whether the jurisdiction of these guidelines should be extended beyond traditional investigator driven research to encompass activities such as government program evaluation. The review of the Guidelines should also engage with those specific issues that attracted detailed discussion in the literature such as: the involvement and participation of Indigenous people in the research process; the dissemination of findings, the compliance and monitoring of approved research and problematic research fields such as genetics. The fact that there has been a significant increase in the number of Indigenous Australians with skills and experience in health research; and the development of new collaborative research models, should also be considered in the review of the Australian guidelines.

In the section below we will consider in more detail two specific of the issues raised through this review process: the ethical assessment of the relevance or benefit of research to the researched community and ethics of consultation and collective consent. We have chosen these issues as case studies in order to demonstrate the difficulty in developing guidelines that anticipate all the possible contexts in which research is developed. Furthermore, as we contend in the concluding section of this paper, guidelines that *only* contain specific principles, rules or benchmarks are limited in the extent to which they can guide researchers and research ethics committees about the critical values that are foundational, from the perspective of Aboriginal and Torres Strait Islander peoples, to ethical relationships in research.

Relevance and Benefit

A theme that emerged from our review of the literature in this field was concerned with the ethical assessment of the relevance of research, the need for new knowledge, and the value or benefit of any intervention subsequently developed (Anderson, 1996; Ellis, 1997; Mathews, 1998; Miller, 1997; Schapper, 1970). Those who advocated a focus on this issue were in general concerned to develop an approach that balanced the interests of the researcher with the material and other interests of Indigenous communities. Arguably, it could be considered unethical, in the context of Indigenous social disadvantage, to disrupt community life and process and redirect community resources for a research initiative that offered little tangible return to that community in particular or to Aboriginal and Torres Strait Islander peoples in general. Kothera, in fact, proposed that the 'Right to Research Benefit' should, as a principle, complement the concept of 'Intellectual Property Rights' (1997).

The *Guidelines* cover this cluster of issues in the section on consultation in which it is stated that the 'research proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general' (NH&MRC, 1991). However, the *Guidelines* do not provide criteria against which this can be assessed. Nevertheless, in NH&MRC research grant applications for 2000 and 2001, researchers were asked to articulate how their proposed research would lead to sustainable, transferable solutions and how the research process would foster community participation (McAullay *et al.*, 2001).

Most of the literature in this field takes the concept of benefit as self-evident and its value is frequently and somewhat repetitiously asserted, without a detailed discussion about how it should be assessed. Only three articles provide a more detailed discussion of the concept of benefit, all of which suggest that the assessment of research benefit is not straightforward. One of us (Anderson, 1996) argued that there were a number of dimensions of benefit that should be considered, noting that there are short-term, medium and long-term timeframes through which the benefits (and risks) in research accrue. Torzillo (1997) suggested that the concept of benefit is sometimes narrowly limited to 'action based research' or qualitative research. While he supported the principle of benefit, Torzillo argued that it in the process of ethical assessment it is likely that only the more immediate benefits will be manifest. He argues, that long-term benefits should also be facilitated even though they may develop unpredictably from advances in knowledge.

Consider the complexity in the ethical assessment of benefit in the following contexts:

- a local program evaluation, that assesses the cultural acceptability of particular services and other barriers to effective access;
- a local health workforce study that analyses the supply of health professionals against need;
- vaccine trials that aim to evaluate vaccine effectiveness in particular populations.

In all these instances the time frames through which benefit may accrue will vary from immediate in the case of a local program evaluation, to the potential long-term generational impact of vaccine research. A vaccine research program may have the potential to delivery significant health gains, but there is a significant risk that it will be shown to be ineffective. Different research initiatives may also differ in the extent to which benefit accrues locally. Findings from a program evaluation may be quite specific to the context of the evaluation, and may not be suitably generalised to other communities. On the other hand, a vaccine trial that aims to evaluate the effectiveness of a vaccine in an Aboriginal population would have implications beyond the study population. Furthermore, research studies vary in the extent to which the benefit might be accurately anticipated or within the control of the researcher. Findings from a health workforce study might influence the supply of health professionals depending on the responsiveness of health funding agencies and professional bodies to the findings of the study. In a vaccine trial that assesses the biological safety of a proposed vaccine, the longer term potential benefit can only be argued on the basis of theory and biological models.

Given that research outcomes cannot be pre-determined at the proposal stage; and allowing Aboriginal and Torres Strait Islander communities the right to engage with the spectrum of research activity, it is not feasible for guidelines to predetermine the quality of benefit. However, guidelines can be developed that promote transparent negotiation with Indigenous Australians concerning the potential benefits of proposed research. For example: a guideline might state that researchers should consider and clearly articulate in their proposal that the research:

- Is premised on the demonstrative intent to contribute to the advancement of the health and wellbeing of participants and participating communities;
- · Clearly linked to Indigenous community priorities;
- Responsive to existing or emerging needs articulated in health advancement plans and strategies;
- Contributing to tangible, useable and accessible outcomes for participants.

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.

Consultation and Consent

The issue of consultation was a focus in the *Guidelines*. The *Guidelines* directed researchers to consult with local community-controlled Aboriginal health services as well as State, Territory and Federal Aboriginal and health agencies with respect to any proposed research. The *Guidelines* also state that written documentation of community consent should be obtained and, where this is not possible, reasons why should be documented. The *Guidelines* require that any changes to the research protocol, procedure or methodology will be negotiated with and consented to by the community involved (NH&MRC, 1991).

Aboriginal and Torres Strait Islander community consultation was raised in the literature many times, and there was a consensus that consultation with the Indigenous community is an ethically fundamental requirement that creates the conditions for meaningful Indigenous participation in the research process (Gilson, 1995; Jamrozik, 1999; Wyatt, 1991). In the literature, a distinction is made between community level or collective consent and the procedures required for the consent of individual subjects in the research process. The consent of individual research subjects is one of the bedrock principles of research ethics and has not been considered in detail within this particular literature. Community consent refers to the decision-making processes of a social collectivity. As such, the application of this principle is distinct to that of individual consent (Kaufert, 1999; Weijer, 1999; Workshop Discussion Paper, 1995).

There is a significant focus in this body of literature on community consultation and consent strategies. In an article outlining the consultation and recruitment process of the special cohorts of the Australian Longitudinal Study on Women's Health in 1998 the authors argued that appropriate consultation was potentially undermined when the media inappropriately identified communities and when those involved in research processes simplistically conceptualised the notion of 'community' (Manderson et al., 1998). Other writers also stress, in the application of ethical guidelines, that it is important not to take 'community' for granted as a selfevident entity (Brady, 1990; Israel et al., 1998; Weijer, 1999). Israel et al. argued that research processes should recognise and engage with 'community' whilst at the same time they raised significant issues about identifying who represents a particular 'community' and how it is defined (1998). Weijer et al. (1999) and Weijer (1999) stressed the importance of community involvement in the development stage of research through consultation, but at the same time stressed the need for a clear definition of community and critical engagement with application of this principle in practice.

The ethical assessment of consultation and community consent to participate in a research study may be relatively straightforward in some circumstances. For example, in the case of a geographically discrete community with a broadly supported representative structure all that may be required is written evidence that the community has been properly consulted with, and at a collective level agrees to participate. There are a number of possible contexts in which it may be more difficult to assess whether these processes have been adequate or appropriate. Different research proposals may require distinct and particular consultation strategies. Consider for instance the following contexts:

- A study is proposed in a major metropolitan area with a large dispersed Indigenous population and a large number of Indigenous community organisations on a topic that covers health, education, housing and community services. Who should the researchers consult with in this instance? Who has the right to speak for this community? Which organisations should be asked to sign off on any agreement to participate?
- A regional study is proposed which encompasses a number of discrete communities. Are the researchers required to

consult directly with all stakeholders across this region – or should they negotiate with a regional Indigenous organisation if such exists?

- A researcher proposes to study Indigenous women's health in a particular community, but is consulting with a local women's group who have an antagonist relationship with the local Aboriginal co-operative. Is this ethically justifiable?
- A researcher proposes to investigate Indigenous health in a community that does not have a clearly identifiable community structure to negotiate with. How is this engaged ethically?

Given the range of possible contexts in which ethical assessment occurs, it is not feasible to develop guidelines on community consultation that set clear and unambiguous defined endpoints. There is regional variation in the types of Indigenous collective structures that could be potentially involved in the agreement making process – and as such there are also some differences in the preferred processes of negotiation. There is also an increasing interest in the development of research partnerships, which by implication involve significantly more engaged and active relationships with Aboriginal and Torres Strait Islander communities. As such, research guidelines need to both allow for some flexibility in the process of consultation and consent, whilst at the same time setting a framework through which such processes should occur, leading to either a formal partnership or agreement. In order to be both effective and appropriate in their consultation and negotiation, researchers need to understand and engage with the social dynamics of Indigenous communities.

Promoting Ethical Relationships or Regulating Practice?

It is our contention that guidelines in Aboriginal and Torres Strait Islander health research that address ethical concerns only through specific rules and minimum standards are problematic on two grounds. First, as we have considered above, not all contexts can be anticipated in such specific statements. Making an ethical assessment of research practice in a context that is not clearly articulated in guidelines requires institutional ethics committees (which by and large are still dominated by non-Indigenous interests) to make a judgement. In the absence of any other guidance the values that guide such a judgement will reflect those of the ethics committee as opposed to those of the Indigenous community in which research is proposed.

Second, research in Indigenous Australia, occurs in a context in which most non-Indigenous researchers have a poor understanding of Aboriginal and Torres Strait Islander cultures in general. More pointedly, through the history of colonialism, Indigenous cultures and values have been explicitly undermined and disregarded. An ethical research process requires that cultural and social differences are clearly recognised and recognised for what they are: 'To "misrecognise or fail to recognise can inflict harm, can be a form of oppression, imprisoning someone [or a group] in a false, distorted and reduce model of being", research cannot be "difference-blind" (Taylor, 1994). Research relationships in the inter-cultural setting are also influenced by what is not said - by undeclared assumptions or silent evaluations of other people's practices and life world. Exclusion of the minority is a product of failing to resolve the spoken or unspoken conflicts that may emerge when the dominant party to a relationship has different core cultural values. Such exclusion limits the potential of the minority, and undermines their dignity and worth. As such it is unethical.

Our fundamental challenge is to simultaneously change the social dynamics of research to enable Indigenous Australians to show leadership in research, actively participate in the development of research projects (as researchers not research assistants) and to develop collaborative models for research and partnership structures between research institutions and Aboriginal and Torres Strait Islander community structures. If researchers are to develop ethical research relationships with Indigenous communities the social connections between research structures and Aboriginal and Torres Strait Islander people need to be reformed. If Indigenous Australians and their communities are always socially positioned as either research subjects or research clients and if researchers continue to have fundamentally poor social connections with Indigenous Australian people so that they are not skilled in understanding communication processes, agreement making and values from an Indigenous perspective – then it is unlikely that this will change. Aboriginal and Torres Strait Islander claims for greater control of the research process are rarely about exclusivity, and most often about setting Indigenous values as the bedrock for the development of research relationship. There is a growing sophistication within Indigenous community structures in managing research processes, a growing number of Indigenous Australians who have research careers and the development of an Indigenous

critique of 'western' epistemologies and research practices. Similarly there is a increasing number of non-Aboriginal researchers with experience of conducting research within such value frameworks.

In order to establish the foundations for ethical research in Aboriginal and Torres Strait Islander health it is critical that guidelines provide a more explicit framework for incorporating the key values that, from an Indigenous perspective, are foundational to an ethical relationship. Whilst the current guidelines reflect some of the concerns of Indigenous Australians they do not clearly embrace Indigenous values. In saying this we do not wish to imply that Aboriginal and Torres Strait Islander people have fundamental disagreements with the content of the existing guidelines - our review processes indicated that this is not the case. Further, we do not wish to imply that there is not a place for explicitly defined rules or minimum standards. Researchers, should for instance, be required to provide documentation of, for example, their consultation strategies, agreement making, or approach to data management or publication. However, there are values (such as reciprocity or cultural respect) that for Indigenous Australians people are the pre-condition to an ethical relationship that are not articulated in the existing guidelines. One possibility, for the further development of these guidelines is to integrate the existing guidelines, with modification, into a framework that more clearly articulates those Indigenous values that are identified by Aboriginal and Torres Strait Islander people as fundamental to the possibility of ethical research in Indigenous contexts. In 2002 a national workshop convened by the Australian Health Ethics Committee proposed revising the current guidelines into a framework of values that included: reciprocity; respect; equality; responsibility (including to country, kin and others; and the maintenance of harmony and balance within and between the physical and spiritual realms); survival and protection (of people, culture and land) and; spirit and integrity (which encompasses the spirit of action and motivation and the integrity of process and intent) (AHEC, 2002). This approach is yet to be tested through consultation. However, it holds promise in that it integrates both process and principles within Aboriginal and Torres Strait Islander cultural terms. This will not eliminate tension or contest in the process of Indigenous health research. As Indigenous Australians attempt to assert control over the processes of knowledge development they will, inevitably, at times confront the intellectual autonomy of researchers.

Nevertheless, clearly articulating the Indigenous values that underlie such relationships gives researchers, both Aboriginal and non-Aboriginal, the possibility of developing a value based engagement through which such conflicts could be resolved.

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commentary

on Humphery and Anderson, Griew and McAullay

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The two papers in this journal on guidelines for research involving indigenous people approach the topic from two distinct but complementary directions. When read together the papers provide an overview of the issues involved in developing and implementing such guidelines and provide salient lessons for the future direction of health research involving indigenous peoples.

One of these lessons is that such official guidelines are very slow to change. In Australia, interim guidelines were ten years old before a substantive review was undertaken. In New Zealand, the Health Research Council's (HRC's) guidelines remain unchanged since their initial publication in 1998, despite a declared intention to review them every year.

However, research practice in this area is not similarly static as the review by Humphery attests. As a result, guidelines that seek to specify and/or prescribe specific health research practices can become rapidly out of date, overtaken by the evolution of novel and or sustained research relationships between communities and researchers. It is impossible for national guidelines to describe best practice for the diversity of research fields, research designs and forms of local community involvement. Not only is such a prescriptive approach unlikely to encompass the diversity of health research practice, it also limits the very indigenous autonomy (in determining the nature of its own research relationships) that such guidelines seek to protect.

Consequently, researchers and research appraisers should not treat any national guidelines as the sole arbiter of research acceptability. The application of any guidelines needs to be in the context of community consultation and successful models of community involvement that may be regionally, institutionally or research topic specific. This places two other obligations upon the research community – first is for consultation and the second is for publication. Consultation