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Ethics of Indigenous Health Research

An examination of codes of ethics governing indigenous health research in Australia and New Zealand

Module 4.2 WS 2009/2010

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1. Introduction

In 2002, as a student at Drew University, I was given the opportunity to participate in a medical research study run by Morristown Memorial Hospital. The goal study was to test the effects of a vaccine for the Human Papilloma Virus (HPV) that affects over 20 million Americans, and can lead to certain types of cancer. (United States Department of Health and Human Services, 2010) I agreed to participate as research subject, and I was involved in the study and subsequent follow-up studies for almost five years. Since that time, I have participated in numerous other studies ranging from the effects of energy drinks on concentration to MRI scans to testing a plague vaccine. At the start of each study I was given information about the details of the study and a consent form to sign. It seemed very routine to me at the time, and I knew that it was important for my signature to be on file for liability reasons. There was always a clause in the consent forms informing me that I could cease to participate in the study at any time if I wished, and again, it always seemed like a liability issue. At no point did it ever occur to me that my consent was absolutely essential for ethical reasons. I knew that if I felt uncomfortable or unsafe I had the right to back out with no hard feelings. In fact, a friend of mine who also began as a research participant in the HPV study ended her participation after a few visits because she felt uncomfortable. It seemed so apparent to me that terminating her participation was her right, regardless of whether it was stated in a consent form or not.

The subject of ethics in research is a broad and complex topic and the codes that govern research are equally broad and complex. Codes of conduct and ethics can address various aspects of research depending on the body that develops the code. There are international and national codes of ethics for research, institutional codes, and codes for specific disciplines. Additionally, there are codes of ethics that govern specific types of research, for example, research that involves testing on human subjects. For every research study that I participated in, I was protected by a code of ethics governing research done on human subjects, even if I wasn't conscious of it. The roots of ethical codes on human subjects can be traced to the Nuremburg Code, developed in August 1947 (Shuster, 1997). The Nuremburg Code was developed "by American judges sitting in judgment of Nazi doctors accused of conducting murderous and torturous human experiments in the concentration camps (the so-called Doctors' Trial)." (Shuster, 1997, p. 1) Perhaps predictably, the Code focuses on the rights of subjects and avoiding unnecessary suffering, and is relatively simple, consisting of just ten points. These ten points give a very basic guideline for using humans as research subjects, and most modern codes contain the same principles. However, over time the guidelines for research involving human subjects have become more complex and specific. In 1964, the 18th World Medical Assembly adopted the Declaration of Helsinki, a document that guides researchers conducting biomedical research on human subjects. The Declaration was amended in 1975, 1983, 1989, 1996, 2000, 2002, 2004, and 2008. (World Medical Association, 2010) The Helsinki Declaration is widely used and the guidelines are universally applicable, but again, the guidelines are specific to biomedical research.

In the 60 plus years since the adoption of the Nuremberg Code, ethics in human research have evolved to meet emerging demands. A strand of specialization that I find particularly interesting is the specific guidelines that have arisen for research involving indigenous peoples. Neither the Nuremberg Code nor the Helsinki Declaration have any conditions regarding the type of human subject, be it a child, woman, mentally handicapped subject, or specific ethnic group. The guidelines exist for the protection of all subjects. When addressing the ethical issues of human subjects in research, it could be argued that one code of ethics should be applicable to every category of participant, regardless of race, gender etc. But clearly, the need for specific guidelines is real, as research councils in several countries have developed these separate documents. This paper will focus on the guidelines developed by the nations of Australia and New Zealand for the research involving their indigenous populations, the Aborigines and Torres Strait Islanders of Australia, and the Maoris of New Zealand. It should be mentioned that in the discussion of indigenous research in general, examples are taken from other indigenous groups apart from Aborigines, Torres Strait Islanders and Maoris.

2. Important Historical Notes

In order to understand the specific ethical guidelines for research involving the Aborigines and Maoris, it is important to understand a bit of the history between the indigenous group and the European settlers. While there are long and complex histories of the Aboriginal and Maori people in their respective countries, this section will not go into great detail of the histories. The relevant aspects are those that offer context to the current guidelines for research. Settlements by

Europeans in Australia and New Zealand began in the seventeenth century. By the nineteenth century, both countries were fully colonized, despite the resistance of the indigenous populations. (Armitage, 1995, p. 3) Comparisons are often drawn between Australia and New Zealand, as well as between the indigenous populations, (this paper as an example), but the histories and struggles after colonization are extraordinarily different. The following sections will focus on the post-colonization periods, and the seeds of the current state of the indigenous populations.

2.1 Indigenous Australians

The term “Aboriginal” is frequently used to refer to all indigenous Australians; however the Torres Strait Islanders are a different people from the Aborigines, coming from the Torres Strait Islands rather than mainland Australia. However, because the Australian Guidelines encompass both Aborigines and Torres Strait Islanders together, and for the sake of simplicity, this paper will refer to “indigenous Australians” when discussing the Aborigines and Torres Strait Islanders of Australia, unless specific groups or tribes are mentioned.

The history between indigenous Australians and “white” Australians is tumultuous, to say the least. Henry Reynolds (1984) writes of the “great silence” in the first half of the twentieth century in Australia in which Aboriginals were essentially written out of Australian history. (Reynolds, 1984) His research on the subject unearths horrifying events. According to Reynolds, apparent justification for the complete ignoring of Aboriginal history in Australia is the belief that the “black man” was dying out, and thus there was no reason to take note of the history. Furthermore, the early twentieth century was a period of fierce nationalism, and acknowledging the Aboriginal past would dredge up shame at the racial violence of early settlement. "To create doubts about the means of European occupation was to question the morality of settlement, even the right to the continent." (Reynolds, 1984, p. 5) As such, a staggering percentage of national literature from the time period makes no mention of indigenous people at all, or only in an anthropological footnote. Reynolds captures the mood of the era with the following quote from Walter Murdoch, one of the most distinguished literary figures of the first half of the 20th century. Murdoch wrote in the Introductory History of Australia, written for use in schools:

> ‘When people talk about "the history of Australia they mean the history of the white people who have lived in Australia. There is good reason why we should not stretch the term to make it include the story of the dark skinned wandering tribes who hurled boomerangs and ate snakes in their native land for long ages before the arrival of the first intruders from Europe ... [The historian] is concerned with Australia only as the dwelling place of white men and women, settlers from overseas. It is his business to tell us how these white folk found the land, how they settled in it, how they explored it and how they gradually made it the Australia we know today.’" (Reynolds, 1984, pp. 1–2)

To date, the indigenous people of Australia still have no formal treaty with the Australian State, (the European “newcomers”). (Jackson & Ward, 1999, p. 438) While the Maori people of New Zealand gained legal equal status with the Treaty of Waitangi (discussed below), indigenous Australians were given no such offer from the British Crown. Furthermore, the common law of Terra Nullius a territory belonging to no one -- was applied unilaterally. “The British "took possession" of the land because they considered it to be unoccupied.” (Jackson & Ward, 1999, p. 438) This is detrimental to any population, and certainly occurred in other countries apart from Australia, but the issue of the Aborigine’s stolen land has been a point of contention for centuries, and affects the population immensely. "Aboriginal people have a spiritual link with the land which provides a sense of identity, and which lies at the centre of their spiritual beliefs" (Jackson & Ward, 1999, p. 439) With a long history of suppression, violence and dismissal, it is little wonder that there is a history of great mistrust between the indigenous and white populations.

2.2 Maoris

The history of European settlement in New Zealand seems to parallel the Australian experience, and in fact New Zealand was at one point part of the Australian colony, essentially an “extension of the Australian frontier”. (Brooking, 2004, p. 23) However, the experience of the Maori people has been very different from that of indigenous Australians. In 1840 the Treaty of Waitangi was signed in the present Bay of Islands, giving the Maori people legal equality. (Brooking, 2004) The Treaty was drawn up in the matter of a few days and translated quickly from English to Maori. Given the relative inexperience of the authors, it's hardly surprising that historians would call it "hastily and inexpertly drawn up, ambiguous and contradictory in content, chaotic in its execution." (Brooking, 2004, p. 39) However, despite claims that the document was intended to defraud the Maori people, it is widely recognized that the aims of the treaty were sincere, and the Maori chiefs saw that the benefits of signing far outweighed any difficulties of translation or implementation. (Brooking, 2004) Though the signing of the treaty did not end all racial discrimination in New Zealand, it is regarded as the founding document of New Zealand, and one that the Maoris look to as a guarantee of their rights. Perhaps one of the most important aspects of the Treaty, especially considering the plight of the indigenous Australians, is that the Treaty gave the Maori people full control of their own land. (Brooking, 2004)

In the twentieth century, unlike the Aborigines in Australia, the Maori people were acknowledged and welcomed into New Zealand culture. W.H. Oliver writes that "The great silence which Henry Reynolds explores, and which went far to eliminate Aborigines from the historical memory of twentieth-century 'white' Australians, has never fallen upon New Zealand. Few Pakeha [non-Maori] children in the first half of the twentieth century would have grown up with historical memories in which Maori did not figure." (Oliver, 2001, p. 145) It would be callous to say that the Maori people had an easy experience with the integration of the Pakeha, as there were conflicts, violence and discrimination just as in Australia. Nevertheless, the Treaty of Waitangi is the cornerstone of peaceful relations in New Zealand, and has had a tremendous impact on Maori-Pakeha relations. The Treaty of Waitangi has been called the founding document of New Zealand (Health Research Council of New Zealand, 2006), and the principles are reflected in several aspects of New Zealand life, especially in the arenas of health and research. In fact, the New Zealand Public Health and Disability Act of 2000 requires health services to recognize the principles of the Treaty of Waitangi. “Because of the treaty, Maori occupy a position that is not afforded other non-indigenous ethnic minority groups, even where comparable standards of health exist." (Durie, 2003, p. 408) Furthermore, the Treaty of Waitangi is prominently referenced in the guidelines for health research involving Maori.

3. Separate Guidelines

Indigenous communities are an important part of many nations around the world. The culture, history, language and traditions of an indigenous people give an added layer to any national identity, and in recent years native peoples are celebrated as such. However, the historic struggles between European settlers and indigenous peoples reveal a long history of mistrust. This feeling of mistrust is manifested in countless areas of interaction, particularly in research. The cases of the Aboriginal and Maori people are no exception. Marlene Brant Castellano (2004) voices this feeling in her paper *Ethics of Aboriginal Research*. She says that in the case of Aboriginals, "Research acquired a bad name among Aboriginal Peoples because the purposes and meanings associated with its practice by academics and government agents were usually alien to the people themselves and the outcomes were, as often as not, misguided and harmful." (Castellano, 2004, p. 98) Linda Tuhiwai Smith asserts a similar point on behalf of the Maori population, noting that "the attitudes and feelings that Maori people have held towards research are shaped by how research has been conducted in their country. Research is implicated in the production of Western ways of knowing and in denying the validity of Maori knowledge, language and culture." (Smith, 2002, p. 225)

The research that has been done on and about indigenous people has been misleading, disrespectful, and even cruel. For instance, in the early years of colonization in Australia, research was preoccupied with “classifying and labeling” in an attempt to “manage” Aboriginal people. (Dodson, 1994) Furthermore, indigenous people were often seen as a problem to be solved, and much of the early research was working towards those aims. (Cochran, Patricia A. L., Marshall, Garcia-Downing, Kendall, Cook et al.) An example of misleading and manipulative research comes from a medical genetics case involving the Havasupai tribe in Arizona. Diabetes was a major concern for the Havasupai people, having been a debilitating disease for many generations. The Havasupai gave their consent for years of ongoing blood collection, with the understanding that the samples would be used to determine genetic precursors of diabetes. However, the blood samples were also used in a series of additional studies concerning schizophrenia and other diseases, and distributed nationally to other researchers, all unbeknownst to the Havasupai people. The experiments done were clearly outside the realm of diabetes research, and the majority was tribally unauthorized. The issue of who owns the tissues and blood is an important part of the case, but the deeper issue is that the researchers involved in the case were invited to assist that Havasupai tribe, and the trust and respect was utterly destroyed. (Cochran et al.)

Even as research concerning indigenous peoples has evolved and become more ethical, good intentions can still result in distress for indigenous people due to simple lack of knowledge, communication and respect. (Cochran et al.) The uncomfortable truths of mistrust cannot be denied in the case of indigenous people, but it is dangerous to back away from research entirely. A large percentage of indigenous populations are frequently in lower economic classes and have less access to medical support and other opportunities. J.C. Altman (2004) of the Centre for Aboriginal Economic Policy Research notes that while the majority of indigenous Australians live in cities and large towns alongside other Australians, the economic disparity between the "urban" indigenous and those who live in separated indigenous villages is quite large. (Altman, 2004) Additionally, in the early 1990's, the average Australian indigenous all-cause mortality rate was 3.15 times the all-Australian rate. (Ring & Firman, 1998) In the case of indigenous populations, it's clear that simply "leaving them alone" to avoid insult or harm can only lead to an increase in the inequality. What is needed in the case of research involving indigenous populations is a new approach, one that involves a cultural sensitivity and an establishment of trust.

As a result, the approach of Community-Based Participatory Research has emerged as a popular research strategy, particularly in cases involving indigenous populations. The method puts a tremendous focus on partnership, emphasizing the sharing of leadership, power and decision making. (Macaulay, Delormier, Cross, McComber, Potvin, Paradis et al., 1998) Participatory research also has a strong element of empowerment, which is extremely important to the success of a research project. Research on indigenous populations has typically been conducted by outsiders (Davis & Reid, 1999) and rarely have the communities had any input. Participatory research encourages active participation on the part of the community, giving them a stake in the project and the outcome. Marlene Brant Castellano (2004) relates an incident from a workshop she chaired in 1992 at a meeting of the Royal Commission on Aboriginal Peoples (RCAP) in Canada. In the session, participants discussed the future research agenda of the RCAP, and the overall feeling was harsh and skeptical. "'We've been researched to death!' they protested. The workshop was not off to a promising start, until an Elder who had opened the meeting spoke quietly from a corner of the room. ‘If we have been researched to death,’ he said, ‘maybe it’s time we started researching ourselves back to life.’" (Castellano, 2004, p. 98)

4. Participatory Research

When working with human participants in research, there are various levels of interaction and reciprocity. The Australian *National Statement on Ethical Conduct in Human Research* notes that the wide range of interaction and risk potential can raise difficult ethical questions, and can be complicated because "research participants may enter into a relationship with researchers whom they may not know but need to trust. This trust adds to the ethical responsibility borne by those in whom it is placed." ("National Statement on Ethical Conduct in Human Research", 2009, pp. preamble) In medical research studies involving human participants, the relationship between researcher and researched is usually very clearly defined. The result of this relationship is obviously that the human subjects have no input into the design or implementation of the research study. Normally this is a desirable arrangement, but in the case of indigenous people it is very disempowering to be excluded from the research that is being conducted on them as a population. For this reason, and reasons of trust explored earlier, the practice of participatory research is becoming very popular in indigenous research, and has proven to be critical to the success of researchers working in indigenous communities. (Davis & Reid, 1999)

Community Based Participatory Research is an approach that focuses on relationships between academic and community partners, with principles of “colearning, mutual benefit, and long-term commitment, and incorporates community theories, participation, and practices into the research efforts.” (Wallerstein & Duran, 2006) In an article written for the Canadian Journal of Medicine, Macauley et al (1998) discuss the merits of participatory research when working with indigenous groups. Their particular project dealt with diabetes prevention in the indigenous Mohawk community of Kahnawake, and the article discusses the development of a code of ethics for participatory research. (Macaulay et al., 1998) Macauley et al state that participatory research "defines a research inquiry which involves: 1) some form of collaboration between the researchers and the researched; 2) a reciprocal process in which both parties educate one another; and 3) a focus on the production of local knowledge to improve interventions or professional practices." (Macaulay et al., 1998, p. 105) Research has also defined an important aspect of participatory research as “bridging the gap between knowledge produced through research and what is practiced in communities to improve health.” (Agency for Healthcare Research and Quality, 2004, p. v)

A vital aspect of participatory research begins before any research is conducted. When projects are being designed, it is extremely important to involve the community in which the research will take place. Davis and Reid (1999) write that in participatory research, "Both scientists and representatives from the intervention population share equally in research planning, implementation, evaluation, and dissemination of results, as well as in any resulting benefits." (Davis & Reid, 1999, pp. 757S) Both the Australian and New Zealand guidelines address this issue. The Australian guidelines specify that only research proposals that are "ethically defensible on the grounds of each of the values of [the] guidelines: conceptualisation, analysis, development and approval, report writing, data collection and management, and dissemination". (National Health and Medical Research Council, 2003, p. 23) The New Zealand guidelines discuss consultation, and declare that “consultation should take place if Maori are to be involved as participants in a project, or the project relates to a health issue of importance to Maori.” (Health Research Council of New Zealand, 2008, p. 13)

The participatory approach brings together external researchers and indigenous community members as equal partners in the full process of research, learning and action. The education of the researchers is reciprocal as well, as the external researcher can provide information or training in research practices, and the community members can provide cultural context for the health issue that is being investigated. (Davis & Reid, 1999) As Macauley et al wrote, "The ultimate aim of participatory research is to empower research subjects to assume ownership of the research process and to use the results to improve their quality of life." (Macaulay et al., 1998, p. 105) In the field of indigenous research, this approach appears to be emerging as the foremost way to proceed. Both the Australian and New Zealand guidelines incorporate these aims, and the unique historical circumstances are reflected as well. The specifics of the guidelines will be explored in the next section.

5. Specifics of the Guidelines

The Australian guidelines and the New Zealand guidelines for research involving indigenous populations reflect the aims of participatory research in their own way. The next sections will discuss the particulars of each of the codes in relation to cultural respect and participatory research, as well as the historical context of the document.

5.1 Australia

In Australia, research involving human participants is governed nation-wide by the *National Statement on Ethical Conduct in Human Research*, and the document that specifically deals with indigenous Australians is the *Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, hereafter referred to as the "Aboriginal Guidelines". The *National Statement* focuses on issues of legality and compliance, and addresses specific research methods, processes of ethical review, handling complaints, and research involving specific groups. This document is extremely important for all research done with human participants in Australia, and of course mentions Aboriginal and Torres Strait Islanders. Section 4.7 of the *National Statement* falls under the chapter discussing research involving specific groups, and concerns Aboriginal and Torres Strait Islanders. The introduction to this section refers researchers to the *Aboriginal Guidelines*, and states that "a cornerstone of an ethical relationship with Aboriginal and Torres Strait Islander Peoples is respect for and valuing of cultural and language diversity."{National Statement on Ethical Conduct 7/15/2009 #3; 69} The *National Statement* declares that research involving Aboriginal and Torres Strait Islanders must respect six core values that are recognized as being important to those communities: Reciprocity, Respect, Equality, Responsibility, Survival and protection, and Spirit and integrity. {National Statement on Ethical Conduct 7/15/2009 #3; 69} The *Aboriginal Guidelines* themselves are actually written around these values, with each of the six values as a section and given separate attention. (National Health and Medical Research Council, 2003)

The *National Statement* has three pages specifically discussing indigenous Australians, but as stated in the introduction to the *Aboriginal Guidelines*, even after the creation of the *National Statement*, "Aboriginal and Torres Strait Islander communities, researchers and health organisations still saw a clear need for a separate, complementary set of guidelines covering research in Aboriginal and Torres Strait Islander health." (National Health and Medical Research

Council, 2003, p. 1) The *Aboriginal Guidelines* are meant to supplement the *National Statement* in the case of indigenous health research, not replace it. Research involving indigenous Australians requires additional consideration in the area of cultural respect, a characteristic not seen or needed in the general codes of ethics. Thus, the *National Statement* discusses the issues of cultural respect, and refers researchers to the *Aboriginal Guidelines* for additional important information. It is also noted explicitly that the *Aboriginal Guidelines* have the same status and authority as the *National Statement.* (National Health and Medical Research Council, 2003)

It is stated that all research proposals must be ethically defensible according to the six values that the guidelines are structured around. Part of this process is consultation with indigenous populations and participants during the design phase of the research project. In fact, it is required that indigenous participation is present in all stages of the process, from conceptualization to data collection to dissemination. (National Health and Medical Research Council, 2003) The *National Statement* also reminds researchers that there is great diversity among the Aboriginal and Torres Strait Islander communities, and the application of these values should be discussed with the indigenous groups involved in the research. {National Statement on Ethical Conduct 7/15/2009 #3; 69} This is a clear manifestation of one of the key aspects of participatory research, which is involvement of the indigenous community in the planning of the research implementation. Additionally, the *National Statement* asserts that there must be support from the communities that are involved, and that the research methods should provide opportunities for development of trust and a sense of equal partnership. {National Statement on Ethical Conduct 7/15/2009 #3; 70} Once again, the aims of participatory research are reflected in this striving for partnership and involvement. The *Aboriginal Guidelines* stress "community ownership" and the importance of involving indigenous people as researchers. (National Health and Medical Research Council, 2003, p. 1) The issue of integrating written guidelines with the development of ethical relationships is also discussed. The title of the document itself mentions values, and there is ample reference to the importance of considering indigenous values. The guidelines warn that it is possible to comply with rule-based requirements, while missing the point of considering values. (National Health and Medical Research Council, 2003) However, as the *Aboriginal Guidelines* poses the question of whether it is possible to reconcile research interests and indigenous values, the answer is also provided in the form of participatory processes. It is noted that several models have been implemented successfully with indigenous populations, and several resources and papers are cited. (National Health and Medical Research Council, 2003)

Perhaps the most striking aspect of the *Aboriginal Guidelines* is that as opposed to the *National Statement*, it is not a dry and rule laden document. Rather, the focus is strongly on respect and understanding, and the importance that these values have on indigenous health research. It reads as a narrative, helping the researcher to understand the importance of such a document. The details of the history between indigenous Australians and the white colonists are not discussed, but the past of disrespect and dismissal is alluded to. The initial actions by the colonial researchers are called “ill-informed”, and it is admitted that the standard of comparison was set against European ideas. "Colonists judged the civility and worthiness of Aboriginal and Torres Strait Islander cultures and societies by the degree to which they perceived it conforming to European customs and norms. Not surprisingly the early observers knew nothing about Aboriginal and Torres Strait Islander Peoples and cultures. The substantial errors of judgement that followed have had a significant impact on Aboriginal and Torres Strait Islander Peoples ever since." (National Health and Medical Research Council, 2003, pp. 1–2) As we will see, the “significant impact” that is mentioned is more of a debilitating effect, with roots in numerous facets of indigenous-white relations. But the intention of the document is to lay the groundwork for future success, and with this goal the authors actually quote a paper from the Maori Research and Development Conference of 1998 that resulted in the guidelines for research involving Maori: “In resorting to the past to determine the future course of action in new situations one must look for the principles involved.” (National Health and Medical Research Council, 2003, p. 2) The principles that shape the *Aboriginal Guidelines*, as well as the future of indigenous health research in Australia are steadfast. Again, they are: Reciprocity, Respect, Equality, Responsibility, Survival and protection, and Spirit and integrity. In each section devoted to each one of these principles, there is a discussion of the general meaning, followed by how it relates to research involving indigenous Australians, and a list of *National Statement* requirements that correspond with the discussion. The *Aboriginal Guidelines* and the expected implementation are straightforward and well organized, giving researchers a clear background of indigenous research, and setting solid groundwork for moving forward.

5.2 New Zealand

The New Zealand *Guidelines for Researchers on Health Research involving Maori*, hereafter referred to as the “Maori Guidelines”, were created by the Maori Health Committee of the Health Research Council of New Zealand. (Health Research Council of New Zealand, 2008) The *Maori Guidelines* state at the beginning of the document that the purpose of the guidelines is to develop research partnerships between health researchers and Maori communities, and to develop research practices that health research effectively contributes to Maori health development. (Health Research Council of New Zealand, 2008) The issue of Maori health is a very important one in New Zealand and perhaps health research has a more significant impact on the development of Maori health than on the health of the general population. The *Maori Guidelines* also refer to other health documents, the HRC’s *Health Research Strategy to Improve Maori Health and Well-being*, and the Ministry of Health’s *Maori Health Strategy*. (Health Research Council of New Zealand, 2008) The question of how a research project will impact Maori health is one of the main considerations listed in the *Maori Guidelines*.

The *Maori Guidelines* read very differently from the *Aboriginal Guidelines*. While the Australian document takes great care to establish the importance of respect, the New Zealand guidelines assume that this will be the norm. Under the heading “Baseline Assumptions”, the document states that it was developed with the understanding that researchers are familiar with the principles of the Treaty of Waitangi, and that the research is part of an ongoing and respectful collaboration. (Health Research Council of New Zealand, 2008) The guidelines also restate a piece from the New Zealand *Guidelines on Ethics for Health Research* that introduces the Treaty of Waitangi. "The Treaty of Waitangi is the founding document of New Zealand. The principles of partnership and sharing implicit in the Treaty should be respected by all researchers and, where applicable, should be incorporated into all health research proposals." (Health Research Council of New Zealand, 2006, p. 1) As mentioned previously, the signing of the Treaty of Waitangi is an extremely important event in New Zealand’s history, and as we will see, it has had a tremendous effect on the success of the Maori population. The *Maori Guidelines* also mention three specific principles of the Treaty of Waitangi that must be incorporated into the process of all ethics committees. The three principles are: partnership, participation, and protection. (Health Research Council of New Zealand, 2008) In keeping with these principles, it is also required that research respondents are given the chance to respond in their native language, Te Reo Maori. Te Reo Maori is an official language of New Zealand, and therefore arrangements must be made for respondents to use Te Reo Maori, including providing translators if necessary. (Health Research Council of New Zealand, 2008)

The *Maori Guidelines* pay a great deal of attention to the process of consultation, 13 pages in fact. There are sections dealing with why to consult, when to consult, and who to consult. The reasons why to consult are dealt with throughout the whole of the guidelines, but it is specifically mentioned that consultation can help to resolve potentially difficult issues, or even diffuse contentious situations before they arise. (Health Research Council of New Zealand, 2008) The question of when to consult is answered in two ways. First, if researchers are unsure of whether they should consult with Maori at all, the guidelines suggest as a general rule that if Maori are involved as participants or if the project relates to a health issue of importance to Maori, then consultation should take place. Secondly, the question of when in the research process consultation should take place is also answered. The short answer is “the entire time”. The guidelines stress the importance of conversation early in the research design, throughout the project, and during dissemination. (Health Research Council of New Zealand, 2008) The section dealing with who to consult is a bit more complex, as the avenues of consultation are many depending on the specifics of the project. The guidelines recommend beginning within one’s own research institution, and then seeking advice from external sources. There are several Maori health organizations and providers, local Maori organizations, and Maori research units.

The extensive attention given to the importance of consultation is a good sign that researchers in New Zealand are encouraged to explore participatory research. As mentioned above, consultation is a key aspect of participatory research, and the HRC in New Zealand is well aware of the advantage. The benefits of consultation that are given in the *Maori Guidelines* are similar to the benefits mentioned in the *Aboriginal Guidelines*: researchers are given the opportunity to ask questions to a particular audience and gain clarity, allowing the chance for input and contributions, and setting the groundwork for a long-lasting relationship. The *Maori Guidelines* also mention the specific benefit that consultation will provide opportunities for building Maori workforce capacity from within the community. (Health Research Council of New Zealand, 2008) There is also a great deal of consideration given to the promotion of Maori researchers. It is rare that Maori are given a researcher role in projects that are not done from within the community, and the guidelines encourage the inclusion of Maori researchers through mutual mentoring. (Health Research Council of New Zealand, 2008) This is especially important within the realm of Kaupapa Maori research, which will be discussed in the next section.

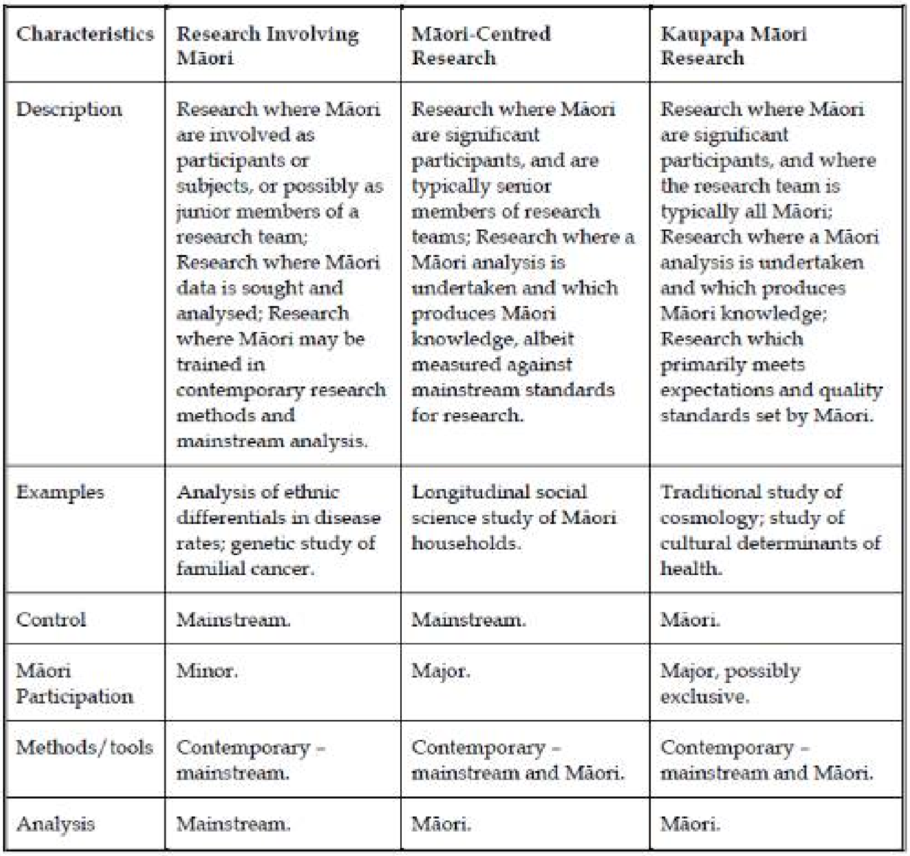
An interesting inclusion in the *Maori Guidelines* is the mention of genetic studies. Genetic research is an extremely delicate topic amongst Maori, and is often not well received. The guidelines note that the Maori population is of great interest to genetic researchers because they are viewed as a "founder population", with well described lineages. (Health Research Council of New Zealand, 2008, p. 19) The guidelines recommend that researchers proceed with caution, but if the process of consultation and discussion is undertaken in good faith, the project can have good success. It is also extremely important for researchers to know that when obtaining informed consent for genetic research, the consent must often come from more than just an individual. (Health Research Council of New Zealand, 2008) Maoris are extremely community based, but consent from one member of a community does not guarantee consent from others. It is interesting to note that the subject of genetic research is addressed in the *Maori Guidelines*, not because of the contentiousness of it, but because genetic research is not mentioned anywhere in the *Aboriginal Guidelines*. Aboriginal writings on research, as well as documents pertaining to Aboriginal research, have discussed the controversial nature of genetic research. While genetic research is mentioned in the Australian *National Statement*, the topic is curiously absent from the *Aboriginal Guidelines*.

5.2.1 Kaupapa Maori Research

As previously mentioned, the inappropriate ways that research have been conducted on indigenous populations in the past has had a considerable negative effect on how all research is viewed. This is obviously not an ideal situation for researchers, both within and outside of the Maori communities. On the other side of the coin of controversy is the attitude from non-Maori researchers that Maori are uncooperative, or that the situation is simply too troublesome and should be avoided. Kaupapa Maori research is an attempt by Maori researchers to bridge this divide. (Smith, 2002) Linda Tuhiwi Smith discusses the role of identity in Kaupapa Maori research, noting the argument that "being Maori, identifying as Maori and as a Maori researcher, is a critical element of Kaupapa research." (Smith, 2002, p. 229) However, Smith recognizes that Maori researchers are also systematic, ethical and scientific. A similar discussion has arisen in the sphere of feminist research, in the view that only women can carry out feminist research.

This approach to specific kinds of research could result in a very divisive research culture, which is exactly what most research institutions are hoping to avoid. Thus there needs to be a balance between the respect for the cultural and inclusive participation. The *Guidelines for Research Involving Maori* seek to achieve this balance, by making all researchers aware of the cultural factors. In a sense, Kaupapa Maori research is a type of participatory research, but instead of being initiated from side of the non-indigenous researchers, it begins within the Maori population, and begins the process of "researching themselves back to life."

It is important for researchers to be aware of Kaupapa Maori research, regardless of whether they are participating in a Kaupapa Maori project or not. This approach to research is very indicative of the Maori attitude towards research, and should be respected. Non-Maori researchers may be involved in Kaupapa Maori research projects, and therefore the distinction is important. The chart below explains the differences between research involving Maori, Maori-centered research, and Kaupapa Maori research.



Characteristics	**Research Involving Māori**	**Māori-Centred Research**	**Kaupapa Māori Research**
Description	Research where Māori are involved as participants or subjects, or possibly as junior members of a research team; Research where Māori data is sought and analysed; Research where Māori may be trained in contemporary research methods and mainstream analysis.	Research where Māori are significant participants, and are typically senior members of research teams; Research where a Māori analysis is undertaken and which produces Māori knowledge, albeit measured against mainstream standards for research.	Research where Māori are significant participants, and where the research team is typically all Māori; Research where a Māori analysis is undertaken and which produces Māori knowledge; Research which primarily meets expectations and quality standards set by Māori.
Examples	Analysis of ethnic differentials in disease rates; genetic study of familial cancer.	Longitudinal social science study of Māori households.	Traditional study of cosmology; study of cultural determinants of health.
Control	Mainstream.	Mainstream.	Māori.
Māori Participation	Minor.	Major.	Major, possibly exclusive.
Methods/tools	Contemporary – mainstream.	Contemporary – mainstream and Māori.	Contemporary – mainstream and Māori.
Analysis	Mainstream.	Māori.	Māori.

(Health Research Council of New Zealand, 2008, p. 8)

6. Conclusion

Codes of conduct for research involving human subjects exist to protect the rights and dignity of the participants. The Nuremburg Code set the groundwork for future codes of ethics, and because of the context in which it was created, the main objectives of the Nuremburg Code is to protect participants from bodily harm. The simplicity of the Code is striking, and underscores the gravity of its' content. As research involving human participants has evolved, so have codes of ethics that govern the research. In the case of indigenous peoples, the Nuremburg Code and subsequent codes of conduct were adhered to, but often the culture was not respected or protected. The creation of specific guidelines for research involving indigenous peoples is entirely necessary to protect the intangible aspects of human dignity. A disregard and disrespect for tradition and culture can have very real consequences in the health of a community or population. The history of the indigenous people in Australia took a much more violent and unfortunate track, and the groundwork of mistrust has carried into the research areas. As shown in the graph below, mortality rates among indigenous Australians is much higher than that of indigenous New Zealanders, Native Americans and all Australians, and not declining in any significant way.

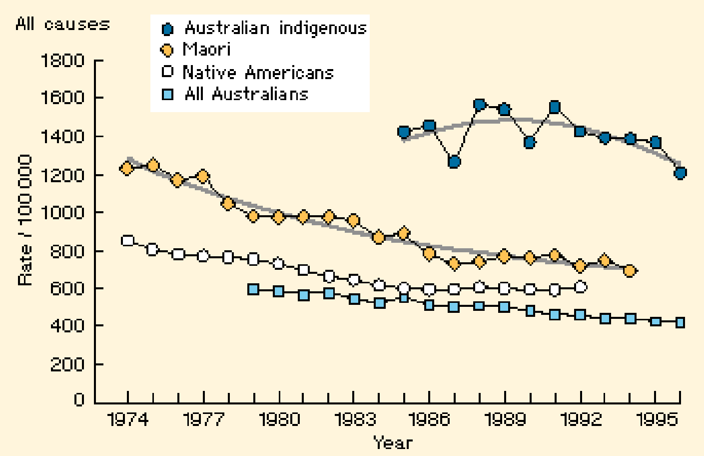


Figure 1: Trends in annual directly standardised* all-cause mortality rates for indigenous people in Australia, the United States and New Zealand, and for all Australians. * Standardised to the World Standard Population, 1960.

(Ring & Firman, 1998)

In the case of indigenous Australians, the treatment they received historically, such as the taking of their land, taking of their children, and attempts to deny their existence, could have an extremely adverse effect on health. Ring and Firman (1999) argue that “colonial paternalism [and] and official policy of assimilation” have created a sense of powerlessness in indigenous Australians, and it is very likely that these intangible factors are in part responsible for the dismal state of indigenous health. (Ring & Firman, 1998) Ring and Firman note that the policy of assimilation eliminated the possibility for specialized indigenous health programs, coupled with the lack of self that many indigenous tribes now feel. Because many tribes were artificially grouped together, rarely on their own land, the sense of identity faltered. (Ring & Firman, 1998) Jackson and Ward (1999) also discuss the issue of land, noting that "Aboriginal people have a spiritual link with the land which provides a sense of identity, and which lies at the centre of their spiritual beliefs". (Jackson & Ward, 1999, p. 439) It is hardly surprising that with poor spiritual health comes poor physical health. This issue again reminds us that the indigenous people of Australia were never granted a treaty of any kind from the colonizing British or the Australian government. Ring and Firman remind us that the Treaty of Waitangi is essential in the relationship between Maori and non-Maori in New Zealand, establishing an official legal status. “Treaties, no matter how loosely worded, have appeared to play a significant and useful role in the development of health services, and in social and economic issues, for the indigenous people of New Zealand, the United States and Canada.” (Ring & Firman, 1998, p. 532)

The troubles that indigenous Australians have dealt with in these regards are not directly related to research ethics. However, the point of the official guidelines is to recognize the uniqueness of the Aboriginal and Torres Strait Islander communities, as well as the past injustices that have been committed, and the special consideration that must therefore be given to research with these groups. The ethical issues implicated in research involving human participants are extremely broad, and touch upon many different levels. My experience in medical research studies gave me a unique perspective on my rights as a participant, and knowing that my rights are protected by the Nuremburg Code and other codes of ethics is reassuring. In delving further into ethical research codes, I was exposed to the many other aspects of ethics in research that are perhaps less well known. Of course, my participation in research studies has never involved indigenous peoples, and I haven’t been a part of any that were conducted with the method of participatory research. But the idea remains that my rights and dignity were always protected, and it is difficult to reconcile that the rights and dignity of indigenous populations have not always had similar protection. Indigenous research is unique in a sense, because it involves a community and deals specifically with issues of concern to that community. Ethical codes of conduct for research involving indigenous people are important for several reasons; protection of dignity, fostering of trust, and foundation of relationships. All of these aspects can lead to improved health in indigenous populations and the end of an attitude of neglect. And perhaps this aspect is the most ethically important step to be taken.

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