

*When Research is a Dirty Word: Sovereignty and
Bicultural Politics in Canada, Australia and New
Zealand Ethics Policies*

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Abstract

Unlike Canada and Australia, New Zealand has not produced a nationwide ethics policy to guide research within indigenous communities. To explain this divergence historical comparative analysis was used to document the manner in which each of these three countries' ethical frameworks were negotiated. This analysis found that an interplay between the differing use of national-level Indigenous political strategies and the nature of the 'mainstream' research oversight institutions unique to each country explained the difference in ethics policy development. In Canada and Australia, what I defined as sovereignty politics aspired to create separate Indigenous space where issues of direct concern to Indigenous communities were brought under Indigenous control and social practices. New Zealand's bicultural politics focused on Māori gaining a partnership role in the governance over all New Zealand, and by implication, all New Zealand research. In both Canada and Australia, an alignment to Indigenous aspirations of sovereignty politics encouraged the development of separate ethics policy dedicated to research with Indigenous communities. Indigenous ethics policy in Canada and Australia also benefited from centralised research oversight structures that encouraged a single point of ethical negotiation, allowed public health research funders to support Indigenous ethics development, and minimised the influence of ministerial politics. In New Zealand, bicultural aspirations assumed that once Māori gained an equal partnership role that ethics policy development responsive to Māori would follow. This level of partnership never eventuated. Relegated to a junior partnership role, Māori were not in a position to drive ethics policy development. Māori influence was also fragmented across both the health sector and in New Zealand's tertiary institutions. Unlike Canada or Australia's centralised research oversight system, New Zealand's was undermined by unsupportive Ministerial involvement and lacked the benefit of the public health research council's support. The experience of Canada and Australia, in contrast to that of New Zealand, demonstrates the value of discrete and defensible institutional space dedicated to Indigenous ethical concerns and of centralised research oversight regimes.

Acknowledgements

When I was about fourteen years old, my father came home with a tired-looking car. It was orange, made in Britain, and had rust holes in the doors that you could put your hand through. But dad was also armed with a plan: my brothers and I would help him restore it, and we would then sell it at a profit to pay for recreation that we otherwise could not afford. As is often the case with dad's plans, it worked. After restoring two cars and a small wooden sailboat, we purchased the speedboat that accompanied us on many adventures. I don't believe that I have ever seen the world in the same way since. My father has shown me many times that a good life is not simply reacting to what confronts us, but rather it is the magic of creating something new. Thanks dad.

About a year ago (no doubt in reaction to my less-than-stellar note taking skills), my supervisors suggested that I record our thesis meetings to capture our discussions more accurately. These recordings reveal the supportive environment that Associate Professor Martin Tolich and Dr Bryndl Hohmann-Marriott encourage and are filled with engaged discussions, helpful advice and good humour. Your care and support has made completing this thesis an enriching and enjoyable experience. Thank you both.

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Preface

I have long been fascinated by the nation-building themes of biculturalism. A bicultural view of New Zealand allows us to bring our painful colonial past to light, and also to reference our 1840 birth at the signing of the Treaty of Waitangi in a manner that encourages societal inclusion for both Māori and non-Indigenous New Zealanders. As a non-Indigenous New Zealander, the Treaty of Waitangi legitimises my place in this land, but also calls me to respect Māori visibility and engagement at all levels of our society.

Consistent with the above aspirations, I take the legitimacy of Māori wishes to be involved in research ethics as a given, and therefore concentrate on how this influence developed in the production of ethics policy. I add to this analysis by charting these developments in New Zealand, Canada and Australia. In so doing I align with research concerned with the aspirations of Canadian, Australian and New Zealand Indigenous peoples such as: Indigenous peoples rights (Havemann 1999; Iorns Magallanes 1999), experiences of justice (Hazlehurst 1995), emerging Indigenous constitutional theory (Oliver 2005), Indigenous development (Dainow 1938), and claims to cultural property (Simpson 1994).

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1

Introduction

The ethical requirement to conduct research *with* (and not *on*) Indigenous communities is well established in Canada, Australia and New Zealand. In 2002, the national health research councils of these three countries reflected this understanding when they signed a cooperation agreement recognising

... the desire of Indigenous people for research to be undertaken on terms acceptable to them, in particular the protection of cultural knowledge and values, the participation of Indigenous people in research and research decision-making, and the promotion of Indigenous research by Indigenous researchers (NHMRC, CIHRC, & HRC 2002, p. 1).

In all three countries, ethics policies have been developed in order to guide researchers and ethics committees when researching with Indigenous communities, but there are important differences between the policy frameworks of Canada and Australia from those of New Zealand.

In Canada and Australia, the assertions of Indigenous research ethics (hereafter Indigenous ethics) have been translated into national ethics policy frameworks (NHMRC 2003, 2014; CIHR et al. 2014). This allows researchers and ethics committees in these two countries to consult a central point of consistent ethics policy advice. The ethics policy frameworks of Canada and Australia are found by this thesis to have proven stable over time, were developed using extensive Indigenous community consultation, and consistently require researchers to engage in Indigenous community consultation.

New Zealand, by contrast, did not develop a national ethics policy standard. New Zealand-based researchers who include Māori as participants must adhere to different ethics policy depending on factors such as the funding source of a research project, university affiliation, or the research discipline used by the project. Recent criticism of the oversight of New Zealand research found it to be an ‘*ad hoc*’, ‘fragmented’ structure that provided inconsistent policy advice on Māori consultation (NEAC 2015, p. 1, 10, 13). New Zealand’s ethics policy frameworks for research with Māori are shown by this thesis to have been undermined over time, were developed without widespread Maori community consultation, and lack a consistent requirement that researchers engage in Indigenous community consultation.

Accepting both New Zealand’s recognition of the needs of Indigenous ethics and its failure to create cohesive ethics policy for research, where Māori act as participants, leads to the following thesis question: why does the New Zealand development of Indigenous research ethics policy differ so markedly from that of Canada and Australia?

The research question required a focus on explaining change in ethics policy. Consequently, this thesis does not consider the implications of ethics in practice. It does not, in other words, concern itself with the potential slippage between the intentions of ethics policy and either its practice by researchers, or the rulings of ethics committees.

In order to highlight the differences in ethics policy development in Canada, Australia and New Zealand, this thesis introduces three frames. The first frame creates a value judgment of what is robust Indigenous ethics policy based on affirmative answers to the following five questions. 1. Did the ethics policy prove to be stable over time and withstand threats to its aspirations/existence? 2. Were the policies developed with the benefit of widespread Indigenous community consultation? The

requirement to consult Indigenous communities is a central principle of the aspirations of Indigenous ethics. 3. Were the policy development frameworks sufficiently robust to allow the policies to develop over time? Ethics policy is an evolving field requiring that ethics policies be periodically updated to reflect changes in ethical thought. 4. Do the policy frameworks give coverage to all human research within a national context? And 5. Do the ethics policies reflect the aspirations of Indigenous ethics by requiring Indigenous community consultation?

The second frame is that of centralised research oversight. This terminology allows the thesis to define and distinguish between the contrasting bureaucratic structures that each country used to develop ethics policy. Centralised research oversight is defined by the presence of four features: the production of a national statement for all human research; ethics committees bound to use the national statement; a national standing committee charged with the ongoing development of ethics policy; and an independence from day-to-day Ministerial oversight. Centralised research oversight structures proved more supportive of the development of Indigenous ethics policy development than non-centralised research oversight structures.

The third frame is a distinction between sovereignty and bicultural Indigenous political assertions. In its simplest form, sovereignty politics desires influence over areas of direct importance to Indigenous Peoples, such as control over land and the creation of public services that adhere to Indigenous worldviews and practices. Bicultural politics includes ideals of sovereignty politics, but also extends Māori interest into all the public governance of New Zealand. These framings of sovereignty and bicultural politics are used in the three case studies to show how bicultural aspirations for research oversight in New Zealand created substantively different expectations of how this oversight should be structured than was

found in Canada and Australia where sovereignty political aspirations were more prevalent.

These three frames provide a language that can bring to the reader structural features that influenced the development of Indigenous ethics policy in Canada, Australia, and New Zealand. Defining what is robust Indigenous ethics policy clarifies New Zealand's lack of ethics policy development compared to Canada and Australia. The frame of centralised research oversight and the distinction between sovereignty and bicultural politics enable analysis to define and discuss the differences in national contexts of research oversight, and the contrasting aspirations of Indigenous communities towards ethics policy development.

Chapter 2 introduces a methodological and theoretical lens in order to guide the above analysis. It presents historical comparative analysis (Lange 2013; Mahoney & Rueschemeyer 2003) as a theory aligned to the scope of this thesis as it allows an examination of both change through time and comparison across contexts. The historical comparative method of punctuated equilibrium (Capoccia & Kelemen 2007; Pierson 2000) is introduced as a means of ordering ideographic histories into a structure that allows the isolation of factors that explain change over time. In the language of this thesis, historical comparative encourages analysis to pinpoint the factors that encouraged New Zealand's development of Indigenous ethics policy to differ from those of Canada and Australia.

Chapter 3 locates common colonial features and differing methods of Indigenous resistance found in Canada, Australia and New Zealand. Each of these white settler nations similarly undermined the economic, cultural and societal positions of Indigenous peoples (Armitage 1995; Fleras 1999; Hutchins 2010). This thesis characterises contemporary Indigenous calls for recognition as conforming to *sovereignty* politics in Canada and Australia, and *bicultural* politics in New Zealand. Chapter 3 explains these

aspirations in depth as they represent differing conceptions of what relationship Indigenous Peoples can expect with regards to the governance of Canada, Australia and New Zealand. Understandings of how ethics policies should enhance and protect indigenous research developed from these political aspirations.

Case study 1, Canada

Chapter 4 investigates Canada's development of research oversight as it emerged from a 'perfect storm' of time and context, which aligned the needs of a wide range of research disciplines. This convergence of interests is symbolised by the formation of the Canadian Tri-Council (McDonald 2009) as a structure formally including all government-funded research disciplines (Israel 2015). Beginning in 1994 (Onyemelukwe & Downie 2011), the Tri-Council facilitated the production of national ethics policy designed for all human research (CIHR et al. 1998, 2010, 2014), and later formed a national standing committee responsible for all future ethics policy development (PRE 2009). This chapter categorises Canadian research oversight as reflecting centralised research oversight. This categorisation allows this chapter to define the nature of Canada's research oversight regimes, and later note the similarities with those found in Australia, and distinguish them from those found in New Zealand.

Chapter 5 considers how Canadian Indigenous ethics aligned with sovereignty politics to encourage the formation of separate ethics policy dedicated to the needs of research within First Nations, Inuit and Métis communities as negotiated within Canada's centralised research oversight structures. Initially, the Tri-Council resisted calls for separate Indigenous ethics policy when it used multicultural ideals to conflate the needs of Indigenous ethics with other ethnicities and communities (Tri-Council

Working Group 1997). However, Canada's centralised research oversight afforded multiple opportunities for the support of Indigenous ethics. Indirectly, both the social science and humanities council and the Department of Justice emerged as early supporters of Indigenous ethics (McDonald 2009). Subsequent to this early backing, the Canadian Medical Research Council's confirmation of its long-term support for Indigenous public health research in 2001 (CIHR 2001, 2003) foreshadowed its active support of Indigenous ethics. Once Indigenous ethics became a feature of Canada's national statements (CIHRC et al. 1998, 2010), Indigenous ethics advocates were able to leverage the Tri-Council centralised research oversight structures, such as the national ethics standing committee (PRE 2005), to produce an Indigenous chapter in the 2010 Tri-Council national statement.

Case study 2, Australia

Chapter 6 examines how Australian research oversight developed into a similar centralised form to that of Canada, despite its different historical development. Unlike Canada, Australia did not experience a perfect storm of events needed to create an alignment of multiple research disciplines (Chalmers 2001). Instead, the medical and public health research council expanded over time to control research oversight in Australia across all human research disciplines (Dodds 2000; Israel & Wales 2004). The dominant position of Australia's medical and public health council allowed it to produce a national ethics policy statement (NHMRC 1992, 1999, 2014) and control its ongoing development through the formation of a national standing committee (Chalmers et al. 1996; NHMRC 2015a). As in Canada, the centralised ethics policy development of Australia allowed challenges to its policy to focus resources towards a single institution.

Chapter 7 begins by tracing the influence of sovereignty politics on Australia's Indigenous ethics challenge to its centralised research oversight structures. Consistent with sovereignty ideals, Indigenous ethical advocates have called for the creation of separate ethics policy documents (Humphery 2002; Israel 2015; VicHealth 2004). Similar to Canada, Australian research oversight resisted separate Indigenous ethics policy through the introduction of a multicultural chapter into early drafts of the national statement (Chalmers, Dunne, Finlay-Jones, & Rayner 1996). Also similar to Canada, centralised research oversight in Australia formed structures that allowed the support of Indigenous ethics to manifest. Increasing government pressure on the Australian medical and public health research council to focus on Indigenous public health research (Australian Government Department of Health 1994; NHMRC 1993), combined with Aboriginal and Torres Strait Islander demands that medical and public health research priorities reflect community consultation (for example: National Health Working Party 1989) encouraged the NHMRC to give priority to Indigenous ethics. In September 1998, the NHMRC confirmed that it would draft a separate ethics policy document giving Indigenous ethics singular priority (NHMRC 1998). As in Canada, when Indigenous ethics became part of the centralised policy framework, Indigenous ethics advocates were able to leverage the Australia medical and public health research council's structures, such as the Aboriginal and Torres Strait Islander Agenda Working Group, to produce discrete Indigenous ethics policy (HREC 2002).

Case study 3, New Zealand

Chapter 8 traces the outsized impact of the Associate Professor Green research scandal in New Zealand (Coney 1988; Davis 1988; Manning 2009; Rotondo 1996). Responses to the scandal dominated the development of research oversight (Tolich 2001) and created conditions

that appear unsupportive to the creation of a centralised research oversight institution such as are found in Canada and Australia. Following the research scandal, New Zealand's research oversight fractured over ten institutions: the Ministry of Health (NEAC 2008), the Health Research Council (HRC 2005; HRCEC 2012) and the separate regimes of the eight New Zealand universities (AUT University 2014; Lincoln University 2013; Massey University 2014; University of Auckland 2014; University of Canterbury 2014; University of Otago 2014; University of Waikato 2014; Victoria University of Wellington 2014). Each of these research oversight institutions operated under differing accountability structures and developed unique ethics policy documents (Rotondo 1996). The formation of these fragmented research oversight institutions left challenges to ethics policy development without a central place to negotiate consideration.

Chapter 9 investigates how bicultural politics and the fractured development of research oversight influenced the development of Indigenous ethics policy in New Zealand. The themes of bicultural politics required that Māori form half of the membership of ethics committees and the national ethical standing committee. Unlike the success of Canadian and Australian sovereignty ethics, bicultural ethics failed to gain more than a symbolic expression, leaving Māori without either the sufficient influence to demand ethics policy development on terms acceptable to Māori, or the clear definition of separate policy from which to defend their position. In addition to the impact of bicultural politics on the development of Indigenous ethics policy, New Zealand's fragmented research oversight structures frustrated the formation of the alliances necessary to urge the development of national Indigenous ethics policy.

Chapter 10 utilises comparative analysis to explain the thesis question: why does the New Zealand development of Indigenous research ethics policy differ so markedly from that of Canada and Australia? This analysis

points to the importance of four factors. The first factor is the success or failure of the method of resistance employed by Indigenous political action. The second is the number of research ethics institutions with which Indigenous ethics would need to engage. The third is the coherence of the relationship between the funding of public health and medical research and research oversight, and final factor is the influence of ministerial politics.

Chapter 11 concludes this thesis by extending its findings to make recommendations to the development of ethics policy for research with Māori in New Zealand. Two themes are central to these proposals. It is recommended that New Zealand centralise its research oversight, and that Māori interest in ethics policy development be focused on the inclusion of separate Indigenous chapters in a national ethics statement.

2

Methodology: historical comparative analysis

This chapter introduces historical comparative analysis as a method suited to explaining both how change occurs over time, and why change can manifest in different ways across contexts. It begins with a brief overview of the three generations of historical comparative analysis and situates the research of this thesis alongside other third generation analysis. The chapter continues on to examine the three foci of the discipline: explaining change over time, constructing ideographic comparison, and establishing causal inferences. The final section explains the use of method and the employment of punctuated equilibrium as an organising narrative mechanism to explain change over time.

A history of historical comparative analysis

Historical comparative analysis has classically focused on the interrogation of subject areas such as democratisation, imperialism, warfare and revolutions, capitalist development and industrialisation, state building, nationalism, technological development, social movements, secularisation, and globalisation (Lange 2013, p. 1). This large-scale preoccupation has been in evidence as early as the first social scientists who conformed to historical comparative such as Adam Smith, Alexis de Tocqueville, Otto Hintze, Max Weber and Mark Bloch (Thelen 2003).

In what Lange (2013) calls the ‘second generation’ historical comparative analyses, a later generation of researchers in the years following World War II produced a significant body of work. Bonnell considers the awarding of the prestigious Sorokin sociology prize to historical sociologists in 1976 and 77 as the confirmation of historical comparative analysis as a full discipline within sociology (1980). Examples of second

generation historical comparative analysis are Polanyi's (1944) interrogation of rise of the market economy, Moore Jr.'s (1966) comparison of national modernisation paths, and Eisenstadt's (1963) analysis of the rise, transformation and fall of Empires. Also conforming to second generation historical comparative analysis are Wallerstein's (1974, 1980, 1989, 2011) explanation of disparities between state-level development across world regions, Mann's (1986, 1993, 2012a, 2012b) analysis of the sources of social power within nations, and Skocpol's (1979) interrogation of 'social revolutions'. Each of these examples consider large-scale processes that explain dominant features of nation states or their antecedents.

By the 1990s, what can be called the third-generation of historical comparative analysis began to move away from the broad questions of earlier works, to consider social change at a smaller scale. In their (2003) review of more recent historical comparative research, Mahoney and Rueschemeyer illustrate how historical comparative analysis moved into more discrete areas of concern such as social policy (Amenta 1998; Kitschelt 1994; Steinmetz 1993), health care, education, welfare and pensions (De Swann 1989; Immergut 1992; Orloff 1993; Skocpol 1992), welfare capitalism (Esping-Andersen 1990; Hicks 1999; Huber & Stephens 2001; Pierson 1994), and democratic taxation regimes (Steinmo 1996).

Regarding state formation and change, third generation historical comparative analysis is likewise less global in its focus. Such work concentrated areas such as the negotiation between peasant and elite affiliation to the Ottoman state (Barkey 1994), the origins of Central State authority in the United States (Bensel 1990), the emergence of the sovereign state (Spruyt 1996), and the impact of war on nation building (Angel 2002; Tilly 1992). Likewise, the aftermath of political crises in East Central Europe was chartered (Ekiert 1996), as were state and regime building in mediaeval and early modern Europe (Ertman 1997), and

bureaucratic development in France, Japan, the United States, and Great Britain (Silberman 1993). State building, furthermore, was examined with an eye to uncover factors that promoted or impeded economic growth (Waldner 1999), or 'state failure' (Robinson 2002).

Within an economic and labour lens, historical comparative work of this period considered the rise of the large industrial corporation in America (Roy 1999), workers movements in Brazil and South Africa (Seidman 1994), the oil economies of the Gulf States (Chaudhry 1997) and other 'petro-states' (Karl 1997). Other authors considered 18th-century industrial policy in the United States, Britain and France (Dobbin 1997), state intervention and industrial transformation (Evans 1995), agrarian change in Western Europe between the 14th and 18th centuries (Hopcroft 1999), and neoliberalism and the informal economy in Costa Rica and the Dominican Republic (Itzigsohn 2000).

Mahoney and Rueschemeyer also revealed how third-generation historical comparative analysis was also categorised by an increased focus on sub-national concerns such as a concern for gender (Brubaker 1992), race (Marx 1998), slavery and social control (Stinchcombe 1995), women's suffrage (Banaszak 1996), women's rights (Charrad 2001), the impact on social policy on gender relations (O'Connor, Orloff, & Shaver 1999), religious movements and violence (Hall, Schuyler, & Trinh 2000), and national passports as a means to control population movement (Torpey 2000).

The work of historical comparative analysts since 2003 is too numerous to be outlined in detail here. Instead, a summary of historical comparative research released in 2014 confirms the continuation of the trend to construct research on a finer, less global, scope. Amongst this group is a concern for subject matters such as a consideration on ageing policy reforms (Berho & Calvo 2014), the negotiation of state power (Puett 2014),

urban social sustainability (Laguna 2014), the ‘local’ emergence of the ‘Swedish model’ Social Democrats (Forsell 2014), and the link between education and economic development (Carmichael 2009). Also considered were the link between the wartime medical profession and gender (Michl 2014), negotiations against the mining ‘resource curse’ in the ‘strong state’ of Chile and the ‘weaker state’ of Peru (Orihuela 2014), labour market governance (Soentken & Weishaupt 2014), civil perceptions of the ‘legitimacy’ of state violence (Schoon 2014), welfare reforms (Vázquez-D’Elía 2014), the development of municipal theatres (Carnwath 2013), and the economics of bicycle distribution (Burr 2014).

Despite historical comparative research moving into increasingly diverse subject matters, there has been no analysis directly relatable to the history of the oversight of Indigenous research ethics. There have been several works that have created histories of the rise of the ethical oversight of research in international settings (Israel 2015; McNeill 1993), but these works do not contain a controlled comparative component. In a similar manner, significant works have studied the history of Jewish medical ethics (Jakobovits 1975), the rise of the British ‘ethics industry’ (Wilson 2011) and the transformation of medical decision-making as a result of bioethics (Rothman 1991), without the inclusion of a controlled comparison.

As the following chapter will demonstrate, the subject area of Indigenous social and political movements is an extensively researched area. Within the methodology of historical comparative analysis, however, the numbers appear to be limited to a single study – Deborah Yashar’s (1998) *Contesting Citizenship: Indigenous movements and democracy in Latin America*. It is alongside Yashar’s work that this thesis resides. Both are third generation historical comparative analyses that scrutinise the negotiation of the demands of Indigenous political movements within

multiple national contexts. Both, furthermore, adhere to investigative patterns of historical comparative analysis.

The analytical foci of historical comparative analysis

Thelen (2003) outlines three interlinking features that mark historical comparative analysis as distinct: a consideration of change over time; the use of ideographic comparison; and a concern for causal analysis. Used together, they explain why particular outcomes appear in some contexts and not others.

Considering change over time

A common way in which historical comparative analysis studies change in processes over time is by use of the concept of path dependency. Sewell defines path dependency as making a seemingly straightforward assumption that “what has happened at an earlier point in time will affect the possible outcomes of a sequence of events occurring at a later point in time” (1996, p. 262–3). Pierson (2000) qualifies this notion further by arguing that ‘large’ outcomes do not require ‘large’ causes, but rather may result from ‘small’ or contingent events. Mahoney ties both these ideas together when contending that the culmination of these large and small events “set into motion institutional patterns or event chains” that may culminate in significant change (Mahoney 2000, p. 507).

Allied to this idea of change is a focus on the time-critical nature of each event. Charles Tilly further defines this insight by arguing that “... *when* things happen within a sequence effect *how* they happen” (1984, p. 14). An argument often used to explain the time-sensitive nature of events is that of the wide scale adoption of the QWERTY typing keyboard (Thelen 2003). The success of the QWERTY keyboard over its competitors is attributed to it being the first keyboard arrangement to be widely used

(rather than it representing the most advanced configuration). Once users had learnt to type on a QWERTY keyboard, such investment reinforced this initial choice. Even if competing keyboards were revealed as more efficient, the requirement to relearn the new typing keypad undermined efforts at moving to a different industry standard.

Following a concentration on change over time, historical comparative analysis shifts to comparing over contexts.

Ideographic comparison

Ideographic comparison orders time-sensitive histories into narrative accounts containing ‘clusters’ of complex and unique socio-historical information (Axtmann 1993, p. 69) that it then compares across cases (Møller 2015). This is an active process. Bendix advocates asking similar questions of divergent contexts to “... make more transparent the divergence among structures” and the ways in which societies have responded to challenges (Bendix 1976, p. 247).

Bendix’s consideration of both structure and response suggests an active evaluation of historical information. Lange (2013) asserts that the strength of this approach is that it does not simply designate a relationship between variables but instead highlights the actual processes and mechanisms of the phenomenon in question. Following the introduction of such ideographic comparisons (Møller 2015), analysis is further advanced when it explains a measure of cause.

Causal inferences

Historical comparative researchers most often use the concept of causal inferences to capture an idea of determination. Griffin and Stryker note that this conceptualisation of cause does not tend to make bold generalisable claims but rather produces “limited causal regularities

among a set of carefully chosen cases” (2001, p. 386). To return to the QWERTY keyboard analogy, by way of explanation, the historical comparative understanding of cause inferences would suggest that the cause of its success was tied to it being ‘first to the marketplace’. Within this view of cause, the initial success of the QWERTY keyboard in the marketplace *caused* the barriers to successful entry into the marketplace of competing keyboard designs to rise significantly. Or, to use the language of John Mahoney, this event “set into motion institutional patterns or event chains that have deterministic properties” (Mahoney 2000, p. 507). The early success of the QWERTY keyboard created the conditions for its ongoing market dominance.

It is not simply enough, however, for historical comparative work to show a correlation between a variable and its effect, it must demonstrate *how* this effect was produced over time. Capoccia and Ziblatt (2010) illustrate something of the complexity of this task as the use of discrete variables is abandoned in preference for clusters of information to explain change. To Capoccia and Ziblatt, democracy

... did not emerge as a singular coherent whole but rather as a set of different institutions, which resulted from conflicts across multiple lines of social and political cleavage that took place at different moments in time (Capoccia & Ziblatt 2010, p. 931).

Rather than concentrate on class as a sole variable, for example, this methodology requires an analysis of mutually influencing societal institutions as they are constructed and reconstructed across time. To gain an understanding of cause, therefore, Capoccia and Ziblatt (2010) argue that attention needs to be paid to the social and political conflicts that birthed, sustained and moulded change in societal institutions.

The historical comparative conceptualisation of cause defies easy categorisations along the qualitative/quantitative scale. Sewell asserts

that historical comparative ideas of cause do not conform to empirical notions of experimental and correlational design which argue a uniformity of causal laws across time and a causal independence of each sequence of occurrences (1996, p. 262). Likewise, historical comparative analysis rejects 'interpretive' approaches to knowledge that are singularly concerned with culturally situated meaning (Bonnell & Hunt 1999; Mahoney & Rueschemeyer 2003). Instead, Kumar (2014) emphasises that historical comparative analysis is the search for explanations of the cause of historical outcomes that may yield insight into contemporary concerns.

With regard to the generalizability and strength of causal claims in historical comparative, an analysis of Theda Skocpol's (1979) work is instructive. Skocpol begins by limiting her causal claims to 'social revolutions'. Skocpol defined social revolutions as those that contain both a political and social reorganisation and had a substantial peasant population. Skocpol then described how social revolutions are created in a three-step process.

- I, The existing political regime suffers a crisis.
- II, Peasant insurrections further challenge and ultimately undermine the government.
- III, The new state power must grapple with the conditions that undermined the earlier regime.

These seemingly straightforward statements contain a number of ramifications relevant to the cause of social revolutions. For example, this ordering of cause undermines a belief that peasants *caused* these social revolutions. Skocpol's timing contention argues that peasant insurrections required a regime to be vulnerable in order to effect societal and political change. Likewise, the third stage revealed that the behaviour of these new political states was not simply moulded by ideology, but

rather informed by the structural vulnerabilities that each had inherited from the former regime.

Skocpol's causal claims about social revolutions illustrate how historical comparative analysis can provide insight into historical change through a concentration on change over time, ideographic comparison and an examination of cause. While these explanations give theoretical justifications of historical comparative's three foci, they do not adequately inform the reader of their practical use. For this, a discussion of methodology is required.

Methodology

One of the features of historical comparative analysis is that there is very little written on its practical use as a method (Lange 2013). Works such as Skocpol's (1984) edited volume *Vision and method in historical sociology* and Tilly's (1984) *Big structures, large processes, huge comparisons* concentrate on the theoretical virtues and concerns of historical comparative analysis and do not share an equal concern for practice. This thesis intends to compensate for this lack of concrete guidance by negotiating four methodological concerns: the use of theory, data collection, organisational paradigms, and the need to compensate for weaknesses.

Theory

Skocpol defines the central position of theory in historical comparative analysis when stating,

Historical comparative analysis is no substitute to theory... It cannot select appropriate units of analysis or say which historical cases should be studied. Nor can it provide the causal

hypotheses to be explored. All of these must come from macro sociological imagination, informed by the theoretical debates of the day, and sensitive to the patterns of evidence for sets of historical cases (Skocpol 1979, p. 39).

Far from requiring the use of a pre-existing theory, Skocpol is suggesting that an awareness of sociological debates, imagination, and sensitivity to the case studies in question should inform the production of theory by the research project. Skocpol's three-step explanation (on page 17) of how successful social revolutions evolve is an example of this form of theory production. Lange (2013) notes that historical comparative analysis can also be used to introduce theory testing to analysis, but this thesis restricts itself to theory production as guided by the theoretical perspective of historical institutionalism.

Historical institutionalism is a sub-category of historical comparative analysis that concentrates on institutional change. This categorisation is open to critique given the sometimes overlapping terminologies of historical comparative analysis, historical institutionalism, and historical sociology. To illustrate this point, Theda Skocpol is considered a historical comparative analyst (Lange 2013), a historical sociologist (Skocpol 1984) and a leading historical institutionalist (Amenta 2012). For her part, Skocpol and Pierson consider historical institutionalism itself as comprising broad range of views held together by "elective affinities" (Pierson & Skocpol 2002, p. 2). Mahoney and Rueschemeyer (2003) further complicate this picture by insisting that one way in which historical institutionalism is distinct from historical comparative analysis is that historical institutionalism can include works that do not contain systematic comparison (2003). Rather than enter into these debates here, this section will simply define how historical institutionalism was conceived by this thesis.

Historical institutionalism is primarily interested in sub-national institutions. It therefore concentrates on the ways in which “institutions structure and shape political behaviour and outcomes” (Steinmo 2008, p. 150). Thelen and Steinmo (1992) also posit a concurrent concentration on the reverse causal direction: how the machinery of politics structure relations of power between groups and/or institutions. Historical institutionalism adheres to the ideas of change over time and cause already introduced here, but with a specific focus on institutions. Amenta states as much when she argues

Historical institutionalism holds that institutions are not typically created for functional reasons; instead, institutions are often results of large-scale and long-term processes that have little to do with modern political issues, and institutions often have routine if unintended consequences. In part for these reasons, historical institutionalism engages in historical research to trace the processes behind the persistence of institutions and the influence on policies and other political outcomes (Amenta 1998, p. 47–48).

The focus on institutions by historical institutionalism contained promise for this thesis, as it was the institutions of research oversight in Canada, Australia and New Zealand that facilitated the construction of Indigenous ethics code in reaction to Indigenous political agitation.

Data collection

This thesis collected data to uncover the factors that influenced the development of Indigenous ethics in Canada, Australia and New Zealand. Consistent with historical institutionalism, the data collection focused on finding explanations for change in research oversight institutions. In this way, data was collected from the following sources:

- Peer-reviewed journal articles, academic books and edited book chapters;
- Reports: government and institutional;
- Government legislation;
- On-line newspaper records;
- Blogs of involved or prominent actors;
- Press releases of related institutions such as the Canadian Institute of Health Research Council's (CIHRC) release of its Indigenous research guidelines (May, 2007);
- Meeting notes from key institutions such as the Australian Health Ethics Committee;
- Research policy and research guidelines;
- Released information relating to academic conferences concerned with ethical oversight;
- A single formal interview with an individual who was involved in the development of New Zealand Ministry of Health ethics policy development. Ethical approval was gained for this interview by means of formal University of Otago ethics committee processes. Six informal interviews were also conducted with individuals who were directly involved in ethics policy development in Canada, Australia and New Zealand. These seven interviews did not inform the explicit citations used in this thesis. Rather, they were an opportunity to allow the author to compare the interviewee recollections of the histories with those of this thesis with a view to include important elements if they had not been included in the thesis narrative.

An invaluable tool in this process proved to be the Internet archive website called WayBackMachine.com. Waybackmachine has created an ongoing archive of the Internet since 1996 in which a vast array of websites have been archived at multiple time points. The benefit of this

feature is that it allows a researcher to find reports or information no longer available on a website, either because the website has removed the report or the website no longer exists. A more detailed explanation of Waybackmachine is provided in Appendix A.

Once the data collection was completed, the ordering method of punctuated equilibrium was used to guide the formation of a narrative structure.

Punctuated equilibrium

Punctuated equilibrium is the methodology most associated with ordering change over time in the discipline of historical comparative analysis (Capoccia & Kelemen 2007; Peters, Pierre & King 2005). Mahoney and Thelen (2009) define the central feature of punctuated equilibrium as an assumption that institutions are generally stable over time until punctuated by a convergence of processes that lead an institution down a radically altered path. A degree of change is possible following this abrupt shift, but it must now negotiate within (and be subject to) the overarching logic of the now dominant framework. An example of punctuated equilibrium could be the change from Indigenous self-rule to the formation of the colonial regime following the signing of the Treaty of Waitangi in New Zealand. After punctuating the former ruling structures, the New Zealand state has created structures and institutions that have embedded patterns of logic and processes in a way that has proved resistant to fundamental change (Rumbles 1999). Māori have more recently renegotiated their position following the end of assimilation policies, but these points of change have not undermined the dominant structures of the New Zealand state (O'Sullivan 2007).

Punctuated equilibrium requires that the researcher organise data into three distinct time periods: pre-critical juncture, critical juncture and

post-critical juncture. During a pre-critical juncture, a combination of factors converged to destabilise the status quo (Lange 2013). To explain this destabilisation, Thelen (1999) maintains that a researcher must consider likely destabilising factors both within and without an institution. This task required this thesis to consider such diverse impacts on ethical oversight as legislative frameworks, media reports of scandals, governmental economic policies, and evolving ethical thought.

The critical-juncture time period signifies a space when the factors impinging on pre-existing conditions realign in a way that leads to a fundamentally different institution. In this period, the available choices of institutional responses are at their most broad as neither the former nor the future institutional structures constrict contemporary choices (Capoccia & Kelemen 2007). Capoccia and Kelemen (2007) argue further that consideration of critical-junctures allows the researcher to explore plausible alternatives to the chosen path and therefore focus analysis on why a given path was selected.

The post-critical juncture denotes a period where the previous negotiation forms into a new 'normal'. Pierson (2000) maintains that the introduction of a new normal introduces dominant features into an institution that are then highly resistant to change. This permanence, however, does require some qualification. Punctuated equilibrium argues that while these structures become consistent over time in the post-critical juncture, the outworking of these structures may take some time to develop (Lange 2013, p. 77). Lange (2013) provides an example from the work of Mahoney to illustrate this effect. According to Mahoney (2001), the difference in the speed of liberal reforms in Guatemala, El Salvador, and Costa Rica explain their divergence into democratic and militarised states. In the case of Costa Rica, where liberal reforms were sensitive to class conflicts, Mahoney argues that this critical juncture template of class-sensitive change allowed the gradual shift to democratic structures to be an

ongoing feature of the post-critical juncture (Lange 2013). The example of Costa Rica, therefore, confirms how the post-critical juncture period is not necessarily static, but exhibits ongoing change based on the logic formed during the critical juncture time period in each case study.

This thesis adheres to narrative-ordering requirements of punctuated equilibrium by forming a chapter that creates a history of the pre-juncture and critical juncture of emergence of research oversight for each of the three case studies. In explaining how research oversight emerged and came to be in its current form, chapters four, six and eight lay a foundation for the later explanation, in chapters five, seven and nine, of how Indigenous ethics negotiated a position within the larger context of research oversight as representing the post-critical period. These chapters express their adherence to punctuated equilibrium through their ordering of information and do not explicitly refer to terminologies such as critical junctures. Organising the chapters in this manner allows consistency with punctuated equilibrium methodologies to be maintained, while not burdening the histories with information that does not explicitly advance their narrative.

The above descriptions explain the rationale behind the methodologies of historical comparative analysis used by this thesis, but it does not show how decisions are made that weigh these ideas. The section below outlines its practical application.

The research of each case study began by examination of histories of research oversight in Canada, Australia and New Zealand, as produced by other researchers. These histories provided the starting point from which to explain change in each context even though none were directly concerned with the themes of this thesis. Using a structure akin to snowball sampling each claim in these histories was examined. When further research led by these histories uncovered further potential factors,

these are added to the data. As the thesis also uses direct comparison, all the factors referenced in one case study needed to be researched in the other two case studies.

Answering several questions enabled this thesis to weigh and give meaning to its research data:

- What did this factor resist or respond too? This assumes that contrary factors encourage change. If this factor is a policy document, it is important to note how the document framed the then-current status quo and what it introduced as a better alternative.
- What impact did this factor have over time? It is necessary to show what impact a particular factor exhibited. The speed of change is also important. If change occurred immediately, the likelihood of a direct and perhaps singular impact is increased. If change occurs after a longer period of time has elapsed (but along the lines introduced by this factor) further evidence is required to show why this delay occurred and what other factors may have also encouraged change.
- What is significant change? The researcher needs to develop an understanding as to what represents a radical change point within the logic of the research as a critical juncture. This understanding encourages the analysis to explain how each factor influenced radical change. It is important to consider structures that might be reasonably expected to influence a given context such as: economic, political (both government and within an organisation), competing institutions, changes in societal norms or expectations, legislative frameworks, and media influences.
- Does the narrative credibly explain why and how change occurred? This final question involves the use of logic and a degree of intuition on the part of the researcher. Is the explanation sufficient to explain

to the reader why change has occurred? If the answer to this question is not apparent, more research may be required.

In addition to use of such questions, this thesis placed its case study histories into diagram form in order to aid explicit concentration on change over time and factors that may have encouraged change. These diagrams show the order of significant factors and the direction of influence. An example is found in Appendix E.

Limitations

In committing to historical comparative analysis and its sub-discipline of historical institutionalism, this thesis implicates itself in the limitations of the perspective. A distinct disadvantage is the time-intensive nature of analysis that restricts the number of cases a research can study at one time. As Lange (2013) notes, the consequence of small-N cases of narrative analysis is an inability to make causal inferences beyond the case studies in question. This thesis recognises this limitation by not claiming that its insights will extend beyond the three case studies.

Banks (1989) highlights the problem of 'arguments from silence' in historical comparative analysis where researchers must build up explanations for historical phenomena that cannot be gained through direct interviews. Arguments from silence therefore require the researcher to use as many information-gathering sources as is reasonably possible to gain an insight into a phenomenon. The broad range of data collections sources described by this chapter served to mitigate against this limitation.

Ragin (1981) isolates a further limitation of historical comparative analysis when noting that its units of analysis and comparison differ from study to study (Ragin 1981). Møller contends that at its weakest, historical comparative analysis risks choosing irrelevant variables that

could create 'false historical analogies' which do not control for relevant explanatory factors (2015, p. 2). Additionally, the complexity of historical comparative analysis means that perfect controls for all potentially relevant variables can never be achieved. Skocpol (1979) expresses a concern that a failure to control for variables in historical comparative analysis may lead to focus on contextual features that are irrelevant, or are not noted or found.

While a certain level of divergence across studies is inevitable given the focus of historical comparative analysis is on idiographic comparison, this thesis addressed the above limitations by explicit alignment to well-used historical comparative methodology and theory.

The following chapter begins the task of historical comparative analysis with an introduction to a historical framing of the relationship between the Indigenous Peoples of Canada, Australia and New Zealand and the nation states in which they reside.

3

Theorising Indigenous sovereign and bicultural politics

The histories of Canada, Australia and New Zealand are sombre reading for Indigenous Peoples¹. These histories represented loss of land, disruption of economic structures and assimilation. However, despite the uneven outcomes of the colonial process, Indigenous Peoples in Canada, Australia and New Zealand have long resisted colonial policies and gained limited concessions in recent decades. This chapter charts this history of resistance and ends with an explanation of the use of sovereignty politics as resistance in Canada and Australia, and expressions of bicultural politics in New

¹ This thesis is acutely aware of Pearson's contention that there is no neutral language to describe persons and positions of Aboriginal status (2001, p. 12). Compounding this complication is that fact that there are no universally accepted terminologies to refer to Indigenous peoples within the contexts of Canada, Australia and New Zealand. Not all Indigenous peoples designated by the term First Nations, for example, accept this terminology and prefer instead to be referred to by the name of their tribe. Likewise, some Indigenous New Zealanders wish to be acknowledged by their iwi affiliations in preference to the blanket term Māori. This thesis addresses the above difficulties in a manner consistent with the latest iterations of Indigenous research ethics policy codes in Canada, Australia and New Zealand. In each case these policy documents have chosen terminologies considered most appropriate by the Indigenous communities of each context, and added a caveat explaining that these terminologies inevitably gloss over the significant diversity that exists across the Indigenous peoples of each context. Therefore, the terminology of First Nations, Inuit and Métis are used to describe the Indigenous peoples of Canada and the terminologies of Aboriginal and Torres Strait Islander's and Māori are used to describe the Indigenous peoples of Australia and New Zealand respectively. This thesis only breaks this rule when using direct historical quotes where the author has used a different terminology – for example, before the terminology of Aboriginal and Torres Strait Islanders became preferred, many documents used the word Aboriginal instead.

Zealand. These conceptualisations are original and unique to this thesis, and form the basis of later comparative analysis.

Colonising Canada, Australia and New Zealand

Let's be honest. Since the initial European-indigenous meetings in North America, Australia, and New Zealand, the prize has been lands and their resources. Indigenous peoples lived on and among them; European colonizers coveted them. Had Europeans applied their own common law to these meetings, the hostilities would have been over before they began (Hutchins 2010, p. 215–216).

The colonising of Canada, Australia and New Zealand did not occur in the conditions of fair exchange but instead through the subjugation of Indigenous interests to those of the British empire. Rather than view the peoples and lands of what would become Canada, Australia and New Zealand on their own terms, the British empire wished to incorporate each into the 'economic requirements' of settlement (Evans, 2003). Colonialism, argued Wolfe (2006), became the foundation to the success of the industrial revolution because the revolution itself

... required colonial land and labour to produce its raw materials just as centrally as it required metropolitan factories and an industrial proletariat to process them, whereupon the colonies were again required as a market. The expropriated Aboriginal, enslaved African American, or indentured Asian is as thoroughly modern as the factory worker, bureaucrat, or flâneur of the metropolitan centre (Wolfe 2006, p. 394).

The Indigenous Peoples experience of loss of land was similar in all three countries. As the following Figure 1 graphically demonstrates, the loss of land controlled by Māori over the course of a single lifetime was extensive. In

Canada, Usher (2003) found that the signing of treaties typically left Indigenous communities with about 1% of their original land base, while Pollack (2001) notes that prior to 1966, no Australian Indigenous communities possessed legal protection for their landholdings.

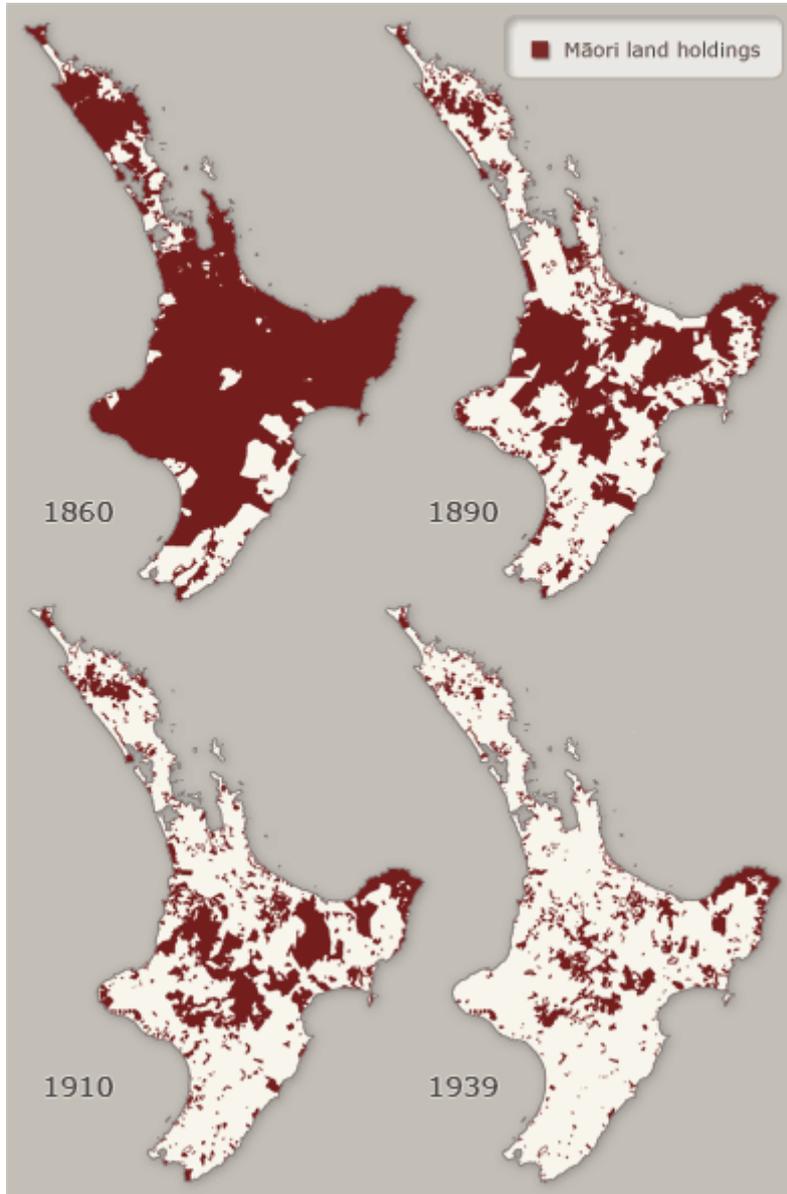


Figure 1, New Zealand North Island Māori land loss between 1860 and 1939. Source: <http://www.teara.govt.nz/en/map/19476/loss-of-maori-land>.

Beyond the control of land, the settler societies of Canada, Australia and New Zealand wished to create a 'second British Isles empire' (Akenson 1995, p. 395). Settlers, according to Bell, are "a particular kind of colonizer, those who seek to make a new home on the lands of others" (2014, p. 7). Stasiulis and Yuval-Davis stress that single direction of 'homemaking' when they insist that Canada, Australia and New Zealand set about creating a dominant culture "fashioned directly from the 'mother' country" (1995, p. 3). Such was the success of this impetus, that the nature of these three national contexts would become 'overwhelmingly European in character' (Marshall, 2001, p. 7).

In order to ensure the 'European character' of these projects, Canada, Australia and New Zealand began a process designed to 'civilize' the Indigenous populations through policies that came to be known as assimilation (Armitage 1995). Scholtz defined the goal of assimilation as to create the conditions in which Indigenous peoples would "shed their cultural ties and linkages to their communities" and enter fully into mainstream society (2013, p. 42). Under the political conditions of assimilation, Armitage (1995) found that all the levers of central and regional governance could be used in aid of its central cause. While it is important to recognise the ideologies and practices of assimilation changed over time and place (Moran 2005), a non-exhaustive list of its ongoing features in Canada, Australia and New Zealand is consistent with the following:

- A focus on requiring the education of Indigenous children in systems that singularly drew on colonial curriculums and language (Battiste 1998; Havemann 1999a; Welch 1988; Smith 1997).
- The use of state apparatus to remove Indigenous children from their families and into adoptive, state or foster care (Fournier & Crey 1997; Haenga-Collins 2013; Wilkie 1997).

- A national reinterpretation of colonial brutalities as benign (Coombes, 2006; Hodge, 1991; Jalata 2013; Moran 2005; Pollock 2004; Regan, 2006).
- The creation of legislative frameworks that lessened Indigenous voices in the political system (Attwood 2007; Dussault, Erasmus, & Canada, 1996; Jackson & Wood 1964).

The conditions of assimilation, as one might assume from the above list, drastically reduced the 'public sphere' spaces left available to Indigenous peoples who possessed the desire to live as such (Kymlicka 1996).

There are several points of difference between Canadian, Australian and New Zealand assimilation policies such as the methods of land appropriation, the use of special separation and the timings of assimilation policies (Armitage 1995; Havemann 1999b). But as Armitage notes, similarities in the main policy themes between Canada, Australia and New Zealand are

... strong and recurrent, while the differences are more often a matter of emphasis and degree rather than of kind (Armitage 1995, p. 217).

Confirmation of the comparatively poor standing of indigenous peoples in Canada, Australia and New Zealand is found in their relative placement across the United Nations Development Programme's Human Development rankings (Human Development Index) – a standardised measure of poverty, literacy, education, life expectancy and comparative buying power (United Nations 2012). By dividing the populations of Canada, Australia and New Zealand into Indigenous and non-Indigenous groups, significant gaps in human development become apparent. When calculated as the total population, Australians rated as fourth on the Human Development Index, while Aboriginal and Torres Strait Islander Australians were 103rd. Likewise,

the inclusive Canadians population rated as 8th, while its First Nations, Inuit and Métis Peoples received a 37nd on the index. In New Zealand, the whole population rated 20th on the Human Development Index, while Māori were 73rd (Cooke, Mitrou, Lawrence, Guimond, & Beavon 2007).

If one concentrates on Indigenous health, the picture is similarly bleak. Stephens et al. (2005) reveal that Indigenous Peoples suffer poorer health as a reflection of relative societal marginalisation. Shea, et al. (2011) highlight the comparatively poor position of Indigenous Peoples in Canada, Australia and New Zealand by noting that there are significant disparities between the health of Indigenous and non-Indigenous populations even as all three countries possess publicly funded healthcare systems (Shea, et al. 2011). A small subsample of these trends establish that the Indigenous peoples of Canada, Australia and New Zealand suffer higher “incidence and mortality rates for specific cancers and lower survival rates as a result of late diagnosis, lower participation and poorer compliance with treatment” (Shahid 2009, p. 109), significantly higher mortality rates from diabetes (Naqshbandi 2008), and chronic kidney disease (Yeates et al. 2009).

Human development and health research, such as listed above, legitimise Indigenous claims that colonial processes have tilted the development of Canada, Australia and New Zealand in favour of non-Indigenous citizens over Indigenous Peoples. However, research in Canada, Australia and New Zealand has been far from a benign feature of the colonial process. As Linda Smith (1999) argues repeatedly, research is a dirty word in Indigenous communities.

Research as a colonisation act

At its worst, research has been used to

... justify the exploitative relationships created by colonisers with Indigenous peoples through the production of research 'findings' which justified theft of Indigenous resources, discriminatory cultural and social policies, and genocide (Kelly & O'Faircheallaigh 2001, p. 1).

A key theme of much of this research was the positioning of Indigenous peoples as a 'problem' in ways that would later enable their exploitation (Ermine, Sinclair, & Jeffery 2004). Consequently, First Nations, Inuit and Métis peoples have been categorised by research as dysfunctional (Reading & Nowgesic 2002), while Aboriginal and Torres Strait Islanders were referred to variously as 'an inferior race', 'a dying race' (not worthy of significant health services), and 'passive, powerless victims' (Thomas 2004, p. 29). Likewise, Māori have been designated as culturally, racially and intellectually inferior (Rangiwai 2010). In academic contexts, negative labels repeatedly changed over time. Peterson revealed how Australian anthropologists first viewed Aboriginal and Torres Strait Islander peoples prior to 1880 as moral degenerates, later as 'unevolved' people, and later still under the evolutionary prototype of the 'hunting and gathering' existence (1990, p. 3). The consistency between these disparate conceptions of Aboriginal and Torres Strait Islander was their perceived inferiority to white settler Australians.

In more recent years, research on the Indigenous populations of Canada, Australia and New Zealand has been variously criticised as fixating on perceived negatives in Indigenous populations (Reading & Nowgesic 2002; Wyeth, Derrett, Hokowhitu, Hall, & Langley 2010), conflating assimilation goals with that of research (Pearson 1984), failing to accurately describe the

meanings inherent in Indigenous customs (Castellano 2004), enabling colonial exploitation (Ball & Janyst 2008; Cunningham 2000; Jahnke & Taiapa 1999), glossing over Indigenous diversities (Young 2003), enabling the wide-scale theft of Indigenous artefacts (Mulvaney 2006; Pishief 1998), engaging in research without any attempt to gain Indigenous benefit (Thomas 2004), and propagating myths about Indigenous life (Pishief 1998; R. Walker 1992).

Change did occur, all be it unevenly. Resistance to research on Indigenous peoples in Canada and New Zealand began to emerge in the late 1960s and early 1970s (Humphery 2001; Smith 1999). While this trend appeared in Australia slightly later, by the 1980s Australian health researchers became sensitive to their work being subject to questioning in relation to research 'on' Aboriginal and Torres Strait Islander peoples (Humphery 2001). By this time in New Zealand, non-Māori anthropologists met resistance when studying study Māori society (King & Morrison 1991; Sissons 1999; Tolich 2002).

Many researchers responded to this resistance by creating guidelines or conceptual frameworks that were intended to instruct researchers (for example: Bishop 1994, 1998, 1998; Boyer & Barden 1993; Boyer & Red Horse 1993; Cram 1993; Gamble 1986; Gilchrist 1997; Irwin 1994; Johnstone 1991; Mihesuah 1993; St. Denis 2004; Wyatt 1991). Common themes in such work are linking research with the colonial project and advocating for Indigenous communities to gain control over, or at least significant input into, all stages of research.

The most influential work of this period was Linda Tuhiwai Smith's book *Decolonizing methodologies: Research and Indigenous peoples* (1999). Smith's work has been extensively cited (it has received over 9,500 citations) and favourably compared in influence to Edward Said's 1978 book *Orientalism* (Cloete 2011, p. 38). As mentioned briefly above, Smith began her work by

identifying one of the 'colonized' and linked settler research with European imperialism and colonialism. In her second sentence Smith stated

The word itself, 'research' is probably one of the dirtiest words in the Indigenous world's vocabulary... scientific research is implicated in the worst excesses of colonialism and remains a powerful remembered history for many of the world's colonized peoples (Smith 1999, p. 1).

Smith explains this reaction on the part of Indigenous communities as a reaction to exploitative research that places Western knowledge over Indigenous knowledge (p. 189), portrays Indigenous peoples as 'problems' (p. 92), and creates an elite form of knowledge that lacks relevance to Indigenous communities (p. 129). The way beyond such difficulties, according to Smith, is to return control to Indigenous communities and Indigenous researchers (p. 125).

The success of Smith's work is likely due to its timing – her work was released when Indigenous research ethics were reaching a critical mass. Evidence of this growth is found in a Canadian literature review of Indigenous research ethics produced in 2004. The review found that the Indigenous research themes described by Smith and others had become entrenched in Canada, Australia and New Zealand. It states that

There is little distinction to be made between Canada, the United States, and Australia/New Zealand in regard to research founded on Indigenous knowledge... a critical mass, with respect to research issues and Indigenous peoples, has been reached worldwide. Native people are no longer willing to act as passive recipients of research (Ermine et al. 2004, p. 13).

The signing of the tripartite agreement between the medical health councils of Canada, Australia and New Zealand was a confirmation of broad

acceptance of Indigenous community desires for a deep engagement with research (NHMRC, CIHRC, & HRC 2002). The cooperation agreement was resigned in 2012 as a letter of intent (NHMRC, CIHRC, & HRC 2012), but as the introduction argued, this agreement does not include guidance on an ethics policy code.

Chapters four to nine will examine how these policies developed in Canada, Australia and New Zealand, but to explain the context of these histories, it is necessary to introduce a description of national-level Indigenous political resistance in each context. The remainder of this chapter briefly notes the long history of Indigenous resistance to colonisation before charting the more recent use of what can be labelled sovereignty politics in Canada and Australia, and bicultural politics in New Zealand. These two political strategies were present during the development of Indigenous ethics policy in Canada, Australia and New Zealand. The author does not claim the originality of these frames, but rather seeks to define how they will be used in this research.

Indigenous political resistance

Protest against the settler states of Canada, Australia and New Zealand has been a feature of Indigenous actions since the beginning of the colonisation process. Walker (1984) has described how Māori protest activity responded to changing conditions since 1840 through recourse to actions as varied as armed conflict, pacifist movements, petitions to the Queen of England, direct engagement in politics, the formation of civil Māori groups designed to pressure government, class-based action, and land marches and occupations. In Canada, resistance emerged to the gathering of census data as early as the 1850s (Hubner 2007), and in 1857 through the blockade of settler miner trade groups through Indigenous-controlled lands (Anderson 2010, p. 11). Aboriginal and Torres Strait Islanders have variously been

involved in armed struggle (Parry 2007), guerrilla warfare (Ryan, 2013), petitions to the Australian government (Lippmann 1981), political demands for self-determination (Mudrooroo 1995), and passive resistance (Broome 2010). Scholtz (2013) is at pains to note that it was Indigenous social action that forced Canada, Australia and New Zealand to abandon their assimilation policies. The withdrawal of assimilation policies, in other words, is not the reflection of state generosity, but rather a reaction to long-term Indigenous resistance.

Following the abandonment of assimilation policies (Armitage places the end of assimilation at 1950, 1970s and 1960 in Canada, Australia and New Zealand respectively (1995)), differences emerged in the politics of resistance as Canada and Australia Indigenous Peoples pursued sovereignty politics, while New Zealand Māori indicated a preference for the use of bicultural ideals. The distinction between sovereignty and bicultural politics is a central claim of this thesis.

Sovereignty politics

Sovereignty politics in Canada and Australia is defined here as demanding the return of items of particular concern to Indigenous peoples such as the control over land, mechanisms of self-governance and culturally relevant means of expression. Sovereignty politics tends not to concern itself with gaining influence in areas of governance that do not directly impact Indigenous Peoples, but concentrates instead on the creation of separate structures dedicated to Indigenous needs. The notion of sovereignty politics has many expressions.

The 1996 *Royal Commission on Aboriginal Peoples* is a clear Canadian articulation of sovereignty politics. The Commission was tasked with investigating the evolution of the relationship among “Aboriginal peoples (Indian, Inuit and Métis), the Canadian government, and Canadian society

as a whole” (Dussault et al. 1996, para. 6). The Commission framed Aboriginal Peoples as belonging to Nations within three orders of Canadian Government: Federal, Provincial/territorial, and Aboriginal (Fleras 1999). As Nations, the Commission argued the

... right of Aboriginal peoples to fashion their own lives and control their own governments and lands (RCAP 1996, sec. 4).

The release of the *Royal Commission on Aboriginal Peoples* represented the outcome of longstanding Indigenous demands. The instigation of the Commission itself was in response to First Nations, Inuit and Métis use of road blockades as a form of land protest (Blomley 1996; Foster 1999; McGregor 2011), which had culminated in the 1990 Oka blockade crisis in which Corporal Marcel Lemay died of a gunshot wound (Lackenbauer 2008). Also important was the Supreme Court of Canada decision in the *Calder* case that established the legal validity of pre-existing Indigenous rights (Asch 1997) and the resultant Constitution Act 1982 section 35 (1). Section 35 (1) states, “The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed” (1999). Further pressure was applied to the governments of Canada by the 1989 Royal Commission on the Donald Marshall Jr Prosecution (Royal Commission on the Donald Marshall & Hickman, 1989) and the 1988 Manitoba Public Inquiry into the Administration of Justice in Aboriginal People (Furniss, 2001). Both of these inquiries were concerned with Indigenous treatment at the hands of the justice system (Clark & Cove 1999).

Sovereignty politics manifests itself in Australia in a similar way. The 1989 *National Aboriginal Health Strategy* is such an expression. The report conformed to sovereignty politics when it argued that Aboriginal and Torres Strait Islander community involvement should be a feature of future health services to Indigenous communities. Rather than cast Aboriginal and Torres Strait Islander involvement as an ‘add-on’ to health services, the report

argued that health services should orient themselves to the Indigenous conceptions of cultural, political and environmental worlds (NAHSWP 1989).

In a further reflection of sovereignty politics, the Australian government established the now decommissioned Aboriginal and Torres Strait Islanders Commission 1990–2005 (ATSIC 1995; Bailie & Wayte 2006). The first order of its functions was to formulate and implement programmes for Aboriginals and Torres Strait Islanders (Fleras 1999). In aid of these functions, the Commission established 35 Councils around Australia to represent the interest of their local Indigenous communities and foster self-determination (ATSIC 1995).

As in Canada, the above expressions of sovereignty politics did not occur in a vacuum but as one point in a long list of Indigenous political actions. Following the 1967 gain of the right of Aboriginal and Torres Strait Islander Peoples to be included in the census (Hill 1995), the 1970s were marked by land rights protests that called for the repealing of a fundamental legal and discursive doctrine of Australia law – *terra nullius* (Poirier & Ostergren 2002). It was under *terra nullius* that “empty lands” under Aboriginal and Torres Strait Islander control could be claimed for the Crown (Reynolds 1999). Westbury & Sanders found that by the 1980s and 90s, much Aboriginal activism had moved from the ‘adversarial’ politics of land rights into other policy areas such as the push for the development of community government councils in remote Aboriginal communities (2000, p. 2) and the advancement of Aboriginal community-controlled medical services (Hunter 2001). Unlike bicultural politics, the expressions of sovereignty politics did not extend to the desire to gain authority greater Canada and Australian society.

The 1992 *Mabo v Queensland (No.2)* High Court decision was a defining legal ruling for Aboriginal and Torres Strait Islander authority over previously occupied land. The *Mabo (No 2)* decision officially undermined *terra nullius* in

law (Reynolds 1999) and recognised that Aboriginal and Torres Strait Islanders did retain rights to land occupied at the time of crown acquisition (McNeil 2010). The statutory recognition of this change is found in the 1993 Native Title Act 1993 (Havemann 1999a). The Native Title Act 1993 states in its explanatory notes that its purpose is to

... provide a national system for the recognition and protection of native title and to provide for its co-existence with the national land management system.

The above examples establish that the Indigenous Peoples of Canada and Australia have made gains following the end of assimilation practices. However, as Kymlicka (1996) argues, as each of these Peoples were fully functioning societies before the advent of colonialism, the gains of sovereignty politics clearly do not allow the return of a level of influence to former levels.

A number of features unique to Canada and Australia explain the use of the limited claims sovereignty politics. The Indigenous Peoples of Canada and Australia represent but 4.2% (NHS 2011) and 3% (ABS 2011) of the total populations respectively and are spread over national structures that include Federal and State-level governance. Organising social action around signed Treaties is complicated in Canada by the existence of over 500 different Treaties (Borrows 2016), while in Australia there does not exist a Treaty with which to galvanise Indigenous political actions (Ross & Pickering 2002). Both Canada and Australia are large landmasses representing 9 million and 7.8 million square kilometres respectively (CIA 2016), which add to the logistical challenges of coordinating common strategies.

Bicultural politics

Māori, by contrast, currently represent 15.4% of the total New Zealand population (SATS 2015). New Zealand is also a much smaller country of

271,000 square kilometres (STATSNZ 2016) with a single level of Parliamentary governance (Gauld 2003) legitimised by the signing of a single treaty, the Treaty of Waitangi (Orange 2011). The Treaty of Waitangi is considered to have established a partnership between Māori and the New Zealand government (Barrett & Connolly-Stone 1998). For more information regarding the Treaty of Waitangi, see Appendix B.

These differences help explain why Māori were able to extend beyond ideals of sovereignty politics and argue for a larger role in the governance of New Zealand.

The fundamental difference between sovereignty and bicultural politics is the latter's expanded vision of where Indigenous Peoples might influence the state. Bicultural politics demand that Māori gain influence over all public governance in partnership with the New Zealand government as encouraged by the Treaty of Waitangi (Barrett & Connolly-Stone 1998; Grant 2012; Ritchie 2008). Where sovereignty politics limits itself to issues of direct relevance to Indigenous Peoples, such as control over land and issues of self-governance, bicultural politics argues that all public functioning of New Zealand is of relevance to Māori. Table 1 below compares the different goals, intended structures and policy outcomes of bicultural and sovereignty politics.

	Bicultural politics	Sovereignty politics
Goals	Māori partnership in all New Zealand's governance	Indigenous self-determination over areas of direct concern to Indigenous Peoples
Structures	Active Māori involvement with the central mission of government institutions	Indigenous control over public governance that directly relates to Indigenous Peoples
Policy outcomes	Inclusive, shared institutional space	Exclusive institutional space for Indigenous Peoples

Table 1, Comparison of bicultural and sovereignty politics. Note: this table was developed from the work of Durie (1995) and Wright (2006).

Henare and Henare's eleven chapters in the (1988) *Report of the Royal Commission on Social Policy: Te Komihana a te Karauna mo nga Ahuatanga-A-Iwi* (April report) provides an example of the ideals behind bicultural politics when they argue that the Treaty of Waitangi implies that New Zealand governance should occur in partnership with Māori. The April report defines partnership as "sharing power, and sharing control" (Henare & Douglass 1988, p. 111) and cites government departments already conforming to (or implementing some of the features of) bicultural governance such as the Ministry of Women's Affairs, the Department of Labour, the Department of Internal Affairs and the Department of Social Welfare. Importantly, all of the above government departments were national in character and not designed specifically for Māori *per se*, but under the ideal of bicultural politics Māori demanded a partnership role in the governance of each. Of these Departments, the Ministry of Women's Affairs is valorised as it is concerned with the "a partnership between Māori and non-Māori, equal sharing of

power and resources; and the recognition of both cultures and languages” (Henare & Douglass 1988, p. 113). Henare and Douglas also make a further bicultural distinction when they argue that Māori do not express partnership as a collection of individuals but instead as representatives of their respective whanau, hapu and iwi. Explained in this way, the bicultural partnership is between the functions of New Zealand’s governance and Māori collectives.

As in Canada and Australia, the advances of bicultural politics in the 1970s were gained through longstanding Māori political agitation. Māori political struggle centred on the demand that the Treaty of Waitangi be honoured in contemporary New Zealand (Walker 1999). Key to this struggle was the social action group Nga Tamatoa. Nga Tamatoa assumed responsibility for conscious raising of both Māori and non-Māori New Zealanders on the contemporary relevance of the Treaty of Waitangi (Simmons, Mafile’o, Webster, Jakobs, & Thomas 2008; Walker 1989). This group organised the 1975 Land March down the length of the North Island to the steps of Parliament to gain support and publicity for this end (Beary 2011). Other protest were to follow such as the occupations of Bastion Point and Raglan in 1978 (Fleras 1999). Greenland (19991) observes that these occupations represented a more confrontational approach to protests that encouraged a widespread public belief that the New Zealand state was entering a period of protracted conflict with Māori.

In 1981, the racially selected ‘white only’ apartheid-era South African rugby team toured New Zealand (Pollock 2004). Reaction to the tour was unprecedented and divisive. Resistance to the tour led to levels of violence and civil disobedience not before seen in New Zealand (Shears & Gidley 1981), yet support for the tour cut across social, ethnic and political boundaries (Fahey 2009). In 1982, the New Zealand Human Rights Commission released a report titled *Race against time* that confirmed the urgency of New Zealand’s ‘race relations’ problems (Blackburn, 1982).

The Fourth Labour government (1984–1990) responded by creating space in legislation that either referenced the Treaty of Waitangi or gave Māori formal recognition. Examples of this legislation include the *State Owned Enterprises Act 1986* (Hill 2010), the *Education Act 1989* (Barrett & Connolly-Stone, 1998), and the update of the *Treaty of Waitangi Act 1975* (Hill 2010). The introduction of the *State Sector Act 1988* encouraged the state to proactively seek to include and employ Maori. While the *State Sector Act 1988* did not directly reference the Treaty of Waitangi, it required that the New Zealand state recognise the ‘aspirations and employment requirements of Māori’ (Kelsey 1996, p. 185) and legislated the employment of more Māori in the public service (sec. 56). The Act implied, in other words, that the public sector should operate in a bicultural partnership (Jones, Pringle, & Shepherd 2000). As part of the public sector, the oversight of research in New Zealand could now be expected to give some expression to a bicultural partnership in fulfilling its duties.

Labelling the different approaches to Indigenous resistance as sovereignty or bicultural politics endowed this thesis with a consistent language with which to explain the different scope of the aims of Indigenous politics in Canada and Australia and to differentiate them from those observed in New Zealand. This is important because the terminology used to describe Indigenous political actions are different across Canada, Australia and New Zealand. In Canada, for example, what this thesis has described as sovereignty politics has been designated as the assertions of ‘First Nations’ or ‘Nation-to-Nation’ discourse (Dickason 2002; Fleras 1992; RCAP 1996). In Australia, these ideals have been expressed as the desire for ‘self-determination’ (Kowal 2008; Corntassel & Holder 2001; Hollinsworth 1996).

The designation of bicultural politics to New Zealand delineates two differing biculturalisms. The New Zealand use of the terminology of biculturalism is often evoked (for example: Hill, 2010; Matahaere 1995; Meredith 1989; O’Sullivan 2007; Ritchie 1992; Sharp 1990; Sibley & Liu 2007), but it is not

always defined as a coherent framework. Rather it can be viewed as a choice between competing bicultural ideals of partnership and sovereignty. Professor Mason Durie's (1995) 'workable biculturalisms' are instructive in this regard. Durie's two recommended biculturalisms conform to bicultural and sovereignty politics. The former encourages partnership within public institutions (as consistent with bicultural politics), the latter argues for the creation of separate Māori institutional structures (as consistent with sovereignty politics). In the language of this thesis, therefore, one of the tensions in New Zealand lies between the claims of bicultural and sovereignty politics. This tension was not static over time. The popularity of bicultural politics as a vehicle of Māori political action waned as the 1990s drew to a close (O'Sullivan 2007), and it has since fallen out of favour with New Zealand governments (Tolich & Smith 2014). However, as chapter nine argues, the prominence of bicultural politics was at its peak during a formative period in the development of research oversight in New Zealand and it is the dominant lens through which Māori ethics policy claims for research are viewed. Sovereignty politics does influence New Zealand research oversight, but its impact is overshadowed by bicultural politics.

The following six chapters are divided into three case studies to reveal how advocates of Indigenous ethics negotiated ethics policy consideration over time within the political framings of sovereignty and bicultural politics. Each case study begins by charting a history of research oversight in the relevant national context, followed by a chapter charting how Indigenous ethics negotiated ethics policy consideration.

Case Study I: Canada

4

Establishing Canada's centralised research oversight

The development of research oversight in Canada conforms closely to the conceptual ordering of punctuated equilibrium. Research oversight mechanisms introduced in the late 1970s (McGill 1993; Kinsella 2010) were undermined by destabilising factors which reformed into a new oversight institution. The release of the 1998 *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998 TCPS) symbolised this reformation into a structure marked by its centralised organisation. Centralised research oversight consists of four features: the production of a national statement for all human research (the 1998 TCPS), ethical committees bound to use the national statement, a national standing committee charged with the ongoing development of ethics policy, and an independence from day-to-day Ministerial oversight. Using implicit punctuated equilibrium ordering, this chapter traces the destabilisation of the pre-1998 Canadian research oversight and its reformation into the Tri-Council as its contemporary form. The second chapter of this case study tracks the interplay between the use of sovereignty politics by Indigenous ethics advocates and their engagement with the centralised research oversight of the Tri-Council.

Prior to the advent of contemporary research oversight in Canada in 1998, each of the three councils operated separately to oversee research ethics. For example, by 1978, the Medical Research Council had developed ethics policy (McGill 1993). This Council required research to be overseen by a formal process involving Research Ethics Boards (Salter & Hearn 1997) and had created institutional mechanisms to support the ongoing development of ethics policy and ethics oversight functions (Rolleston et

al. 1997). However, McDonald (2009) claims that these mechanisms did not conform to international expectations².

In 1977, the Social Science and Humanities Research Council introduced its ethics policy (Kinsella 2010). The Social Science and Humanities Research Council did not mandate that all of its funded research be subject to the oversight of research ethics boards (for example, Canadian Psychological Association 2000, p. 5). In the absence of an ability to compel researchers to submit to ethical oversight, the Social Science and Humanities Research Council policy codes were little used by social science researchers (Rocher 1999). No evidence was found of the Social Science and Humanities Research Council attempting to further develop the 1977 ethics policy or create a national ethics committee to ensure ongoing development of ethics policy (Kinsella 2010).

Of the three Councils, the National Science and Engineering Research Council gave the least concern for research oversight. Up until work began on Canada's national statement the 1994, the National Science and Engineering Research Council had given almost no concern to ethics policy (Rocher 1999). Thus, the history of National Science and Engineering Research Council research oversight is a short one. Until the release of the 1998 Tri-Council national statement, the Council simply did not have ethics policy for researchers to reference (Kinsella 2010; Rocher 1999).

While the unevenness of activity does not suggest an easy conflation of research oversight interests, four factors encouraged the three Councils to

² McDonald was instrumental in the development of Canada's first national statement. His history *From code to policy statement: Creating Canadian policy for ethical research involving humans* (2009) guided much of the structure of this chapter.

form a centralised research oversight regime: increasing government pressure to gain international research funding; the increasing practice of public health research undermined the former strict separation between medical and social science ethics policy; a fear that the government would introduce U.S.-style legislation containing the possibility of legal liability should research be revealed as unethical; and the implications of a research scandal.

Funding pressure

As a major recipient of the U.S. National Institutes of Health research funding, Canada had a vested interest in adhering to these funding requests. However, the National Institutes of Health began to require that international research provide assurance that U.S. research oversight standards were being adhered to (McDonald 2009). The difficulty with these requirements was that Canada had yet to achieve the levels of research oversight that the U.S. National Institutes of Health required (McDonald 2009). The Canadian government addressed the economic needs of international research by shortening the time needed to launch clinical trials (McDonald & Meslin 2003), but if access to international funding were to be maintained, the needs of the research oversight would also need to be addressed.

In the humanities and social sciences, changes in government funding models also created pressure for research oversight. Beginning in the early 1990s, the Canadian government constricted research funding for social science research and argued that researchers should make up this shortfall by seeking international research funding (Amit 2000). The Social Science and Humanities Research Council responded by focusing on research partnerships (Kondro 1998), but would find itself increasingly required by international funding agencies to provide evidence of robust research oversight (Amit 2000).

The inability in Canada to provide robust research oversight was highlighted by a 1990 National Council on Bioethics in Human Research report that noted ‘significant’ deficits in human research protection (McDonald 2009). Prominent Canadian medical ethicist Douglas Kinsella added to this critique by describing Canada’s research oversight as

...one of confusion. We do not have a cohesive picture of research regulation, from an ethical perspective, in Canada (Kinsella 2010, para. 38).

If Canadian research communities were to continue to gain international funding, they would need re-examine their structures of research oversight.

The rise of public health research

Charbonneau (2000) contends that the steady rise of public health research in the 1990s represented a sea change in the conceptualisation of medical research³. The growth of public health research would undermine strict separation between the needs of medical and social science research oversight. Israel, Schoulz & Parker (1998) traced this shift as emerging from U.S. government reports such as the *Future of Health* 1988. Israel et al. (1998) described a conceptual shift from a singular concern for individual medical approaches to health, to a broader view that also incorporates social and environmental determinants. Public health research, in other words, problematised the effectiveness of medical intervention without considerations of the social and environmental worlds that persons and communities inhabit (Chen, Diaz, Lucas, & Rosenthal 2010; Soto, Abel, & Dievler 1996). This shift required

³ For more information see: Soto, M., Abel, C., & Dievler, A. (1996). *Healthy Communities: New Partnerships for the Future of Public Health*. (Institute of Medicine, Ed.). National Academies Press.

researchers and health agencies to become involved in communities themselves to discover health determinants (Jones & Wells 2007), and in doing so they needed to consider the use of methodologies more traditionally associated with social science research.

Medical researchers would, therefore, increasingly have to contend with multidisciplinary research teams (Rolleston et al. 1997). Crucially, from an ethical perspective, no policy yet existed that was sensitive to both the needs of medical and social science models of inquiry (Rocher 1999). Throughout the 1990s, the rise of public health research began to influence ethics policy discourse (McDonald 2009) and ultimately led to a name change from the Medical Research Council to the Canadian Institutes of Health Research Council in 2000. It is noteworthy that New Zealand did not have the same level of collaboration.

Fear of U.S.-style legislation

Unlike the U.S. context, Canadian research oversight did not have the force of law – or its potential for the prosecution of individual researchers and institutions (Kinsella 2010). Arguments for a new nationalised ethical oversight framework contained a ‘forced-choice’ logic that argued in favour of an oversight structure chosen by Canadian researchers themselves over the potential for a legalised solution defined by the federal government (Kinsella 2010). It is difficult to gauge to what degree this fear encouraged the initial moves to create a Canadian national statement. What is clear, however, is that prominent actors wielded this forced-choice argument to quieten the discontent of (predominantly) social scientists who viewed the development of the national statement as unnecessary (Adair 2001; Furedy 1997; Kinsella 2010).

Research scandal

In August 1992, Canada experienced a research scandal. Valery Fabrikant, an associate professor at Concordia University, Montreal, entered the campus armed with several revolvers and shot dead four members of the faculty (Monahan 1995). Fabrikant had held the belief that his academic work did not receive the recognition it deserved owing to the behaviour of several professors of his department (Horn 1999). A report by the Independent Committee of Inquiry into Academic and Scientific Integrity confirmed 'a number of Fabrikant's more specific allegations'. In particular, the report found that three of the professors had "indulged themselves in the conduct in which they have variously engaged: conflicts of interest, other contractual irregularities, excessive outside professional work, and misappropriation of authorial credit" (Arthurs, Blais, & Thompson 1994)⁴.

In response to the Fabrikant murders, Canada's three research Councils behaved in a way entirely new to the Canadian context: they acted cooperatively. Legislation did not call for such an intersected response, nor did it appear to be a response to federal requests. Instead, the three Councils released a Tri-Council policy statement in January 1994 (Israel & Hay 2006) out of a perception of shared interest in the public legitimacy of research. The ability of the three Councils to act cooperatively was unique to Canada. Australia and New Zealand could not mount such a broad response as they do not possess three Councils representing the medical and public health, natural science and engineering, and social science and humanities.

⁴ For more information regarding the inquiry, see: Arthurs, H. W., Blais, R., A., & Thompson, J. (1994). *Integrity in Scholarship: A Report to Concordia University* (pp. 1-71). Canada: Independent Committee of Inquiry into Academic and Scientific Integrity.

The Tri-Council's 1994 *Integrity in Research and Scholarship* statement was sent to all Canadian universities and outlined the responsibilities incumbent "on individual researchers and on universities in promoting integrity and in investigations of allegations of misconduct" (Lytton 1996, p. 229). At four pages in length, the report clearly did not represent a move to write a combined and comprehensive ethics policy document. It did signify, however, an early example of a shift towards the bureaucratically distinct funding of Councils by combining resources to protect and inform the practice of ethical research in Canada.

Together these four convergent factors of competition for research funding, the rise of public health research, fear of U.S.-style legislation, and research scandal appeared to encourage a perception amongst many in Canada's research community that it was at a crisis point. This sense of peril was mobilised by a key research oversight actor when he stated

If we go through more scandals of the sort we have seen in Canada in the last few years, public trust will decline and so will public funding; as well, we could get the sort of legislation mentioned by Justice David Marshall (Dr Jean Joly, cited in: McDonald 2009, p. 18).

Dr Joly's reference to public funding was significant as it was at the initiative of the federal government that the Tri-Council began work on its first national statement (Onyemelukwe & Downie 2011).

Forming Canada's national oversight structures

In 1994, the Tri-Council received impetus when Canada's Ministry of Health and the Ministry of Industry and Commerce encouraged the formation of the Tri-Council Policy Working Group to produce a national statement (Onyemelukwe & Downie 2011). The Tri-Council Policy Working

Group members were appointed in July 1994 and charged with facilitating the creation of ethics policy relevant to all human research (McDonald & Meslin 2003). It is here that the work on joint policy began, leading to the creation of Canada's national statement in 1998. The presence of a national statement for all human research is unique to Canada and Australia. No such nationwide policy exists in New Zealand.

Even though the formation of the Tri-Council Policy Working Group was encouraged by two government Ministries, the decision to create a Tri-Council research oversight institution was voluntary. Rocher (1999) maintains that any of the three Councils could have withdrawn from the process and doomed the enterprise at any stage of the drafting. The Tri-Council countered the vulnerability of this process by actively facilitating the inclusion of the various research disciplines found in the three funding Councils.

Much of the first year of the Tri-Council was spent simply developing mutual understandings of the often implicit but divergent disciplinary assumptions bound in vocabularies, paradigms, cultures and concepts (McDonald 2009; Rolleston et al. 1997, p. 68). From these developments, the Tri-Council Policy Working Group produced three ethics policy documents; the 1994 *Issues Paper* (McAullay, Anderson, & Griew 2002, p. 22); a discussion draft in May 1996; and the *Code of Ethical Conduct for Research Involving Humans* in July 1997 (Tri-Council 1998).

The working group understood that the writing of national ethics policy should take into consideration the reactions of researchers and Research Ethics Boards (O'Neill 2011) and consultation followed each of its ethics policy drafts (Onyemelukwe & Downie 2011). The Tri-Council Working Group distributed approximately 14,000 copies to "every institute funded by the council" (gaining some 204 responses totalling 3,000 pages) on the 1996 draft alone (McDonald 2009, p. 16). Following the release of the

1997 Tri-Council Working Group's final report the working group, the Working Group ceased active involvement in the drafting process.

The policy writing process continued as the three Councils revised the national statement in the light of private consultations held between mid-1997 and May 1998 (Tri-Council 1998). Onyemelukwe and Downie (2011) categorise this revision as a second round of policy development where direct lobbying of the Council would inform the final version.

In August of 1998, the three councils released the national statement, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998 TCPS). The 1998 TCPS placed front-and-centre its commitment to the oversight of all human research funded by its Councils when it stated

The fundamental ethical issues and principles in research involving human subjects are common across the social sciences and humanities, the natural sciences and engineering, and the health sciences. They reflect shared fundamental values that are expressed in duties, rights and norms of those involved in research (1998, p. i.2).

The Tri-Council's TCPS national statement has become the 'foremost' policy guidelines for research involving humans in Canada (Onyemelukwe & Downie 2011). In practice this means that for any human research to receive funding from any one of the three Councils (Rolleston et al. 1997), ethical approval by a Tri-Council sanctioned research ethics board is mandatory (Castellano & Reading 2010). The Canadian Tri-Council's research oversight has been stable for close to twenty years.

Canada's contemporary research oversight

Research oversight in Canada has grown to include all the features of centralised research ethics. The Tri-Council developed national ethics

policy for all human research (CIHR et al. 1998, 2010, 2014), and requires that each of Canada's approximately 350 Research Ethics Boards use the TCPS guidelines as the sole governing ethical framework (Guta et al. 2010). The Tri-Council's standing committee, the Interagency Advisory Panel on Research Ethics committee, is charged with the ongoing development ethics policy (Onyemelukwe & Downie 2011; PRE 2015a, 2015b; see: CIHR et al. 2010, 2014). Completing the Tri-Council's adherence to centralised research oversight is the distance it enjoys from day-to-day Ministerial politics (CIHRC 2000; Rolleston et al. 1997). Figure 2 depicts how the Tri-Council does not report directly to the Minister of Health. Instead, the Canadian Institutes of Health Research Council reports to the Minister of Health on matters relevant to its legislative mandate (the Canadian Institutes of Health Research Council Act 2000 does not require it to produce ethics policy codes). This leaves research oversight peripheral to the overall tasks of the Canadian Institutes of Health Research Council when reporting to the Minister. For example, the Canadian Institutes of Health Research Council 2014-15 *Annual Report on Plans and Priorities* to the Minister of Health contains no reference to research ethics (CIHRC 2015b). In New Zealand, the National Ethics Advisory Committee reports directly to the Minister of Health (NEAC 2012a). The likelihood, therefore, of Ministerial interference over the development of ethics policy in Canada is low.

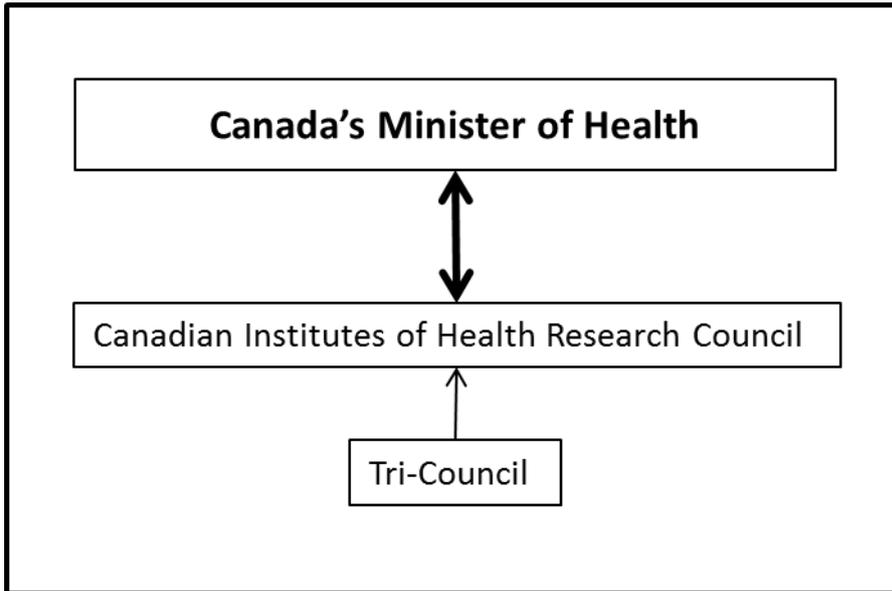


Figure 2: Ministerial distance from the Canadian Tri-Council

The centralised research oversight of the Tri-Council underscores its dominance over ethics policy development in Canada. It is this dominance that the aspirations of Indigenous ethics must negotiate in order to have its ethics policy gain widespread use by ethics committees and researchers. However, the established bureaucratic features of the Tri-Council gives reason for hope that should it could be convinced of the needs of Indigenous ethics that these structures would then be used to aid the development of Indigenous ethics policy in Canada. An example of this outcome is the way in which the Tri-Council Working Group (and the later Tri-Council Interagency Advisory Panel on Research Ethics) set aside resources to aid the development of social science research disciplines (Israel & Hay 2006). This example suggests that Indigenous ethics policy development may gain substantial value by gaining the bureaucratic support of a centralised research oversight institution.

5

The emergence of Canada's sovereign Indigenous national guidelines

By the time the Tri-Council Working Group commenced its early drafting in 1994, much of the groundwork required to convince the Tri-Council of the relevance of Indigenous ethics had already occurred. Both the Social Science and Humanities Research Council and the Medical Research Council had produced ethics policy, as had the Canadian Ethnological Society, the Royal Commission on Aboriginal Peoples, and the Association of Canadian Universities for Northern Studies (Scott & Receveur 1995). All of these policy codes are consistent with sovereignty politics in that they created separate ethics policy space dedicated to the needs of Indigenous ethics. They are not aligned to the ideas of bicultural politics as they did not argue for a role for Indigenous Peoples outside of the development of separate Indigenous ethics policy.

Out of these five Indigenous ethics policies mentioned above, it was the Royal Commission on Aboriginal Peoples and the Association of Canadian Universities for Northern Studies ethics policy guidelines that proved the most influential (Scott & Receveur 1995). The 1982 Association of Canadian Universities for Northern Studies ethics policy stated a strong preference for research conducted 'with' (as opposed to 'on') Indigenous communities. In doing so, it created an expectation that First Nations, Inuit and Métis communities should be consulted throughout a research project (Yukon College 2014). The ethics policy guidelines envisaged research roles for Indigenous participants as diverse as providing information, using the completed research, identifying research needs, and participating as research team members (Castleden, Morgan, & Lamb 2012).

The Royal Commission on Aboriginal Peoples mirrored the Association of Canadian Universities for Northern Studies concerns for the involvement of Indigenous communities in research (RCOAP 1996, vol. 5, appendix E) and engaged in Indigenous ethics capacity building. The Commission funded the production of 241 research projects by a wide range of First Nations, Inuit and Métis organisations (Dussault, Erasmus, & Canada 1996, vol. 5). In September 1992, the Royal Commission organised a workshop of around 80 persons involved in research that included academics, lawyers, consultants, community leaders and elders (Castellano 2004). The chairperson of the event, Dr Marlene Brant Castellano, recalls an Elder responding to participant comments that First Nations, Inuit and Métis peoples have been “researched to death”. The Elder is cited to have responded by saying: “If we have been researched to death, maybe it’s time that we researched ourselves back to life” (Castellano 2004, p. 98). It would be such responses, a theme of research-as-resistance, that Castellano notes “would gather remarkable momentum over the next decade” (2004, p. 98). As early as 1995, Scott and Receveur would proclaim that

... it has become no longer acceptable to conduct research in Indigenous communities without paying attention to the research needs and priorities of the people who live there...In practice, the researcher must persuade the community of the worth of the research, and community decide for itself to what extent it wants to be involved (1995, p. 751-2).

Given this growing legitimacy of Indigenous ethics and already present Social Science and Humanities Research Council and Medical Research Council Indigenous ethics policy, the Tri-Council Working Group would be required to consider Indigenous ethics as it came to draft the 1998 TCPS national statement. Tri-Council Working Group member Professor Michael McDonald confirmed the importance of Indigenous ethics to the Working

Group in his later recollection of its drafting process (McDonald 2009). However, when the Tri-Council's Working Group began to draft ethics policy, it chose to combine the requirements of Indigenous ethics into a single multicultural chapter.

Multicultural ethics as research oversight resistance

In its first year, the Tri-Council Working Group was conceptually challenged. It was required to address the diverse disciplinary requirements inherent in the research funded by the three Councils and develop mutual understandings that addressed the concerns of each (McDonald 2009; Rolleston, Armour, & Stipich 1997)⁵. It is likely with these requirements in mind that the Tri-Council Working Group chose to combine the conceptually similar ethics policy needs of 'minorities' with those of Indigenous ethics as they both added the requirements of community consultation to the needs of individual informed consent. Consequently, the Tri-Council Working Group 1996 and 1997 drafts included a 'collectives' chapter (McDonald 2009).

The 1997 draft put forward a multicultural definition of collectives as "groups in which there is mutual recognition of membership" and claimed a consensus when identifying the main groups in this category as the following

Indigenous peoples, in Canada and elsewhere, and minority groups who are or have been oppressed or discriminated against. Such minorities often have been defined in terms of race, gender, ethnicity, religious belief, physical or mental disability, disease

⁵ Indigenous ethics policy was but one of many research perspectives that the Tri-Council Working Group would need to engage. It needed to consider the relevance of every human-based research discipline in Canada to ethics policy.

status, occupation or class (Tri-Council Working Group 1997, p. VII-4).

While the multicultural categorisation above may have appeared to the Working Group to represent an elegant solution to multiple ethical needs of research with diverse populations, this grouping aligned First Nations, Inuit and Métis peoples into discourses of ‘vulnerable’ populations, instead of a relationship between Nations. This categorisation is opposed to sovereignty discourses where First Nations, Inuit and Métis peoples are valorised as fully functioning societies with a unique historical right to self-governance. When taking the Royal Commission on Aboriginal Peoples and the Association of Canadian Universities for Northern Studies guidelines as a foundation, the collectives chapter undermined the position of First Nations, Inuit and Métis Peoples as requiring a unique relationship with ‘Western’ research because of a history of colonisation (Dussault et al. 1996; Yukon College 2014)⁶.

Resistance to the 1996 and 1997 collectives chapters emerged in the behaviours of the Social Science and Humanities Research Council and the Canadian Department of Justice. As a founding Council in the Tri-Council, the Social Science and Humanities Research Council was uniquely placed to provide powerful resistance to the collectives chapter. The Tri-Council represented a voluntary partnership between the three Councils; each Council could undermine the Tri-Council’s attempts to create the TCPS national statement by withdrawing its support (Rocher 1999, p. 6). Because of this relationship, pressure applied by the Social Science and Humanities Research Council could potentially undermine the development of the Tri-Council national statement. Specifically, it was the Canadian Association of University Teachers who applied this

⁶ Internationally, Linda Tuhiwai Smith’s *Decolonizing Methodologies* (1999) is the most prominent advocate of this view.

pressure to the Social Science and Humanities Research Council following the 1996 and 1997 TCPS drafts. The Association viewed academic freedom as imperilled by the communities chapter in what they believed would amount to censorship that could cause Research Ethics Boards to undermine controversial research (McDonald & Meslin 2003; Seifert 2005).

In 1996, Canadian Association of University Teachers informed its members, that, "This summer the CAUT Executive took vigorous exception to the draft code on research about human subjects proposed by the three federal research councils" (CAUT 1996, para. 1). The Association considered it a "mistake" to extend coverage of the code from individuals to collectives, as they argued that the logic of the collectives chapter would ultimately give collective leadership power over social science research in the guise of veto (CAUT 1996, para. 4). The Canadian Association of University Teachers pressured the Tri-Council Working Group by stating that it would 'go to the wall' to block the collectives chapter (McDonald 2009). Given that the Canadian Association of University Teachers represented a significant academic union (in 2004 it had 35,000 members (CAUT 2004)), the Tri-Council Working Group and the Tri-Council would have been required to take this threat seriously. The Canadian University Teachers were not alone in their concern of the projected increased oversight of the Tri-Council. Van den Hoonaard (2001) likened the increasing ethical concerns of the Tri-Council to moral panic.

Importantly, while the Canadian Association of University Teachers reacted to the perceived threat of empowering collectives, such fears did not apparently extend to Indigenous collective influence over research projects. Clearly, the Canadian Association of University Teachers argument against collective influence over research could equally apply to Indigenous communities, but it appears that the acceptance of Indigenous ethics in Canada undermined this extension. Within this same critique of

community control over research, then, the Canadian Association of University Teachers did not recommend the withdrawal of ethics policy directed at research within Indigenous communities; rather, it suggested that this area would benefit from further study (CAUT 1996, 1998). In addition to this pressure applied to the Tri-Council Working Group, the Canadian Department of Justice recommended that the communities section be withdrawn as the Tri-Council Working Group had not sufficiently consulted with First Nations, Inuit and Métis communities (Kondro 1997).

Onyemelukwe and Downie (2011) affirm that the Tri-Council withdrew the collectives chapter a year before the release of the 1998 TCPS national statement as a result of the pressure applied from the Social Science and Humanities Research Council. Following this removal, the Tri-Council Working Group refused to write an Indigenous ethics chapter as it argued that it had neither Aboriginal members nor a mandate to speak for the First Nations, Inuit and Métis communities of Canada (McDonald 2009). In response, the three councils commissioned consultants to rewrite the collectives section into an Indigenous chapter to be inserted in the forthcoming 1998 TCPS national statement (McDonald 2009).

Practically speaking, the consultants used codes, such as are found in the 1996 Royal Commission on Aboriginal Peoples and the 1982 Association of Canadian Universities for Northern Studies, for guidance as to the emergent themes of Indigenous ethics (Castleden et al. 2012; CIHR et al. 1998, sec. 6.1). The Indigenous chapter was drafted and revised on several occasions, but because of the insufficient time available, it did not receive the results of consultation with First Nations, Inuit and Métis Peoples (Rocher 1999, p. 6). Given these handicaps, it is not surprising that the Indigenous chapter of the 1998 TCPS national statement did not contain the formalised ethics policy code found in the rest of the 1998 TCPS national statement but instead briefly introduced ethical themes.

Amongst the themes introduced was the need to respect Indigenous culture, traditions and knowledge, the need to consult and involve the group in research design, and to shape the research to address the needs and concerns of the group (Tri-Council 1998, sec. 6.1). Despite its lack of substantive ethics policy code, the inclusion of an Indigenous chapter in the 1998 TCPS national statement represents a breakthrough moment. Following the release of the 1998 TCPS, all research with First Nations, Inuit and Métis communities funded by the three Councils would now need to provide evidence to an ethics committee of its alignment with the themes found in the Indigenous chapter (Tri-Council 1998).

Subsequent to the inclusion of the Indigenous chapter, Indigenous ethics could now expect to benefit from use of Tri-Council institutional committees to develop Indigenous ethics from thematic to substantive policy. In the interim, however, the ongoing development of Indigenous ethics by its advocates furthered its advance outside of Tri-Council mechanisms.

The continued development of Indigenous ethics

Following the release of the 1998 TCPS national statement, Indigenous ethics developed further in the writings of authors such as Castellano (2004), Norton and Manson (1996), Schnarch (2004), and Ten Fingers (2005). Ten Fingers argued that while the response of researchers and policy-makers to Indigenous research paradigms was yet to be determined, its continued future was made safe by “the commitment and work of First Nations people” (2005, p. 96). A 2004 study of research in Canada involving First Nations, Inuit and Métis peoples found that Indigenous desires to be dynamically involved in research as participants and co-researchers had reached a critical mass (Ermine, Sinclair, & Jeffery 2004, p. 13). In this vein, Shore et al. (2008) claim that Indigenous

communities of Canada are considered to be world leaders in pro-active governorship and control over research.

Also significant was the 2003 update of the Association of Canadian Universities for Northern Studies guidelines as well as the 2005 introduction of the National Aboriginal Organisation. Ermine et al. (2004) consider the Association of Canadian Universities for Northern Studies guidelines to have “significantly advanced the notion of a renewed research relationship between researchers and communities”, while Castleden et al. highlight the National Aboriginal Organisation frameworks introduction of policy guidance for community empowerment in medical and public health research (2012). Further evidence of First Nations, Inuit and Métis Peoples’ desires to share control of research can be found in the creation of ethical codes by Indigenous communities and organisations such as the: Mi’kmaq Ethics Watch (n.d.), the Aurora (2011) and Nunavut (2011). A consistent feature of this concern for Indigenous ethics is that it all conformed to the ideals of Indigenous ethics as separate sovereignty policy designed for research that includes Indigenous communities.

This ongoing development of Indigenous ethics ensured that when the Tri-Council did consider further development of the Indigenous chapter, it did so within an active field of policy development. As the work of the Tri-Council Working Group ended with the production of its final draft in 1998 (McDonald 2009), the responsibility to further develop Indigenous ethics in the TCPS framework fell to the Tri-Council’s new national ethics committee, the Interagency Advisory Panel on Research Ethics (Israel & Hay 2006).

The Tri-Council Interagency Advisory Panel on Research Ethics

In 2003, two years after its formation, the Interagency Advisory Panel on Research Ethics began its first substantial work on the needs of First Nations, Inuit and Métis Peoples research when it launched a subcommittee called the Aboriginal Research Ethics Initiative (Castellano & Reading 2010). An individual of Aboriginal ancestry, Marlene Brant Castellano, was appointed to lead the subcommittee (PRE 2013). The Interagency Advisory Panel on Research Ethics subsequently called for input from Aboriginal research organisations (Ermine et al. 2004) and commissioned the *Ethics of Research Involving Indigenous Peoples* report produced by the Indigenous Peoples Research Centre (PRE 2013). The report stressed sovereignty politics ideals such as Indigenous control over culture, knowledge, political and intellectual domains; research agreements; community empowerment; benefits in research projects; Indigenous control over research projects conducted within their territories; and policy that would ameliorate conflicts between REB boards and Indigenous ethical requirements (Ermine et al. 2004, p. 7–8). Distinct from the ideals of bicultural politics, the report did not call for Indigenous Peoples to take a larger role in the oversight of Canadian research.

The difficulty with these advances, however, was that they were not completed in a timely manner. The release of the *Ethics of Research Involving Indigenous Peoples* report marked six years since the release of the 1998 TCPS Statement. No formal ethics policy code yet existed that could provide advice for research involving First Nations, Inuit and Métis Peoples, and the Aboriginal Research Ethics Initiative had yet to engage in the consultations required to create ethics policy (Previous codes such as found in the Royal Commission on Aboriginal Peoples report, chapter 6 of the 1998 TCPS, and the Association of Canadian Universities for Northern Studies (2003) either do not contain substantive code, or do not cover all of Canada or both).

The problem for the Canadian Institutes of Health Research was that they were making significant investments in First Nations, Inuit and Métis People's public health research, but as Kishchuch and Gauthier (2009) acknowledge, they did not have substantive contemporary ethics policy to guide the ethics of their research. An additional driver in the development of Indigenous ethics in Canada was the Canadian Institutes of Health Research Council.

Public health research

A major feature of Canadian research oversight is the prominence of public health research. This is symbolised by the renaming of the Medical Research Council to the Canadian Institutes of Health Research Council in 2000 (CIHRC 2002). An important distinction to note here is that the needs of public health research are not directly linked to those of Indigenous ethics. The Canadian Institutes of Health Research Act 2000, for example, does not directly reference First Nations, Inuit and Métis communities. It does, however, require a concern for

... the health of populations, [the] societal and cultural dimensions of health and environmental influences on health (Canadian Institutes of Health Research Council Act 2000, sec 20).

By including such concerns, however, the Act set in motion events that encouraged the Canadian Institutes of Health Research Council to support Indigenous ethics policy development. This process began with a concern for the need of Indigenous public health research.

As the Canadian Institutes of Health Research Council was in transition from the Medical Research Council, a national group of Indigenous and non-Indigenous medical and public health researchers petitioned the federal government (CIHR 2001). They were able to convince the

government to use the Canadian Institutes of Health Research Council mechanisms to give explicit care to Indigenous public health research and support the development of First Nations, Inuit and Métis research capacity (CIHR 2001). At its formation, the Canadian Institutes of Health Research responded to the request by agreeing to increase funding available for First Nations, Inuit and Métis public health research (McGregor 2010) and cast a mission to build public health research capacity in First Nations, Inuit and Métis research organisations at local, regional and national levels (CIHR 2003). In June 2000, the Canadian Institutes of Health Research set up the Institute of Aboriginal Peoples' Health as one of its 13 core initiatives (Castellano & Reading 2010).

Reading and Dean (2005) reveal the breadth of the Canadian Institutes of Health Research's commitment to Indigenous public health research following its launch when they outlined the activities of the Institute of Aboriginal People's Health. By 2005, five years after the formation of the Institute, the Canadian Institutes of Health Research Council oversaw the creation of eight healthcare research training centres to support the emerging research specialising in Aboriginal population health. These healthcare research training facilities receive advice from Aboriginal community advisory boards and operate as the organisational structure behind its network of trainees, researchers and community partners (Reading & Dean 2005). In this context of rising concern for Indigenous public health research, the Canadian Institutes of Health Research Council soon increased its care for Indigenous ethics.

In 2001, the Canadian Institutes of Health Research Council's Institute of First Nations, Inuit and Métis Health set a priority to influence the development of ethical standards for Indigenous Peoples (IAPH 2002). The Canadian Institutes of Health Research's formally encouraged this development when it established the Aboriginal Ethics Working Group in March 2004 (Bull 2010) to operate in parallel to the much slower moving

Tri-Council's Interagency Advisory Panel on Research Ethics committee (Kishchuch & Gauthier 2009).

The Canadian Institutes of Health Research's next move was to partner the Aboriginal Ethics Working Group with the Aboriginal Capacity and Development Research Environments (the Aboriginal Capacity and Development Research Environments is a university-based resource with links with academic researchers and First Nations, Inuit and Métis communities (CIHRC 2005)). The Canadian Institutes of Health Research engaged First Nations, Inuit and Métis political organisations directly and awarded five national Aboriginal organisations a total of \$111,000 to allow them to 'consult with their communities and build their positions (Kishchuch & Gauthier 2009, p. 41). Nation-wide consultations began with First Nations, Inuit and Métis communities and regional authorities and later extended to the academic community and relevant institutions (CIHRC 2005). The Canadian Institutes of Health Research ethics policy guidelines were drafted in 2005, followed by a second round in 2005–6 (Castellano & Reading 2010). Work on the final draft was completed in May 2007 (CIHRC 2007) and came into full use in the first round of Canadian Institutes of Health Research Council funding competitions beginning in July 2008 (Bull 2010).

The Canadian Institutes of Health Research's 2007 *CIHR Guidelines for Health Research Involving Aboriginal People* (2007 CIHR Guidelines) was 'groundbreaking' as it reflected the first nation-wide statement specific for medical and public health research within First Nations, Inuit and Métis communities. Castellano and Reading (2010) maintain that the Guidelines addressed key issues of Indigenous ethics such as protection of cultural knowledge, research partnerships, and collective and individual consent. In time, the significance of the Canadian Institutes of Health Research code would reach beyond the Canadian context as it inspired collaboration and communication between the Canadian Institutes of

Health Research and health research agencies in Australia, New Zealand and the United States (Castellano & Reading 2010).

Upon the release of the 2007 CIHR Guidelines, the Canadian Institutes of Health Research publically expressed a hope that it would contribute to the Interagency Advisory Panel on Research Ethics' process of revising its Indigenous chapter in time for the release of the next TCPS2 National Statement (CIHRC 2005). However, this public expression is contradicted somewhat by a private view of some Canadian Institutes of Health Research members that their work on the code had the effect of "subsidizing the research ethics development in Canada" (Kishchuch & Gauthier 2009, p. 41).

The reason why the Canadian Institutes of Health Research Council ethics policy could only 'inform' the TCPS Indigenous code is that it was designed singularly for medical and public health research. It would need revision to be relevant to the Tri-Council's vision of a national statement 'applicable to all human research'.

The ongoing work of the Tri-Council Interagency Advisory Panel on Research Ethics

As the Canadian Institutes of Health Research Council developed its guidelines in 2007, the Interagency Advisory Panel on Research Ethics continued its incremental progress towards the eventual creation of an Indigenous chapter designed for the next iteration of the TCPS national statement. The next significant move by the Aboriginal Research Ethics Initiative was to form, in November 2005, a Guiding Consortium tasked to engage with the development of the Indigenous chapter (PRE 2005).

The Consortium consisted of five members of 'core' national Aboriginal organisations (the Assembly of First Nations; Métis National Council; Inuit Tapiriit Kanatami; Native Women's Association of Canada; and the Congress of Aboriginal Peoples), and was augmented by the addition of

three council members representing each of the three councils. In time, an Interagency Advisory Panel on Research Ethics representative, and one or more tribal elder(s) would be added (Kishchuch & Gauthier 2009). It was the Guiding Consortium along with a further Interagency Advisory Panel on Research Ethics committee, the Technical Advisory Committee on Aboriginal Research, that guided the discussions around the new Indigenous chapter (Bull 2010).

The Guiding Consortium and Technical Advisory Committee on Aboriginal Research did not engage in further First Nations, Inuit and Métis community consultations but instead relied on the consultation processes that the Canadian Institutes of Health Research had already completed (Kishchuch & Gauthier 2009; Onyemelukwe & Downie 2011). Fundamentally, the task of the Guiding Consortium and Technical Advisory Committee was to reframe the medical and public health-based ethics policy into a form that would also prove acceptable to social science research communities.

In February 2008, the Guiding Consortium and Technical Advisory Committee on Aboriginal Research presented an exploratory report entitled *Research Involving Aboriginal Peoples in the TCPS* which laid out the key concerns of Indigenous ethics that it would need to address (PRE 2013). Key recommendations of the report included the following: explicit adaptation of 'Western' ethical principles to First Nations, Inuit and Métis contexts; allowing Indigenous representative bodies to define the nature of a given research consultation; and an acceptance that individual consent is needed in addition to community consent (2008, p. 21–2). A draft of an Indigenous chapter was then produced in the December 2008 TCPS2 national statement first draft (Bull 2010). From this point on, the drafts were exposed to the academic community and interested public through the Tri-Council consultation processes outlined in chapter 4.

One of the concerns raised during this consultation period was that there appeared to exist variances between the Canadian Institutes of Health Research ethics policy and the first draft of the TCPS2 national statement (AREI 2009). In response, Interagency Advisory Panel on Research Ethics established a harmonisation committee containing representatives from the three Councils, the Canadian Institutes of Health Research Institute of Aboriginal People's Health and the Canadian Institutes of Health Research Ethics Office to clarify points of convergence and resolve differences between the two ethics policy codes (Bull 2010). The Interagency Advisory Panel on Research Ethics released a second draft of the TCPS2 for public comment in December 2009 holding the time available for comments open until March 2010. In a pattern similar to the 1998 TCPS, the three Councils then penned the final edition of TCPS2 into its current form (Onyemelukwe & Downie 2011).

At the release of the 2010 TCPS2 guidelines, the Indigenous research chapter (9) superseded the Canadian Institutes of Health Research guidelines (Baylis & Downie 2012). From this point on, Canada possessed national ethics policy code for all human research operationalised within First Nations, Inuit and Métis communities.

Chapter 9 of the 2010 TCPS2 national statement

Chapter 9 of the 2010 TCPS2 national statement is the current ethics policy document for Indigenous ethics in Canada (the 2014 revision does not change the Indigenous chapter 9 (PRE 2014)). The first article of ethics policy defines when a researcher should engage with First Nations, Inuit and Métis communities as

Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants

belong, researchers shall seek engagement with the relevant community (Article 9.1).

The conditions necessary to affect welfare are further defined thus: when research is conducted on First Nations, Inuit and Métis lands; when the research criteria includes Aboriginal identity as a factor; when research seeks input from participants regarding a community's cultural heritage, artefacts, traditional knowledge or unique characteristics; when Aboriginal identity or community membership is an experimental variable; and when research interpretations refer to Aboriginal communities, peoples, language, history or culture (article 9.1, a – e).

When the above conditions are met, article 9.2 requires the researcher to proceed with community consultation in the following manner: The researcher is required to engage with First Nations, Inuit or Métis communities at the territorial, organizational and local levels; where it can be considered appropriate, representations of such communities should be placed on ethical review and oversight of projects and be in a position to participate in research design execution and interpretation.

Article 9.8 gives the researcher the responsibility to “become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research” (Article 9.8). This does not require the researcher to be fully versed in the communities' culture *per se*, but instead the more specific context of cultural norms as they pertain to research in such a community⁷.

Article 9.8 also asks the researcher to consider, where appropriate, to applying a collaborative and participatory research approach, which

⁷ An example of a First Nations guidelines for researchers can be found at: <http://ideas.repec.org/h/sls/repsls/v1y2001jh.html>.

would ideally culminate in the negotiation of a research agreement between the researcher and the community. With regards to possible discrepancies between institutional ethics policies and community customs and codes of research, the researcher has a duty to resolve this tension by either adapting conventional practice or negotiating a resolution.

While the above guidelines are intended to empower the community in its relationship with the researcher and research community, the Canadian guidelines do not view community authority as absolute. This can be seen when the guidelines stop short of giving communities the ability to block the publications of findings, preferring instead to view community input as “contextualizing the findings” (Article 9.17) of research. A further way the guidelines chart the end points of the authority of community structures (as they pertain to research) is when they require that the researcher make allowances for the needs of individuals and subgroups that may not have a voice in the formal leadership so as to ensure their participation in a relevant research project (article 9.6). Likewise, the guidelines allow for patterns of community engagement that do not necessarily align with the more formal authority structures listed in the paragraphs above (article 9.5). The guidelines do, however, give researchers working outside of accepted community authority structures reason for pause when it requires research to be conducted with an awareness of, and minimization of, the possibility of harm to the communities and individuals where research is undertaken that is critical of societal (Indigenous or otherwise) institutions (article 9.21).

When the Tri-Council released the 2014 TCPS2 version, it introduced the update cycle of rolling review, meaning that future sections of the document would be updated incrementally rather than reviewing the whole document after five or more years (PRE 2014). The decision to move to a rolling review method of document update suggests that the 2014

TCPS2 is considered a mature document unlikely to need major structural revision in future iterations. The likelihood, therefore, of a future removal of the Indigenous chapter appears remote.

Case study summary

The dominance of research oversight in Canada necessitated that advocates of Indigenous ethics policy development negotiate with the Tri-Council. Once the Tri-Council was convinced of the need to develop Indigenous ethics policy however, the bureaucratic strength of the Council worked to the advantage of this policy development. The centralised research oversight in Canada allowed the acceptance of separate Indigenous ethics policy by the Tri-Council to be mirrored across the oversight of all human research in Canada. The inclusive nature of the Tri-Council (as representing the three government funding councils) encouraged the ethical requirements of the Canadian Institutes of Health Research Council's Indigenous public health mandate to be leveraged in the development of the 2010 TCPS2 statement. There also existed an alignment between the ongoing development of Indigenous ethics outside of the TCPS to that within the structures of the Interagency Advisory Panel on Research Ethics. Both emphasised the sovereignty politics requirement of separate ethics policy designed for research that includes Indigenous participants. The current Tri-Council Indigenous ethics chapter in the 2014 TCPS2 is an outworking of these themes.

The development of Indigenous ethics in Canada produced robust ethics policy. Negotiated within the contexts of sovereignty aspirations and centralised research oversight structures code was produced that was stable over time; was developed with widespread Indigenous consultation; was updated over time; covered all human research; and expressed a requirement for research to engage with community consultation.

Case study II: Australia

6

The development of Australia's centralised national statement

The development of research oversight in Australia into a centralised institutional occurred in a gradual, rather than abrupt manner. Distinct from Canada, Australia's research oversight development resulted from the expansion of a single government-funded council, the Australia National Health and Medical Research Council (NHMRC). The NHMRC is similar to the Canadian Institutes of Health Research Council in that its role is to fund and oversee research to improve standards of individual and public health (NHMRC & RAWG 2002). The NHMRC produced its first ethics policy code in 1966 (NHMRC 2007) and gradually introduced the features of centralised research oversight such as a dedicated national oversight institution, ethics committees, a national statement for all human research, and a national standing committee. The release of the NHMRC's ethics policy for all human research, the 1999 *National Statement on Ethical Conduct in Research Involving Humans* (1999 NHMRC Statement), symbolised the culmination of this accrual of oversight mechanisms. Adhering to punctuated equilibrium ordering, this chapter traces the development of Australian research oversight from its first ethics policy in 1966 (NHMRC 2007) to its contemporary form as an institution displaying centralised research oversight. The following chapter tracks the negotiations between the sovereignty politics of Aboriginal and Torres Strait Islander ethics advocates and the centralised research oversight of the NHMRC.

Forming Australia's national oversight structures

The development of research oversight in Australia conforms to Haggerty's concept of ethics creep. Ethics creep refers to the growth of research oversight that expands outward to incorporate new activities and institutions, while intensifying its regulation activities (Becker 2004). Consistent with this theme, researchers describing the history of Australia's research oversight have variously used the words 'evolved', 'gradualist', and referred to the 'growth' of research oversight to explain its development (Chalmers 2001; Dodds 2000; Humphery 2002; Israel & Wales 2004).

The NHMRC produced its first ethics policy, the 1966 *Statement on Human Experimentation*, in reaction to the 1964 Declaration of Helsinki (NHMRC 2007). At this point, the statement did not make any reference to, or require ethics committee oversight (Humphery 2002). Instead, it simply suggested that 'appropriate consultation' should take place (McNeill 1993). This recommendation was sufficiently vague that McNeill suggested it probably meant "consultation between the doctor/researcher and his or her peers" (1993, p. 70).

The requirement to obtain peer assessment by experts was added in 1973 (Dodds 2000; Humphery 2002), followed by the 1976 creation of guidelines for Institutional Ethics Committees (later to be named Human Research Ethics Committees) (Chalmers, Dunne, Finlay-Jones, & Rayner 1996; Humphery 2002). Also in the 1976 *Statement on Human Experimentation*, the NHMRC altered its opening paragraph indicating that it would now be applicable to both medical and social research (Dodds 2000). The Statement did not reflect on how this inclusion of research other than medical might affect ethics policy (Israel & Wales 2004); instead, it simply included a reference to social science research within its framework (Humphery 2002). Significantly, despite the introduction of

these guidelines, oversight by ethics committees in Australia was still essentially voluntary (Chalmers 2001).

In 1982, the NHMRC required medical researchers to submit all research to ethics committees (then called Institutional Ethics Committees) (Humphery 2002), and maintained, for the first time, a national ethics committee charged with addressing emergent ethical concerns. The formation of the Medical Research Ethics Committee allowed the NHMRC to formally maintain ethics policy development and oversee the work of Institutional Ethics Committees in an ongoing fashion (NHMRC 2007, p. 1). Over the next nine years, the Medical Research Ethics Committee would take a formative role in the establishment and oversight of Australia's Institutional Ethics Committee system (Chalmers et al. 1996) and future ethics policy development (Chalmers 2001).

The NHMRC's growing concern for the needs of public health research would be felt in 1985 (McMichael 1986; NHMRC 2007) when it required that all research projects, not just medical research, submit to Institutional Ethics Committee review (Humphery 2002). McNeill recalled that this warning "has been sufficient for almost all committees to comply with the NHMRC's guidelines on committee composition" (1993, p. 75). These 1985 requirements led to the rapid establishment of over 100 Institutional Ethics Committees in Australia, a figure that would reach over 220 by 2005 (NHMRC, AVCC, & ARC 2013). The NHMRC did not capture all university research at this point, as organisations not funded by the NHMRC, such as university departments that focused on social science and humanities research, could avoid its ethics committees (Israel 2014).

In 1992, the Federal government released a new legislative framework for the oversight of medical and health research. The *National Health and Medical Research Council Act 1992* enforced a legislative reformation of the

NHMRC and introduced several features important to the development of research oversight in Australia. It validated the NHMRC's ongoing role in research oversight (sec 10, 1) and explicitly allowed it to withdraw, or refuse, funds to research that did not comply with its ethical guidelines (Walsh, McNeil, & Breen 2005). The Act also charged the reformation of the national ethics committee, the Australian Health Ethics Committee, to continue to develop ethics policy over time (sec 35, 3, (a & b)). In a strictly legislative sense, the requirement to produce health research guidelines did not preclude the possibility of universities or social science associations producing their own guidelines and REBs. However, the dominance that the NHMRC already enjoyed over REB boards, ethics policy and oversight expertise, made such a move all but impossible. In a practical sense, then, the release of the National Health and Medical Research Act 1992 legitimised the NHMRC as the dominant site for the oversight of human research ethics in Australia.

As in the case of the Canadian change from the Health Research Council to the Canadian Institutes of Health Research Council, the introduction of the NHMRC Act 1992 represented an explicit recognition of the needs of public health research in addition to those of medical. Section 3 (c) of the Act states that its object is to “foster medical research and training and public health research and training throughout Australia”. Section 4 of the Act defines public health research in a similar manner to that of this thesis when it states that public health research “includes the study of the health of a community or population for purposes directed at improving or protecting the health of that community or population” (sec 4).

The Australian Health Ethics Committee's release of an ethics policy document for all human research, the 1999 *National Statement on Ethical Conduct in Research Involving Humans* (1999 NHMRC Statement),

completed the NHMRC's gradual introduction of the features of centralised research oversight to Australia.

To justify the claim that research oversight in Australia developed in a gradual manner, it is helpful to note the Australian absence of three features that proved essential to the formation of the Canadian Tri-Council. First, Australian research oversight did not emerge in response to scandal. While there were examples of unethical research in Australia (Chalmers 2001; McNeill 1993), these experiments were not generally known to the public resulting in "almost no public concern with the issues of experimentation of human subjects" (McNeill 1993, p. 69).

Also missing in the Australian context during this period was the threat of government funding cuts for research. The Keating Labor government had promised to increase its spending by 2% during its run up to the election of 1991 (NHMRC 1993). This promised incremental increase would soon lead to growth in federal government medical and public health research spending in the years to come (Deloitte 2011; NHMRC 2015b). The Canadian research community's motivation by fear of funding loss is not relevant in the Australian context.

A third difference with Canada was that Australian social scientist research Councils were not directly involved in Australia's national oversight institution⁸. Similarly, there is no record in Australia of social scientists organising resistance to the national statement in the manner of the Canadian University Teachers Union. Gary Bouma, the chair of Monash Bioethics Standing Committee on Ethics Involving Humans (a university-based centre concerned with Australian research oversight) argued instead that resistance to the NHMRC National Statement's

⁸ The 1992 NHMRC Act makes no reference to a social science council. The Act does encourage social science expertise to be present on the AHEC board, but these individuals were included for their expertise and not as representatives of a council.

emanated from individual social science researchers who (in 1996) numbered 'very few' (Bouma & Diemer 1996, p. 11). A straightforward explanation for this lack of resistance is structural. Social scientists in Australia did not have recourse to an equivalent of the Canadian Social Science and Humanities Research Council to apply pressure. Unlike Canada, Australian social science researchers could not effectively lobby their social science committee (or indeed union) because none of these structures played an ongoing role in the development of Australia's research oversight structures. They simply had no place at the table. The Australian Research Council (a structure similar to the Canadian Social Science and Humanities Research Council) was created by the Australian Research Council Act 2001, three years after the 1999 NHMRC Statement required all social science research projects to be subject to its research oversight.

In the absence of these factors, Australia's research oversight developed within the structures of the NHMRC to its current form.

Australia's contemporary research oversight

Similar to Canada's Tri-Council, Australia's NHMRC developed centralised research oversight. The NHMRC therefore maintained its national statements for all human research (NHMRC 1999, 2014; NHMRC, ARC, & AVCC 2007), and has preserved its influence over ethics committees (now called Human Research Ethics Committees (NHMRC 2014, sec. 5)). The NHMRC's national ethics committee, the Australian Health Ethics Committee operates as the dominant standing committee responsible for ethics policy development (Chalmers et al. 1996; NHMRC 2015a).

Like the Tri-Council, the NHMRC's Australian Health Ethics Committee was distanced from day-to-day Ministerial oversight of its activities. Section 35 of the Act positions the Australian Health Ethics Committee to

advise and be responsible to the NHMRC, and not, by deduction, the Commonwealth Minister of Health (NHMRC Act, sec 35). Figure 3 (below) illustrates how the Australian context is similar to that of Canada, to the degree that the NHMRC's standing committee responsible for ethics (the Australian Health Ethics Committee), did not experience day-to-day Ministerial oversight. While the 1992 NHMRC Act requires the NHMRC to create ethics policy codes for health and medical research, the Australian Health Ethics Committee does not report directly to the Minister of Health.

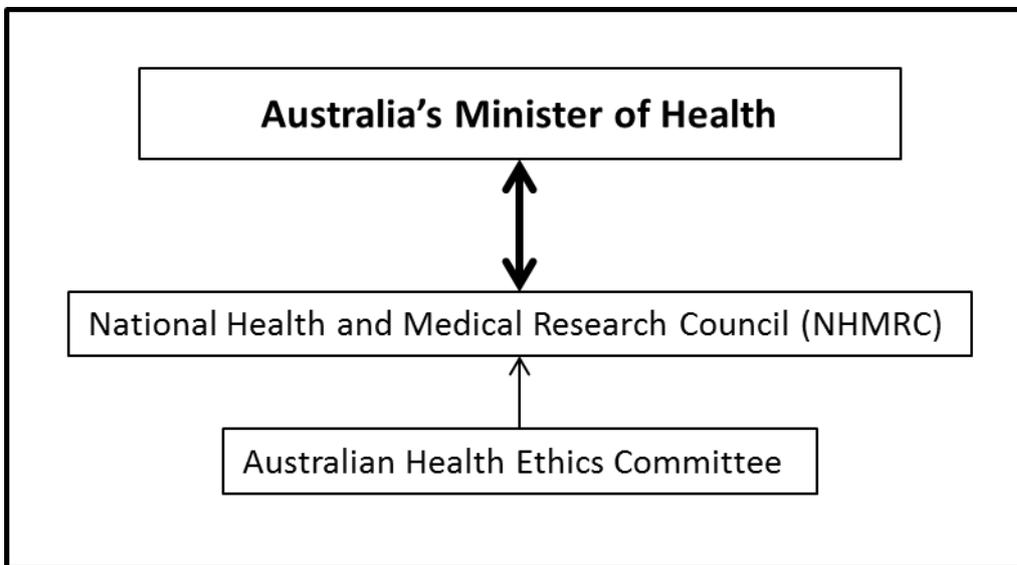


Figure 3, Ministerial distance from the Australian NHMRC

The relevance of the NHMRC to Indigenous ethics in Australia is found in its dominance over research oversight. Any research that is funded by, or takes place under the auspices of the NHMRC, the Australian Research Council, or any Australian university must submit to the NHMRC's research oversight (NHMRC 2014, pt. 2, p. 1). Similar to Canada's Tri-Council, the NHMRC's national ethics committee, the Australian Health Ethics Committee has proven capable of making its ethics policy development infrastructure available to minority research disciplines,

such as social science, as it created a national statement designed for all human research⁹. The formal inclusion of the Australian Research Council in the production of the 2007 NHMRC national statement is an example of this extension (NHMRC et al. 2007). These similarities suggest that if the NHMRC were to be convinced of the requirements of Indigenous ethics, its working committee structures could be used in the development of Indigenous ethics policy.

⁹ As it has developed ethics policy for all human research, the NHMRC's Australian Health Ethics Committee has contributed resources to the development of social science research ethics policy in addition to that of medical and public health research. The Australian Health Ethics Committee used its 'workshop days' held across Australia to consult (in this case) the social science research community (HREC 2000, 2001, 2001, 2004; NHMRC & Taverner Research 2002) and committed itself to consult with 'target stakeholder groups' about prominent issues, or issues where divergent views were presented by the submissions (NHMRC 2005). In the production of its 2007 national statement the NHMRC invited the Australian Research Council to join the Australian Health Ethics Committee in its development (HREC 2004, p. 2). The membership requirements of the Australian Health Ethics Committee also allowed engaged social science researchers to gain influence in the development of ethics policy in Australia (NHMRC Act 1992, sec, 4).

7

Negotiating Australia's sovereign Indigenous national guidelines

The similarities between the centralised research oversight and use of sovereignty politics in Canada and Australia suggest the likelihood of similar ethics policy outcomes. The NHMRC's production of separate ethics policy dedicated to research with Indigenous communities confirms this assumption. Despite these similarities in structure and outcome, less obvious differences between Canada and Australia ensured that Australia travelled an elongated journey to the development of separate Indigenous ethics policy. In contrast to the Indigenous ethics policy development in Canada, where the legitimacy of Indigenous ethics was accepted as the Tri-Council Working Group began its early drafting in 1994 (McDonald 2009), the NHMRC needed to be convinced of the importance of Indigenous ethics policy. The longstanding dominance of the NHMRC ensured that advocates of Indigenous ethics directed their attentions to the NHMRC to legitimise and form Indigenous ethics policy¹⁰. In addition, the medical and public health focus of the NHMRC (compared to the Tri-Council as representing all government-funded research) ensured that the concerns of Indigenous ethics were entwined with the provision of health services to Aboriginal and Torres Strait Islander communities.

¹⁰ The only exception to this focus on the NHMRC as the single instruction within which to develop ethics policy code is the production of the AIATSIS statements (Davis, 2010). The NHMRC made a single reference to the AIATSIS statements in the 1999 NHMRC Statement (NHMRC, 1999b, Chapter 9) but did not include the Australian Institute of Aboriginal and Torres Strait Islander Studies in its policy development.

The rise of Aboriginal and Torres Strait Islander health services

In 1971, the first Aboriginal and Torres Strait Islander community-controlled health service centre opened in Sydney (Copeman 1988). This development would prove internationally significant as it represented the first health service of its kind in the world (Burgmann 1993). In the following year, Australian Government initiatives would encourage further development of Aboriginal and Torres Strait Islander health services provision. Beginning in 1972, the Whitlam government adopted the term 'self-determination' as the key phrase to which they would ascribe Australian Indigenous affairs policy (Sanders 2004). The outworking of this change in policy is seen in contexts such as the Northern Territory. Here the State Department of Aboriginal Affairs replaced many Welfare Branch officers with community advisors who were employed by, and answerable to, local Aboriginal community organisations (Westbury & Sanders 2000)¹¹.

In the 1980s, funding to Aboriginal and Torres Strait Islander community-controlled health services increased significantly. In 1980/81, Commonwealth grants to such community health service organisations were \$5.97 million and by 1990/91 this figure had reached \$35.68 million (Anderson & Sanders 1996, p. 6). This represents a funding boost of almost 600% (not accounting for inflation). These funding increases allowed the continued growth of Aboriginal and Torres Strait Islander community health services organisations. By 1988, there were around 40 such organisations in Australia (Copeman 1988).

¹¹ A history of Aboriginal and Torres Strait public health development by the National Aboriginal Community Controlled Health Organisation (NACCHO) was a useful beginning point to commence this research. See: <http://www.naccho.org.au/about/aboriginal-health/history/>

It is vital to note here that the increase of Aboriginal and Torres Strait Islander health service provision represented government funding of health services, and not NHMRC involvement (Anderson & Sanders 1996). For its part, the NHMRC did not yet consult with Aboriginal and Torres Strait Islander communities about medical and public health research goals or the oversight of research ethics (Humphery 2002). Likewise, the NHMRC had not yet set aside dedicated funding for Aboriginal and Torres Strait Islander medical and public health research or identified Aboriginal and Torres Strait Islander medical and public health research as a strategic area of concern (National Health Working Party 1989).

The relevance of the rise in Indigenous health service funding to the NHMRC was that it allowed capacity building of Aboriginal and Torres Strait Islander health service providers, who would later influence the NHMRC. For many of those who were actively involved in Aboriginal and Torres Strait Islander community health service organisations, the provision of health care in such a manner did not simply reflect an effective service model, but an expression of sovereignty politics. Hunter (2001) argued this point when noting that many of the community facilitators were committed to the ideals of Indigenous rights and community empowerment.

In 1986, Australia's NHMRC found that this growing Indigenous health services workforce demanded increased control over its Aboriginal and Torres Strait Islander medical and public health research priorities. By extension, this demand required that research involving Indigenous communities have concern for the requirements of Indigenous ethics. The pivotal point was the 1986 Alice Springs conference.

The Alice Springs conference and the first Indigenous ethics code

In November 1986, the NHMRC co-organised a three-day conference to consider 'research priorities to improve Aboriginal health' (Humphrey 2002 P.14)¹². It was at this conference that the differing understandings of how to determine Aboriginal and Torres Strait Islander medical and public health research priorities was brought to a head. On one hand, NHMRC-funded researchers assumed that research priorities could be decided on the basis of available health data; on the other hand, Aboriginal and Torres Strait Islander delegates questioned why non-Aboriginal researchers could decide the research priorities of communities they had not explicitly consulted (Humphery 2002).

On the final day of the conference

... the non-Aboriginal conference delegates were, for a time, silenced and made the target of sustained critique...by Aboriginal delegates [who] took control of part of the agenda and redirected the attention of the conference delegates to issues connected with the politics and process of research (Humphery 2002, p. 16 & 27).

The Alice Springs conference marked a point when the NHMRC came to realise that Aboriginal community consultation would now be a fundamental cog in any future ethics policy writing process. NHMRC representative Elizabeth Grant recalls this realisation

... boy it gave us the idea that we weren't going to write things like guidelines quickly. We weren't going to write them ourselves,

¹² Humphrey's oral history of the conference can be found at: Humphery, K. (2002). *The development of the National Health and Medical Research Council guidelines on ethical matters in Aboriginal and Torres Strait Islander health research: A brief documentary and oral history* (pp. 1–43).

without lots of consultation and we weren't necessarily going to get them accepted very quickly... (Elizabeth Grant cited in: Humphery 2002, p. 31).

Subsequent to this challenge, the NHMRC made available resources to develop Indigenous ethics policy. In the following year, this process commenced with a three-day workshop that gathered approximately 30 Aboriginal community representatives and two NHMRC observers (Weijer 1999) to develop further the 87 recommendations of the Alice Springs conference (Humphery 2002). In July 1988, (in the second stage of the writing processes) the NHMRC responded with the release of *Some Advisory Notes on Ethical Matters in Aboriginal Research* (Advisory Notes) (MREC & NHMRC 1988). Ross Kalucy and Elizabeth Grant of the Medical Research Council were responsible for writing the Advisory Notes, with the inclusion of notes from a report of the latest workshop (Humphery 2002). Around the time of the release of the Advisory Notes, the NHMRC's Medical Research Ethics Council initiated a second programme of consultation. The Council formed a working party containing two Aboriginal representatives and one non-Indigenous researcher to fill this task (Humphrey 2002).

After three years of consultation, the NHMRC released the 1991 *Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* (1991 Interim Guidelines). The production of the 1991 Interim Guidelines provided the NHMRC with its first ethics policy code dedicated to Aboriginal and Torres Strait Islander medical and public health research. It included four significant advances

The expectation that researchers will consult with Aboriginal communities and institutions;

An anticipation that the research should benefit such communities;

An assumption that community involvement will extend throughout the research project; and,

A requirement that data and outcomes should be reported to the communities in question (Maddocks 1992).

This call was similar to the demands of sovereignty politics in Canada. Both were concerned that Indigenous communities gain consultation rights where research projects are conducted on Indigenous lands or involve Indigenous individuals as participants.

Concurrent to these trends in Indigenous ethics, support for a national strategy for Aboriginal and Torres Strait Islander health was also building in a manner that would add support to Indigenous ethics in Australia.

The 1989 National Aboriginal Health Strategy

In December 1987, the Commonwealth, State and Territorial Ministers for Aboriginal Affairs and Health met to consider agreeing to a common approach to Aboriginal health services and recommended the establishment of a National Aboriginal Health Strategy Working Party (National Health Working Party 1989). The Working Party commenced its task in April 1988, and in January 1989 produced the *National Aboriginal Health Strategy*.

The report began by noting that until this point there had been no agreed national Aboriginal health strategy, or the necessary coordinating mechanisms between the various arms of Federal and State government, or indeed agreed ways to measure any such strategy. Importantly, the 1989 National Aboriginal Health Strategy nominated the NHMRC as the body responsible for Aboriginal and Torres Strait Islander medical and public health research when it stated of the NHMRC that it

... remains the most appropriate and effective body to promote and administer the necessary research while providing the safeguards for the Aboriginal community which the working party considers essential (National Health Working Party 1989, p. 212).

To this end, the 1989 National Aboriginal Health Strategy recommended that the NHMRC solidify its support of research into Aboriginal and Torres Strait Islander medical and public health by setting aside a fixed proportion of their research monies in their yearly budget (National Health Working Party 1989).

The 1989 National Aboriginal Health Strategy explicitly linked the relevance of Indigenous ethics to improvements in the health of Aboriginal Torres Strait Islander peoples when it provided a separate chapter on 'Aboriginal health research' (1989, p. 200–214). This chapter mirrored many of the concerns raised in the Alice Springs Conference when it argued that much health research 'on' Aboriginal communities to date has been invasive, extractive, and has given little or no benefit to the communities themselves (National Health Working Party 1989).

The lasting impact of the 1989 National Aboriginal Health Strategy was that it represented an early articulation of the separate medical and public health needs of Aboriginal and Torres Strait Islander peoples in a dedicated document (and not as a subpopulation of larger national health concerns). This allowed it to concentrate solely on the specific concerns of Aboriginal and Torres Strait Islander communities as they, and not the NHMRC, defined them. Recognising this focus, the National Aboriginal Community Controlled Health Organisation called the 1989 National Aboriginal Health Strategy a "... landmark document that set the agenda for Aboriginal health and Torres Strait Islander health...that is extensively

used by health services and service providers, and continues to guide policymakers” (NACCHO 2013, para. 4).

The release of the 1989 Aboriginal Health Strategy and the 1991 Interim Guidelines gave support to the visibility of Indigenous ethics in Australia. Even as these gains were made, however, the NHMRC was not yet ready to respond significantly to the 1991 Interim guidelines for two reasons. First, the NHMRC was then ambivalent towards Indigenous ethics. The position of the 1991 Interim Guidelines as endorsed, but not ratified by, the NHMRC (Humphery 2002) undermined the position of the Guidelines. The non-inclusion of the 1991 Interim Guidelines as a Supplementary note in its 1992 NHMRC statement theoretically allowed Institutional Ethics Committees to ignore the 1991 Interim Guidelines.

Second, the recommendations of the National Aboriginal Health Strategy 1989 were almost entirely ignored (Australian Government Department of Health 1994). The NHMRC’s lack of progress on the 1989 National Aboriginal Health Strategy left it ill-equipped to consider the medical and public health research needs of Aboriginal and Torres Strait Islanders. Specifically, the NHMRC had not made significant progress on the measurement of Aboriginal and Torres Strait Islander health (NHMRC 2014b), nor had it allocated a fixed spending allowance on Aboriginal and Torres Strait Islander medical and public health research (NHMRC 2003b). Furthermore, it had not yet created a framework within which it could respond to Aboriginal and Torres Strait Islander-derived research agendas, nor had it designated Aboriginal and Torres Strait Islander medical and public health research as an area of strategic concern.

An explanation of the less-than-wholehearted NHMRC early response to Indigenous ethics and Aboriginal and Torres Strait Islander medical and public health research is found in the shape of the National Health and Medical Research Act 1992. The Act itself charged the NHMRC to improve

Australia's health through research in a generic fashion that did not contain direct reference to Aboriginal and Torres Strait Islander Australians. As the 1989 National Aboriginal Health Strategy pointed out (National Health Working Party 1989), Aboriginal and Torres Strait Islander health would require direct identity-specific intervention, but the demands of the Act encouraged the NHMRC to consider Aboriginal and Torres Strait Islander medical and public health through the prism of national goals.

The first meeting of the NHMRC in 1993 following the establishment of the National Health and Medical Research Council Act 1992 was an opportunity for the NHMRC to outline how it would outwork its new legislative mandate. This meeting, as recorded in the *Report of the 115th session*, reflected a pattern that would repeat until the production of the 1999 NHMRC Statement: the NHMRC would persist with policies that obscured the research needs of Aboriginal and Torres Strait Islanders behind national goals and multicultural policies; and in reaction, pressure would be applied to address this lacuna.

In the field of ethics policy, the Australian Health Ethics Committee behaved in a manner consistent with Canada's Tri-Council Working Group when it demonstrated preference for multicultural over sovereignty Indigenous ethics frameworks. Australian Health Ethics Committee reported to the *Report of the 115th session* that it had co-sponsored a conference concerned with the ethics of health service resource allocation for 'minorities'. The speakers were "representatives of or associated with Aboriginal, Greek and Vietnamese communities, and survivors of torture and trauma" (NHMRC 1993, p. 25)¹³. The *Report of the 115th session* also

¹³ Reports of the NHMRC meetings can be found at http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/sess115.pdf

confirmed the NHMRC to be well advanced in the development of National Health Goals and Targets (NHMRC 1993). As of 1993, four areas of health concern had been chosen: cardiovascular, cancers, mental health and injury. Each of these four areas of concern had already been assigned an 'implementation group' that would be overseen by a joint working group of the Australian Health Ministers Advisory Council and the NHMRC.

Consistent with the pattern outlined above, the *Report of the 115th session* recalled that the Federal Minister for Health commented directly to the session regarding the comparative invisibility of Aboriginal and Torres Strait Islander medical and public health research and urged the NHMRC Council members to raise its profile (NHMRC 1993, p. 43). The session also reported that its four areas of health concern had been criticised as narrowly defining public health in a way that obscured other key health inequalities in Australia such as Aboriginal and Torres Strait Islander health status (NHMRC 1993, p. 11–12).

Even as these concerns were raised, the NHMRC proceeded to concentrate on national health goals and multicultural groupings. The drive to formulate national health goals maintained a high profile in the production of the 1994 *Better Health Outcomes for Australians: National Goals, Targets and Strategies for Health into the Next Century* report. The report would maintain the four priority health areas highlighted in the 115th session (cardiovascular disease, cancer, injury, and mental health) and assign over 140 indicators to measure progress over the whole of Australia (Mitchell & McClure 2006). The NHMRC and the Commonwealth Department of Human Services and Health would continue with the 'four health areas' framework until at least 1998 (AIHW 1998).

Consistent with the overall multicultural ideals of the NHMRC, the NHMRC's Australian Health Ethics Committee was uncomfortable with a singular grouping of Australia's Indigenous peoples for the purposes of

research oversight. It was a decision that they apparently would not have made if given the choice. Dr Donald Chalmers, then chair of the Australian Health Ethics Committee, would later take pains to note that the Australian Health Ethics Committee inherited the 1991 Indigenous Guidelines and insisted that a consensus had hardly been reached regarding the need for Indigenous research guidelines when he stated

The [1991] Interim Guidelines were introduced by the NHMRC in 1991 before the establishment of the Australian Health Ethics Committee. During the public consultations, differences were expressed in this area. Some submissions expressed satisfaction with the existing Interim Guidelines, others suggested new Guidelines and others suggested that the proposed principles on research involving collectivities were sufficient to include Aboriginal and Torres Strait Islander people (Chalmers 2001, p. A-29).

This view was mirrored in the Australian Health Ethics Committee's next major report on the oversight of research in Australia entitled *Report of the Review of the Role and Functioning of Institutional Ethics Committees* (Report of the Review).

In March 1996, the Australian Health Ethics Committee released the Report of the Review in which Dr Donald Chalmers had operated as review chair. The Report of the Review recommended that a revised NHMRC National Statement incorporate the principles of the 1991 Aboriginal and Torres Strait Islander Statement into a collectivities chapter (Chalmers, Dunne, Finlay-Jones, & Rayner 1996). The idea behind the collectivities chapter was borrowed from Canada and could include ethnic groups, Aboriginal and Torres Strait Islander communities, religious groups, and other forms of associations such as local community garden organisations (Chalmers et al. 1996).

Following the release of the Report of the Review, the Australian Health Ethics Committee began work on what would become the 1999 NHMRC Statement. However, during the same period when the Australian Health Ethics Committee persisted with its four health targets and multicultural ethics frameworks (AIHW 1998), increasing pressure came to bear on the NHMRC for its lack of concern for the needs of Aboriginal and Torres Strait Islander medical and public health research.

The 1994 *National Aboriginal Health Strategy: An Evaluation* was produced by the Australian Government Department of Health (the NHMRC operated at this time as a department within the Department of Health) and explicitly evaluated the outcomes of the 1989 National Aboriginal Health Strategy. Given that the Minister of the Department of Health had already asked the NHMRC to concentrate more resources on Aboriginal and Torres Strait Islander medical and public health research, this evaluation can be taken as evidence of increased central government concern for Aboriginal health services.

The evaluation report produced damning evidence of the lack of progress since the 1989 National Aboriginal Health Strategy and it bluntly informed its readers that

The committee established to evaluate the National Aboriginal Health Strategy found little evidence of it. Instead, the Committee found only traces of where the strategy had been – small amounts of money (compared with the need) spent on housing and health services. It found minimal gains in the appalling state of Aboriginal health (Australian Government Department of Health 1994, p. 2).

The evaluation report restated the need for an acceptance of Aboriginal people's holistic view of health and recognised the importance of sovereignty politics ideas such as Aboriginal community control and

participation in the facilitation of health services. It also urged Commonwealth, State and Territorial governments to cooperate in partnership with Aboriginal and Torres Strait Islander peoples (Australian Government Department of Health 1994, p. 2).

The evaluation report argued further that failure to address the ongoing poor overall health of Australia's Aboriginal and Torres Strait Islander populations would come at the risk of international ridicule. The executive summary cited the upcoming Sydney Olympic Games in 2000 and the Centenary of Australia's Federation in 2001 as potential points where the poor health of Aboriginal and Torres Strait Islander Australian's could be unmasked to the world when it stated

Unless governments deliver on their commitments to address Aboriginal and Torres Strait Islander human rights the 'celebration' will be marked with international condemnation (Australian Government Department of Health 1994, p. 2).

Evidence of the NHMRC's increased consideration of the needs of Aboriginal and Torres Strait Islander health following such critiques was provided two years later at the release of its own reports undertaken to review its support of national health advancement (James, Shilton, Lower, & Howat 2001). Importantly, this review of national health advancement would maintain separate reports dedicated to the health of Aboriginal and Torres Strait Islander health alongside national health considerations. This resulted in the production of two reports released in December 1996: *Promoting the health of Australians: Final report* (NHMRC 1996) and the *Promoting the health of Indigenous Australians: a review of infrastructure support for Aboriginal and Torres Strait Islander health advancement* (NHMRC 1996).

The *Promoting the health of Indigenous Australians* report highlighted fundamental infrastructure inadequacies that undermined the health of

Aboriginal and Torres Strait Islander populations (NHMRC 1996). In keeping with the 1989 National Aboriginal Health Strategy and the 1994 evaluation, the report advocated for sovereign Aboriginal and Torres Strait Islander community development and control over health services and insisted that

... all the structures and programs that are developed to promote the health of Australians must be sensitive to the needs of, and develop the capacity to work effectively with Aboriginal people and Torres Strait Islander people (NHMRC 1996, p. xix).

The release of the 1996 report reflected the third report in seven years to criticise the performance of the NHMRC's concern for Aboriginal and Torres Strait Islander medical and public health research.

It was within this context of sustained critique that the NHMRC produced its first substantive change designed to focus on Aboriginal and Torres Strait Islander medical and public health research. It formed, in 1997, the Aboriginal and Torres Strait Islander Research Agenda Working Group (NHMRC 2002). The initial work of the Group was not concentrated on the development of ethics policy but rather on developing broad strategic approaches to research funding for Aboriginal and Torres Strait Islander public health (NHMRC 1999a). While this work would eventually inform the NHMRC's Indigenous ethics policies, Aboriginal and Torres Strait Islander Agenda Working Group did not directly influence the drafting of the 1999 national statement.

Given the growing concern by the NHMRC for the needs of Indigenous medical and public health research, the position of the Australian Health Ethics Committee that the collectives chapter could be an appropriate means to include the needs of Aboriginal and Torres Strait Islander medical and public health research ethics policy appeared increasingly problematic.

Decoupling the collectives chapter from the 1999 national statement drafts

The first point of resistance to the collectivities chapter emerged during the Australian Health Ethics Committees consultation process. Here advocates of Aboriginal and Torres Strait Islander research would argue against the use of the collectivities framework (NHMRC 1998) whose needs were deemed distinct from those of other collectives. A later reaction to the NHMRC's grouping of Aboriginal and Torres Strait Islander communities with other communities responded in the following way

The issue seems to be whether Aboriginal and Torres Strait Islander peoples are to be treated in the same way as other population groups in the National Statement, as another subsection like 'research involving children and young people' (3.2), or 'research involving people highly dependent on medical care'... Aboriginal and Torres Strait Islander peoples have specific rights and needs in relation to research. Those rights and needs are derived from the history of research in Australia, and the history of colonisation. (VicHealth 2004, p. 1).

Not only did Aboriginal and Torres Strait Islander communities and researchers reject the notion of their inclusion in the collectivities chapter but also they made it clear that these ethical oversight codes should be formed in a separate but complementary ethics policy document (Israel 2015).

The impact of these sovereignty politics demands was furthered as they coincided with increasing central government concern for Indigenous public health research. The three reports all demanded that the NHMRC be sensitive to the needs of, and work effectively with, Aboriginal and Torres Strait Islander communities. As the NHMRC became increasingly concerned with Aboriginal and Torres Strait Islander medical and public health research (symbolised by the 1997 formation of the Aboriginal and

Torres Strait Islander Research Agenda Working Group), the need to draw from ethics policy dedicated to the needs of Aboriginal and Torres Strait Islander medical and public health research came into focus.

In September of 1998, the Australian Health Ethics Committee reported to the NHMRC that it had been convinced by the arguments of Aboriginal and Torres Strait Islander communities and researchers. It proposed that

... rather than trying to encompass the complex issues of research in Aboriginal and Torres Strait Islander communities in a separate section of the Statement, there should be a separate document. Through the consultation process a number of clearly expressed opinions and profound ideas from Aboriginal people have been expressed. AHEC has now commenced a process of drafting a separate document (NHMRC 1998, sec. 13, paragraph 4).

The decision to create a distinct document and drafting process for Aboriginal and Torres Strait Islander research would have ramifications as to where Indigenous research policy would be formed in the NHMRCs ethics policy frameworks. From this point on (at the time of writing), the responsibility for drafting this external Aboriginal and Torres Strait Islander research policy framework would sit outside of the NHMRC's national statement working party committees. All national statement working party efforts at creating applicable research policy ceased at this point.

The timing of the decoupling of Indigenous ethics from the communities chapter left insufficient time to include Indigenous ethics policy that had benefited from the Aboriginal and Torres Strait Islander consultation. Similar to Canada, when the NHMRC released its 1999 national statement it contained a chapter that did not include formal ethics policy code similar to the rest of the national statement. Instead, it required that

researchers consult the 1991 Interim Guidelines and added that “These guidelines will be revised by a working group which includes indigenous representatives” (NHMRC 1999b, p. 32). The inclusion of the chapter in the 1999 NHMRC Statement symbolised a shift in the commitment of the NHMRC towards the needs of Aboriginal and Torres Strait Islander research.

Increasing NHMRC commitment to Aboriginal and Torres Strait Islander medical and public health research

Following the release of the 1999 NHMRC national statement, the focus of the NHMRC shifted from a concern over what the NHMRC had not done (in relation to Aboriginal and Torres Strait Islander health) to what the NHMRC (in consultation with Aboriginal and Torres Strait Islander communities) had agreed to do.

In October 2002, the NHMRC decided, for the first time, to invest at least 5% of its funding specifically for Indigenous medical and public health research (Secretariat Australia 2012). In a context of rising government spending on research, this decision led to a dramatic increase in the funds available for Aboriginal and Torres Strait Islander medical and public health research, rising from just over \$4 million in 2000, to more than \$25 million in 2007 (NHMRC 2007a, p. 16). By 2014, this funding had risen to \$44 million dollars in 2013 (NHMRC 2014a), a rise of 1,100% between 2000 and 2014. Correspondingly, the number of active research awards rose from 50 to 125 between the years 2000 and 2007 (NHMRC 2007a, p. 16). Similar to Canada, a commitment by the NHMRC to dedicate resources to Aboriginal and Torres Strait Islander medical and public health research created conditions that encouraged it to eventually increase its investment in Indigenous ethics.

In 2001, the Aboriginal and Torres Strait Islander Agenda Working Group began consultations with Aboriginal and Torres Strait Islander communities with the purpose of “gain[ing] consensus on national priorities in Aboriginal and Torres Strait Islander health research” (NHMRC & RAWG 2002a, p. v). The Road Map would take pains to note that the majority of Aboriginal and Torres Strait Islander Research Agenda Working Group members were of Aboriginal and Torres Strait Islander identity (NHMRC & RAWG 2002a).

The Aboriginal and Torres Strait Islander Research Agenda Working Group consulted with Aboriginal and Torres Strait Islander communities, researchers, health service delivery and policy-makers, in all totalling more than 250 people (NHMRC & RAWG 2002a). In addition, 23 organisations put forward submissions through their consultation-based process (NHMRC & RAWG 2002b). The final production of the Road Map was endorsed by NHMRC in October 2002 and was intended to form the basis of the NHMRC’s strategic plan to increase its support for Aboriginal and Torres Strait Islander medical and public health research (NHMRC & RAWG 2002b), a commitment that the NHMRC would later endorse (NHMRC 2007a). The Road Map is found in two documents that are intended to be read together: *The NHMRC Road Map: Strategic framework for improving Aboriginal and Torres Strait Islander Health through research*, and the *Final report of community consultations on the NHMRC Road Map*.

Having completed the Road Map document, the NHMRC now possessed a framework that intended to align the aspirations of Aboriginal and Torres Strait Islander communities and the NHMRC’s requirement under the NHMRC Act 1992 to issue ethics policy guidelines and advise the government on matters relating to the improvement of the health of Australia’s population. Regarding the ethical oversight of such research, the Road Map explicitly gave the NHMRC the burden to “issue guidelines

on ethical issues relating to human research involving Aboriginal and Torres Strait Islander people” (NHMRC & RAWG 2002b, p. 2).

Given this focus by the NHMRC on the needs of Aboriginal and Torres Strait Islander medical and public health research, and the presence of an Indigenous chapter in the 1999 NHMRC national statement, it is not surprising that its national ethics committee, the Australian Health Ethics Committee, now embraced the development of Indigenous ethics. In 2001, the Australian Health Ethics Committee reflected this commitment by making a firm commitment to update the guidelines (HREC 2001).

The creation of the Indigenous 2003 Values and Ethics guidelines

The Australian Health Ethics Committee approached VicHealth Koori Research and Community Development Unit (VicHealth Koori) in early 2001 with a view to involving them in the process of consultation for the new guidelines (Humphery 2002). VicHealth Koori is a research centre dedicated to supporting Indigenous health (Anderson 2002).

VicHealth Koori accepted this invitation and, in January 2002, compiled an annotated bibliography that would form the ideological basis of the new Indigenous ethics policy (McAullay, Anderson, & Griew 2002). This document, *The Ethics of Aboriginal Research: an Annotated Bibliography* (2002) considered over 100 journal articles or reports directly referencing research in Indigenous communities. The authors found that the majority of the literature reinforced the concerns of the 1991 Indigenous guidelines such as consultation, community involvement, consent and appropriate dissemination of research findings. In June 2002, Aboriginal and Torres Strait Islander Research Agenda Working Group organised a two-day workshop that involved Aboriginal and Torres Strait Islander representatives. It is here that the attendees moulded the frames

introduced by the VicHealth Koori annotated bibliography into a first draft (HREC 2002).

In late 2002, the NHMRC released a document entitled *Draft Values and Ethics in Aboriginal and Torres Strait Islander Health Research* with the intention that this framework would eventually replace the 1991 guidelines (Gillam & Pyett 2003). By March 2003, consultation on the draft guidelines was completed. The Aboriginal and Torres Strait Islander Research Agenda Working Group then compiled the final draft that was then unanimously endorsed by the NHMRC in June of 2003 (HREC 2003). As its name suggests, the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research 2003* (2003 Values and Ethics) is an ethics policy document concerned with Indigenous medical and public health research ethics. In keeping with the earlier Aboriginal and Torres Strait Islander demands, 2003 Values and Ethics is aligned to, and given the same status as the 1999 NHMRC national statement (NHMRC 2006). The release of the 2003 Values and Ethics document represented an important victory in the visibility of Aboriginal and Torres Strait Islander research ethics. It was the first Indigenous ethics policy formed with the benefit of extensive Aboriginal and Torres Strait Islander consultation.

As a distinct ethics policy document, the 2003 Values and Ethics was not required to conform to the structure of the NHMRC Statements. Seizing this opportunity, the 2003 Values and Ethics chose not to include substantive ethics policy code and opted instead for a thematic format (NHMRC 2003a, p. 5). The guidelines used prose to explain and defend its overarching goal: the 'elimination of difference blindness' (p. 4, 5, 11, 14 & 19). From this cornerstone, the guidelines argued that Aboriginal and Torres Strait Islander communities should enjoy research conducted on terms sensitive to their cultural values and principles.

Because 2003 Values and Ethics was intended for the oversight of medical and public health research, social science researchers did not at this point have access to ethics policy relevant to their research paradigms. For this inclusion, researchers would have to wait until the 2007 NHMRC Statement.

The 2007 national statement Indigenous chapter development

When the NHMRC Working Party released its first consultation draft in December 2004, it did not contain any reference to non-medical or public health research (unlike the 2003 Values and Ethics ethics policy, the 2007 NHMRC Statement was produced within the national NHMRC working party structures). Submissions to the first draft were quick to point out that this left social science researchers without an adequate oversight framework if they were to conduct research with Aboriginal and Torres Strait Islander communities (Academy of Social Sciences in Australia 2004; Australian Academy of the Humanities 2005; Davey 2005; McEachern 2005). In response, the NHMRC Working Party introduced actual ethics policy code into its Aboriginal and Torres Strait Islander research chapter. Importantly, the Working Party did not consult Aboriginal and Torres Strait Islander communities but instead adapted the NHMRC's 2003 Values and Ethics framework for use on non-health research (Cordner 2006). The second draft contained a two-page introduction and penned 11 policy points distilled from the guidelines (NHMRC, ARC, & AVCC 2006). After receiving public feedback on the second draft, the National Statement Working Party created the final form of the new NHMRC National Statement (2007) (NHMRC 2007b).

In this final form, the National Statement (2007) contained an Aboriginal and Torres Strait Islander research chapter for non-medical or public health research. Compared to the 2003 Values and Ethics guidelines the National Statement (2007) Aboriginal and Torres Strait Islander chapter is

notable for its brevity (the Aboriginal and Torres Strait Islander peoples chapter stretches to 2 ½ pages) and the fact that it contains 12 points of policy code. Unlike the 2003 Values and Ethics, chapter 4.7 mirrors the format of the larger 2007 NHMRC statement and produces ethics policy code in its formalised structure.

Upon the release of the National Statement (2007), all research projects involving Aboriginal and Torres Strait Islander communities could access NHMRC endorsed policy code. The 2003 Values and Ethics for medical and public health research, and chapter 4.7 of the 2007 NHMRC Statement for non-health research have not reconciled in the manner of the single chapter 9 of the Canadian TCPS2 code. However, as chapter 4.7 was developed directly from the 2003 Values and Ethics document, they share positions on key ethics policy points, despite each preferring different formats and word choice.

Both the 2003 Values and Ethics document and the chapter 4.7 require that researchers engage with Aboriginal and Torres Strait Islander collectives throughout a research project (sec 2.2.5 & sec 4.7.2), and seek a fair distribution of research benefit between the research project and Aboriginal and Torres Strait Islander communities (sec 2.2.3 & sec 4.7.8 – 9). Both ethics policy documents also take care to emphasise the importance of valuing the uniqueness of Aboriginal and Torres Strait Islander communities in research (sec 2.2.5 & sec 4.7.1). As to when a research project should consider community consultations, both documents require community consultation where research is related to a health burden relevant to Aboriginal and Torres Strait Islander communities (sec 2.2 & 4.7.6b). Chapter 4.7 further adds to this by requiring consultation when research is conducted on a geographical location where a significant number of the research participants are likely to be Aboriginal and Torres Strait Islanders (sec 4.7.6a).

Case study summary

The development of Australian Indigenous ethics benefited from the centralised research oversight of the NHMRC as it allowed the acceptance of separate Indigenous policy to gain nationwide authority. This acceptance by the NHMRC did not come easily. Nevertheless, change was furthered by an alignment between Ministry of Health concern for the profile of Aboriginal and Torres Strait Islander public health research, the calls of Aboriginal and Torres Strait Islander health service providers, and reports such as the 1989 Aboriginal and Torres Strait Islander Health Strategy. All of these agitations encouraged the development of separate structures in line with sovereignty political strategies.

The production of Indigenous ethics policy in Australia as encouraged by sovereignty aspirations and centralised research oversight structures produced code that proved stable over time, was developed with widespread Indigenous consultation, updated over time, covered all human research and expressed a requirement for research to engage with community consultation.

The final case study examines New Zealand's use of bicultural politics within the context of research oversight that were fragmented across multiple institutions.

Case study III: New Zealand

8

Forming New Zealand's fractured research oversight

Unlike Canada and Australia, New Zealand's research oversight did not form a national oversight institution responsible for the maintenance of ethical standards in all human research. Instead, government responses to the Associate Professor Green research scandal punctuated the development of research oversight in New Zealand and encouraged the formation of multiple institutions. Each of these oversight institutions created differing spheres of research oversight: the Ministry of Health produces ethics policy for medical and health research (NEAC 2012b, 2012d) and also maintains guidelines for its Health and Disability Ethics Committees (HDEC 2012d). The Health Research Council maintains oversight over medical and health research by deciding which research projects to fund (Collins 1992; Douglass 1993), while its Ethics Committee accredit Health and Disability Ethics Committees, and six of the eight university ethics committees (HRCEC 2013). Each of New Zealand's eight universities, possess unique ethics policy and oversight institutions (Tolich & Smith 2015). Consistent with the form of the Canadian and Australia case studies, this chapter orders this history according to punctuated equilibrium organisation and traces the destabilising effect of the Associate Professor Green research scandal on New Zealand's research oversight and its reactive reformation into multiple regimes. Chapter ten tracks the negotiations between bicultural politics and New Zealand's fractured regimes of research oversight.

One of the ironies of the development of research oversight in New Zealand is that before its radical restructuring following the 1987 Associate Professor Green research scandal, New Zealand research

oversight shared broad similarities with Australia. Like Australia, the New Zealand Medical Research Council initially focused on ethics policy designed for medical research and later expanded to include ethics committees, public health research, and a national ethics committee.

New Zealand began to take an interest in research oversight following the 1964 Declaration of Helsinki (Douglass 1993)¹⁴. In 1968, New Zealand's Medical Research Council resolved to make compliance with the Declaration a condition of its financing of future research (Collins 1992; Douglass 1993). In 1969, the Medical Research Council produced its first ethics policy in the handbook *Projects, Grants and Awards* (Collins 1992), and the later MRC Handbook (the ethics policy of the former was reproduced in the latter). Both documents were periodically updated (MRC 1986). By the early 1970s, New Zealand hospital boards began to introduce ethics committees into their oversight regimes (Chalmers, Dunne, Finlay-Jones, & Rayner 1996). In 1972, the Medical Research Council recommended that the Ministry of Health require major hospitals to set up ethics committees "capable of judging the ethical implications of research proposals" (Collins 1992, p. 134). Until 1993, the Ministry of Health was called the Department of Health. As this name change has no bearing on this thesis, the name Ministry of Health is maintained throughout this chapter for the sake of simplicity.

By 1975, the Medical Research Council required that research applicants sign a statement citing that an ethics committee had approved their research proposal (Chalmers et al. 1996; Collins 1992; McNeill 1993). The number of ethics committees operating in New Zealand would continue to grow and reached a total of 10 by 1978 (McNeill 1993). In 1978, the Medical Research Council recognised the need to consider public health

¹⁴ The histories of New Zealand ethics policy development by Collins (1992), McNeill (1993) and Douglass (1993) informed the early research of this chapter.

research when it established the Health Services Research Committee (HSRC 1983). Also similar to Australia, the New Zealand move to include the needs of public health research can be traced to international developments, in this case, World Health Organisation encouragement (HSRC 1983). In May 1984, the Medical Research Council established the Medical Research Council Committee on Ethics in Research (HDEC 2007). At this establishment, the Medical Research Council created a national ethics committee to review and renew ethics policy, consider emerging ethical issues, and review all research supported by the Medical Research Council (MRC 1986). Two years after its formation, the Medical Research Council Committee on Ethics and Research produced the 1986 version of *Project and Programme Grants*. In this document, the Committee included the needs of public health research in its framework (MRC 1986).

What was different from Australia in this shift to include public health research was that the 1986 *Project and Programme Grants* guidelines did not consider the needs of social science research at the same time (HSRC 1983, p. 1, 13; MRC 1986). Consequently, the extension of the guidelines to include social science research did not occur in New Zealand as it did in Australia. Instead, the professional codes of conduct for many social science and humanities disciplines (HSRC 1983), such as anthropology (Awekotuku & Affairs 1991) and sociology (Rotondo 1996), would be provide their sole means of research oversight.

A year after the release of the 1986 *Project and Programme Grants* guidelines, the Medical Research Council found itself unable to further develop its research oversight in a manner similar to Australia's NHMRC, as the impacts of the Associate Professor Green research scandal radically disrupted research oversight in New Zealand.

Associate Professor Green's 'unfortunate experiment'

In June 1987, authors Sandra Coney and Phillida Bunkle, released an 18-page article entitled "An 'Unfortunate Experiment' at National Women's" in the *Metro*, then a widely-read Auckland city magazine (Coney & Bunkle 1987; Davis 1988). The Coney and Bunkle article began by introducing a woman by the pseudonym 'Ruth' who, upon returning from receiving medical treatment at Auckland's National Women's Hospital

... had told her workmates that she had just been to Auschwitz. "I feel as if they have been experimenting on me," (Coney & Bunkle 1987, p. 47).

The article supported its strong beginning by claiming that Associate Professor Green's research was considered internationally to be unethical; that it violated most articles in the Nuremberg Code; was based on medical assumptions that were essentially 'out on a limb'; and, most damning, that his experiment endangered lives (Manning 2009, p. 28). In a matter of days the story had reached local radio, and then New Zealand's only national news programme, the 'Six O'clock News' (Matheson 2009).

Associate Professor Green's area of interest was a premalignant cell condition on the neck of the womb, known as carcinoma in situ (Davis 1988; McMillan & Bowyer 2014). It was Associate Professor Green's hypothesis that carcinoma in situ was not, as was widely believed, a condition that lead to invasive cancer (Ministry of Women's Affairs & Lynch 1989; Tolich 2001) and his study was intended to contest current assumptions of its treatment. In 1966, Associate Professor Green was able to convince senior medical staff of the value of his study (Jones 2009; Snook 1999) and would continue with his research project for 16 years (Tolich 2001).

Associate Professor Green's experiment contained a significant ethical complication. He had not considered the risks to the women involved in his study if his hypothesis were proved false and their presentations of carcinoma in situ did progress into cancer (Cartwright 1988, p. 67). Consequently, when the disease did act against his hypothesis, the women in Associate Professor Green's study were "systematically deprived of medical intervention that could have saved their lives" (Henaghan 2012, p. 10). This risk to the women in the study emerged as early as 1969, when three cases of invasive cancer had been detected in the study (Davis 1988).

Equally concerning, was that the vast majority of Associate Professor Green's patients were not privy to the most basic level of consent – the knowledge that one is involved in an experiment (Davis 1988). None of the patients, moreover, were aware that Associate Professor Green was withdrawing treatment, nor were they informed at any stage that they had symptoms of cervical cancer (Henaghan 2012).

In response to the revelations of the *Metro* article, the Superintendent-in-Chief of the Auckland Hospital Board recommended that the Minister of Health conduct an official inquiry. Two days later the Minister appointed Judge Silvia Cartwright as inquiry head (Paul 1988). There were 68 days of public hearings in the Cartwright Inquiry from August 1987 until January 1988 (Manning 2009).

As befitting a televised inquiry designed to answer grave charges, national interest in the Cartwright inquiry was 'intense' (Brookes, 2009). Accordingly, the Inquiry generated "daily, headline grabbing reports over a lengthy period" (Matheson 2009, p. 13). Expert witness to the Cartwright Inquiry, David Skegg, recalls the public interest in the following way

Between August 1987 and January 1988, public attention was riveted by what seemed like daily revelations from the hearings

before Judge Sylvia Cartwright. Television cameras captured the drama as witnesses were examined and cross-examined by lawyers (Skegg 2009, p. 7).

The Cartwright Report stated unequivocally that Associate Professor Green's research was unethical (Matheson 2009) and found that his management of carcinoma in situ resulted in unnecessary health complications for many of the women in his study (Davis 1988), and in some cases death (Paul 1988).

Rather than simply blame Associate Professor Green for the ethical breaches of his study, the Cartwright Report also concentrated on failures of research oversight. Judge Cartwright extended the blame for the ethical failures of Associate Professor Green's study "to all those who, having approved the trial, knew or ought to have known of its mounting consequences and design faults and allowed it to continue" (Cartwright 1988, p. 69). Clearly, if the government were to address the findings of the Cartwright Report, it would need to address the oversight of medical research in New Zealand.

From a political perspective, the government had little choice other than to respond to the Cartwright Report. The Cartwright Inquiry concentrated national attention on ethical practice in New Zealand's public hospital system¹⁵. This last point is important because the participants in Associate Professor Green's experiment were not paid volunteers participating in a clinical trial but citizens receiving state-sanctioned

¹⁵ Even more than twenty years later, the Cartwright Inquiry still holds the public imagination of New Zealand. Reaction to the 2009 release of a revisionist history by Professor Linda Bryder, *A History of the 'Unfortunate Experiment' at National Women's Hospital* can be found in a leading New Zealand newspaper: <https://www.odt.co.nz/news/dunedin/profs-join-stand-against-criticism-cartwright-inquiry>

medical treatment who were unaware they were part of an experiment. This factor questioned the government's ability to run a safe and effective public hospital service. Subsequent government reactions to the Associate Professor Green scandal laid the foundations for the contemporary research oversight in New Zealand. Unlike Canada and Australia, these responses did not lead to the formation of a national oversight institution responsible for the maintenance of ethical standards of research.

The Government's first move following the Cartwright Inquiry was to remove the Medical Research Council's national ethics committee, the Medical Research Council Ethics Committee, from all future work on ethics. It then situated medical and public health ethics committees within the structure of New Zealand's health (hospital) sector (Douglass 1993; McNeill 1993) when it placed ethics committees into the fourth Labour Government's recently established 14 regionally based hospital boards (Somjen 2000). Placing ethics committees into hospital boards moved New Zealand into unfamiliar territory as it removed the primary funder of medical and public health research (the Medical Research Council) from active involvement in the oversight of its research funds. Both Canada's Tri-Council and Australia's NHMRC formally included their respective Medical Research Council's in research oversight.

In February 1988 (five months before the release of the Cartwright Report), the Ministry of Health met with representatives of the Area Health Boards ethics committees, the Auckland and Otago University medical schools and the Medical Research Council to consider a draft standard prepared by the Director of the Medical Research Council (HDEC 2007). As already noted, the Medical Research Councils dedicated committee for the oversight of research ethics, the Medical Research Council Ethics Committee, was not involved in this process (HDEC 2007).

The Ministry of Health released its policy code, the 1988 *Standard for Hospital and Area Health Board Ethics Committees* (1988 Standard), in October. The key feature of the 1988 Standard is that it was designed to incorporate the recommendations of the Cartwright Report (Rotondo 1996). It included, therefore, a focus on informed consent (sec 6.1 & 6.2), a requirement that a hypothesis be capable of being disproved (sec 6.2), and protocols for ethics committees on matters such as addressing conflicts of interests (sec 3.2).

Following the implementation of the government's changes, it could argue that concern for patient safety in public hospitals had been addressed as it had created ethics policy in response to the critiques of the Cartwright Report and situated research oversight in the hospital sector. In its haste to contend with the findings of the Cartwright Inquiry, however, the government did not immediately establish a centralised institution for the oversight of all human research similar to that found in Canada and Australia. Instead, the release of the 1988 Standard simply reflected the development of ethics policy to address the needs of medical research.

The next step in the government's plan for the development of research oversight in New Zealand was to create a new legislative framework to return the research oversight to the funders of medical and public health research in accordance with international norms. The incoming legislation, the New Zealand Health Research Council Act 1990, shares two features with Australia's 1992 NHMRC Act. First, the Health Research Council Act 1990 makes explicit a requirement to add the needs of public health research in addition to that of medical research. To this end, the Act mandated the formation of a Public Health Research Committee to be made responsible for assigning funds for public health research (sec 15 & 16). Second, the 1990 Act required the formation of a dedicated national ethics committee (sec 24–26). The Act gave the Health Research Council Ethics Committee a strong mandate to oversee medical and public health

research ethics in New Zealand as the Committee responsible to make recommendations for the following: ethical issues, the approval of the ethics committees of other bodies, and the production and review of ethics policy for the Health Research Council (sec 24–26).

At the release of the Health Research Council Act 1990, the soon-to-be established Health Research Council Ethics Committee was the only legislatively mandated oversight institution responsible to maintain ethical standards of human research in New Zealand. In the Australian context, similar legislative requirements allowed the NHMRC to become the national oversight institution responsible for all human research, to dominate the production of ethics policy guidelines, and to oversee the behaviour of ethics committees. Had the fourth Labour government¹⁶ (1984–1990) remained in power to encourage the full use of its legislation, this outcome may also have taken place in New Zealand. However, one month after the Health Research Council Act 1990 would come into effect, the fourth National government came to power in New Zealand (Collins, 1992).

The new government's treatment of the Health Research Council Act 1990 was unusual in that it did not repeal the Act but undermined its role in the oversight of research by continuing the development of research oversight within the Ministry of Health. In 1993, the government introduced legislation to guide the oversight of New Zealand's hospital sector, the Health and Disability Services Act 1993. The title of the Act (Health and Disability Services) displays the Act's concern for the public funding and provision of health-care services and allied support for those with disabilities (sec 1). As Health and Disability Ethics Committees in New Zealand was now tied to the hospital sector, it was through the lens of the Health and Disability Services Act 1993 that future development of

¹⁶ See appendix D for a list of New Zealand's governments

the oversight of medical and public health research proceeded (and not under the Health Research Council as the previous government had wished). Section 7 of the Health and Disability Services Act 1993 allowed the Minister for Health to form a national ethics standing committee. In an organisational structure unique in Canada, Australia and New Zealand, the Act required that the Ministry of Health's National Advisory Committee on Health and Disability Services Ethics report directly to the Minister of Health.

The presence of two legislatively backed national ethics committees presented a problem for the division of labour of research oversight in New Zealand. In 1994, an interim taskgroup tasked with this concern considered whether the two national ethics committees could coexist if their roles were clearly defined (ITHDSE 1994; NACHDSE 1996). This advice was accepted, and the Ministry of Health's Committee (the National Advisory Committee on Health and Disability Services Ethics) maintained the Ministry's control over research oversight and development of medical and public health research ethics policy. The Health Research Council Ethics Committee would then supplement these oversight mechanisms by acting as accreditors to the Ministry of Health's Health and Disability Ethics Committees (HRC 1996). In a further complication, the Health Research Council would produce its own ethics policy, the *Health Research Council Guidelines on Ethics in Research* (1996), but these guidelines would not be ratified by the Ministry of Health for use with its Health and Disability Ethics Committees (NACHDSE 1996).

In 1996, the Ministry of Health's National Advisory Committee on Health and Disability Services Ethics produced its first ethics policy. The *National Standard for Ethics Committees* (1996 Standard) was designed to guide the ethical decision-making of Ministry of Health ethics committees (NACHDSE 1996, appendix 11). At the release of the 1996 Standard, the Ministry of Health and its National Advisory Committee on Health and

Disability Services Ethics would be responsible for ethics policy development and the Health Research Council would accredit Health and Disability Ethics Committees (NACHDSE 1996, appendix 11).

The purpose of the 1988 and 1996 standards was to guide the behaviour of the Ministry of Health's Health and Disability Ethics Committees (NACHDSE 1996, sec. 1.3) and not, by deduction, non-medical or public health research. This left New Zealand's university-based research in a difficult position. On one hand, universities faced legal exposure generated by the Cartwright Inquiry (Snook 1999). This exposure was confirmed when the Auckland University was sued in relation to its role in the Associate Professor Green scandal (Rotondo 1996). The University was vulnerable to such an action because Associate Professor Green was employed by both the National Women's Hospital and as an academic member of the University of Auckland (Campbell 1989; Green 1970; Smith 2010). On the other hand, social science and humanities researchers in New Zealand universities were coming under increasing pressure to gain research oversight to secure international funding (Perkins 1992). It was their concern that if New Zealand Universities did not create their own codes, the Ministry of Health might impose their 'medical' frameworks on to the university sector (Rotondo, 1996). Responding to this legal vulnerability (Rotondo, 1996; Snook, 1999; Tolich, 2001), and driven by engaged social scientists (Rotondo 1996; Snook 1999), New Zealand universities established ethics committees in the years during or following the Cartwright Inquiry¹⁷.

What is most striking about research oversight in New Zealand universities is that each university created unique research oversight mechanisms. Margret Rotondo's 1996 study of research oversight in

¹⁷ Included in Appendix E is a table detailing the establishment dates of each New Zealand university ethics committees.

university settings provides what is perhaps the only study of this area in the years following the Cartwright Inquiry. Rotondo found that each university possessed a different ethics policy (one had not yet created ethics policy), different ethics committee membership requirements, and each occupied a different place in its university hierarchy. The only constant was a lack of status within each given university structure (1996).

This fractured research oversight as reflected in the Ministry of Health, the Health Research Council, and New Zealand's eight universities has proved durable over time.

New Zealand's contemporary oversight of research

New Zealand's oversight of research did not develop into a centralised form. Consequently, the aspirations of Indigenous ethics in New Zealand would need to negotiate within different structures to that found in Canada and Australia. The New Zealand context is fragmented over multiple institutions.

At the time of writing, the National Ethics Advisory Committee has not extended its ethics policies to include the needs of all human research and has maintained its focus on medical and public health research (MOH 2002, 2006, p. 1, 2012; Moore 2009; NACHDSE 1996; NEAC 2012b). New Zealand university research oversight, furthermore, has not developed a single ethics policy or national ethics committee dedicated for all university research.

Currently the Ministry of Health's national ethics committee, the National Ethics Advisory Committee is responsible for setting the behaviour of its Health and Disability Ethics Committees (HDEC 2012a, 2012b, 2012c, 2014) and the development of its ethics policy documents (NEAC 2012b,

2012c). The Health Research Council accreditation of six of the eight New Zealand university ethics committees goes some way toward acting as an overarching factor across the university ethics committees. However, it does not cover all universities and does not facilitate the creation of common development of ethics policy across the universities (HRCEC 2012). The Health Research Council has also maintained its development of ethics policy (HRC 2005), but to date these codes still lack validity in the Ministry of Health ethics policy documents (NEAC 2012d).

Each university possesses different ethics committee membership requirements and each ethics committee operates at a different place in the university hierarchy. The University of Auckland ethics committee reports directly to the governance group of the University (University of Auckland 2012). The Auckland University of Technology does not refer to the position of its ethics oversight in either its website or its 2013 annual report (Auckland University of Technology 2013). The Massey University ethics committees, Human Ethics Chairs' Committee, reports to the Massey University governing Council (Massey University 2010). The Lincoln University Human Ethics Committee is a committee of the University's Council and it reports annually to the Vice-Chancellor and the Health Research Council Ethics Committee (Lincoln University 2013). The Otago Human Ethics Committee reports to the Risk Management, Ethics and Statutory Compliance Committee, which in turn reports to the University Governing Council (Otago University 2014a, 2014b). The University of Canterbury Human Ethics Committee is responsible directly to the Vice Chancellor (University of Canterbury 2014). The Victoria University Human Ethics Committee was established by the University Council in 1990 (Victoria University of Wellington 2014). It is unclear, however, where it fits into the organisational structure of the University. In the organisational structure chart found in Victoria University Annual Report 2013, the Human Ethics committee was not listed (Victoria

University of Wellington 2013). Finally, the Waikato University Human Research Ethics Committee is responsible to the Academic Board and is an Advisory Committee to the Vice Chancellor (Waikato University 2014). Regarding ethics committee membership, only five of the eight Universities comply with the Health Research Council requirements (HRCEC 2012).

The influence of Ministerial politics over research oversight is uneven in New Zealand. While a new legislative framework reformed the Ministry of Health's national ethics committee, the National Ethics Advisory Committee maintained its unique feature of reporting directly to the Minister of Health (NEAC 2012a). The Health Research Council Ethics Committee, by contrast, is not directly responsible to the Minister of Health (Health Research Council Act 1990). In New Zealand universities, there is no legislative requirement to form ethics committees (Israel 2015), therefore, no mechanism to encourage direct political oversight.

The relevance of the fractured nature of research oversight in New Zealand to Indigenous ethics is that it provides two challenges to the development of Indigenous ethics in New Zealand. The first challenge is the number of oversight institutions in New Zealand who share responsibility for the ethical oversight of human research. If, for example, Indigenous ethics wished to engage with research oversight in Canada or Australia, engagement would occur with a single research oversight institution in each. If New Zealand Indigenous ethics wished to gain similar nationwide influence, it would need to engage with the Ministry of Health, the Health Research Council, and each of New Zealand's eight universities. Each oversight institution possesses different ethics policy that is updated at differing schedules.

The second challenge is the inconsistent influence of politics in the New Zealand context. In particular, the next chapter will demonstrate how Ministerial influence over the Ministry of Health's National Ethics Advisory

Committee proved to be problematic to the development of Indigenous ethics in New Zealand.

9

The fractured development of New Zealand's bicultural Indigenous guidelines

The introduction of Indigenous ethics to New Zealand occurred as the disruption following the 1987–8 Cartwright Inquiry coincided with the influence of bicultural politics. The impact of both these forces is seen in the failure of ethics policy development in New Zealand to match that of Canada and Australia. On one hand, the assertions of bicultural politics did not gain hoped-for influence over the oversight of New Zealand leaving Māori with insufficient levels of partnership with which to drive the development of Indigenous ethics policy. On the other hand, the fragmentation of New Zealand's research oversight institutions led to the development of multiple ethics policy documents that each framed the needs of Indigenous ethics in differing ways. These multiple negotiations occurred at the distinct research oversight frameworks of the Ministry of Health, the Health Research Council Māori Health Committee, and New Zealand's eight university ethics committees. In these areas of research oversight, the development of Indigenous ethics suffered under unique conditions: the Ministry of Health faced political interference. The Health Research Council Māori Health Committee ethics policy lacked formal relevance in the Ministry of Health's Health and Disability Ethics Committees structures; and the eight university ethics committees did not enjoy the benefits of a national ethics committee to develop consistent Indigenous ethics policy across the universities. The first institution to respond to the calls of bicultural politics was the Ministry of Health.

Ministry of Health research oversight

The Ministry of Health introduced the 1988 *Standard for Hospital and Area Health Board Ethics Committees Established to Review Research and Treatment Protocols* (1988 Standard) three months after the release of the Cartwright Report. This timing destined the 1988 Standard to be the first to interpret the calls of bicultural politics into the oversight of research in New Zealand.

Chapter three introduced bicultural politics as calling for Māori to act in partnership with the state in the governance of all New Zealand (Barrett & Connolly-Stone 1998; Grant 2012; Ritchie 2008). While the advances of the 1988 State Sector Act encouraged the New Zealand public service to act in a bicultural partnership with Māori (Jones, Pringle, & Shepherd 2000), one of the features of this new environment was that legislative references to the Treaty of Waitangi lacked clear definition (Durie, Hoskins, & Jones 2012; Kelsey 1990). An outcome of this ambivalence is that there exists no definitive practical meaning of one of the key themes of a bicultural view of the Treaty, that of partnership (Grant 2012; Hayward 1997). Consequently, when New Zealand began to review its research oversight following the Cartwright Report, a widespread understanding that Māori should be involved in research oversight existed (Campbell 1995), but this expectation remained at a conceptual rather than operational level.

That is not to say that ideals of bicultural politics were not clearly articulated. The April report assertions of Henare and Douglass that biculturalism represents “a partnership between Māori and non-Māori, equal sharing of power and resources; and the recognition of both cultures and languages” (1988, p. 113) is an example of concrete expression of bicultural ideals where Māori gain equal power. Implicit in this understanding of power is an expectation that once Māori gain sufficient participation, future policy could reflect the aspirations of Māori. What was not yet defined, however,

was how the New Zealand public service would interpret bicultural aspirations.

At the release of the 1988 Standard, the Ministry of Health introduced its first interpretation of this bicultural partnership in the oversight of research. The Standard required that all Health and Disability Ethics Committees include a Māori perspective amongst its membership (sec 3.4) and stated that the ‘principles of the Treaty of Waitangi shall be incorporated in the proceedings of ethics committees’ (sec 1.4). No further explanation was given as to how the principles of the Treaty of Waitangi would guide ethics committees, and the Standard did not include ethics policy to guide research with Māori.

From a bicultural perspective, such as Henare and Douglass (1988) encouraged, the lack of definition of the meaning of a Treaty of Waitangi partnership (other than the inclusion of a single Māori member of Ministry of Health ethics committees) falls short of an equal sharing of power and resources. However, considering the 1988 Standard was a rushed document to address the findings of the Cartwright Report (of which Māori ethics policy represented a minor point), the Standard is best viewed as a transitional document. For a substantial view of how the Ministry of Health would interpret bicultural politics, the formation of the Ministry of Health standing ethics committee and the 1996 *National Standard for Ethics Committees* (1996 Standard) are instructive.

In 1994, the Ministry of Health formed the Interim Task Group on Health and Disability Services Ethics (Interim Task Group) to facilitate the ongoing development of Ministry of Health ethics policy and consider Māori input into research oversight (ITHDSE 1994, p. 3). The Interim Task Group recommended that the Ministry of Health form a national ethics committee (ITHDSE 1994), and (with additional advice from Te Puni Kōkiri – the Ministry of Māori development) advocated for Māori to serve on Health and

Disability Ethics Committees and the national ethics committees as representatives of Māori (Te Puni Kokiri 1994). The call to include Māori as representative of Māori conforms to bicultural ideals as the Māori members of national ethics committees and ethics committees could represent their iwi and hapu in the oversight of all medical and public health research conducted in New Zealand.

Illustrated in Figure 4, is Te Puni Kokiri's preferred structure of Māori participation in research oversight. It is a clear example of the claims of bicultural politics.

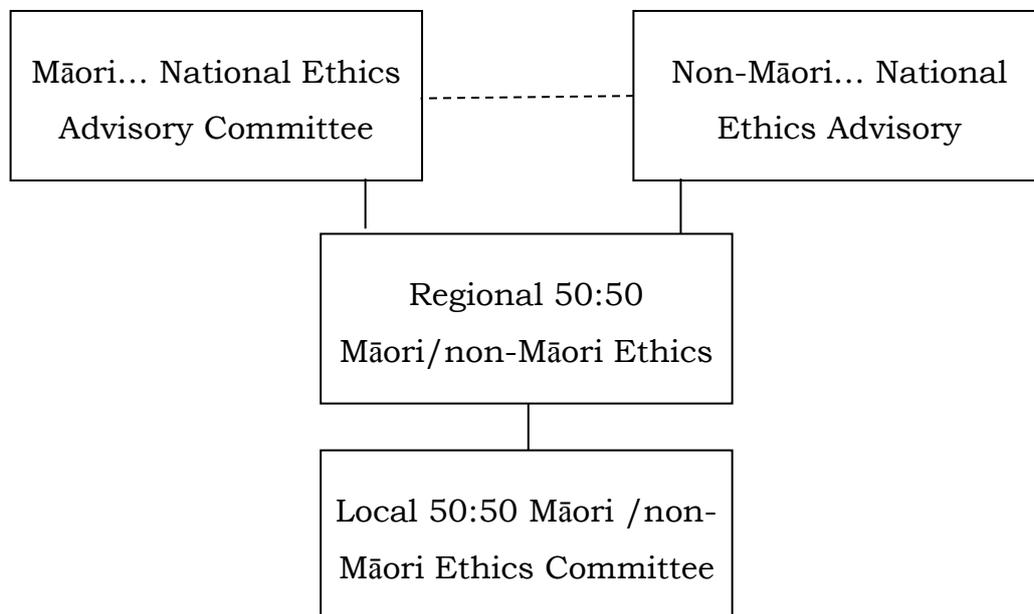


Figure 4, Te Puni Kokiri's recommendation for Māori participation in research oversight (Te Puni Kokiri 1994, p. 22).

Figure 4 shows that Te Puni Kokiri calls for Māori to represent half of all oversight governance in New Zealand. As written, the regional and local ethics committees would allow a 50\50 split between Māori and non-Māori membership (represented by the lower two boxes), while the national ethics committee would divide into a committee composed of Māori and non-Māori members respectively. At no stage did the Te Puni Kokiri report reference

the creation of separate ethics policy for research that involves Māori, because it could be assumed under the above arrangement that Māori would attain sufficient participation to allow further ethics policy development to reflect Māori interests. This assumption is a key difference between the demands and outcomes of sovereignty and bicultural politics on ethics. Sovereignty politics encouraged the creation of separate policy, while bicultural politics encouraged Māori to consider all research and its oversight as of interest to Māori. Under bicultural ideals, separate ethics policy would only constrict the role of Māori in New Zealand.

As late as 1995, a prominent New Zealand bioethicist, Professor Alistair Campbell reported an assumption that the forthcoming national ethics committee would be formed with Māori representing half of its membership (Campbell 1995). It was an assumption that would soon be thwarted. The newly formed National Advisory Committee on Health and Disability Services Ethics was expected to foster a Māori perspective on ethical issues (Angelo 2000, p. 118), but evidence that the make-up of the national committee contained significant Māori inclusion was not forthcoming¹⁸. However, when the national ethics committee was reformed under the name the National Ethics Advisory Committee, it was required to “have at least two Māori members out of a total of 12 members” (NEAC 2007, 2008, 2012a, para. 4). In addition to the inclusion of two Māori members, the National Ethics Advisory Committee was required in its Terms of Reference to develop and promote national ethics policy guidelines relevant to Māori medical and public health research (NEAC 2008, para. 10). While Māori were explicitly

¹⁸ An informal discussion with a central government civil servant who was active during this period suggested that it would be likely that the National Advisory Committee on Health and Disability Services Ethics membership would have included at least one Māori member. If the inclusion of Māori resembled the 50% level ascribed by bicultural politics, it is likely that this would have gained a mention in the definition of the National Advisory Committee on Health and Disability Services Ethics in 1996 Statement.

referenced in these documents, it is difficult to argue that Māori enjoyed equal access to power and resources under this arrangement.

The relevance of Māori aspirations to gain 50% participation on the National Advisory Committee on Health and Disability Services Ethics is underlined by the logical ordering of bicultural political arguments: ethics policy development relevant to Māori will follow as an outcome of Māori gaining equal influence over research oversight. In contrast to the success of Canadian and Australian sovereignty politics in attaining separate Indigenous ethics policy, the inability of Māori to gain hoped-for influence over research oversight left Māori without the means to drive New Zealand-wide ethics policy. This lack of influence is evidenced by the paucity of code related to research with Māori in the 1996 *National Standard for Ethics Committees* (1996 Standard) as produced by the National Advisory Committee on Health and Disability Services Ethics (NACHDSE 1996). In its main body (section 5), the 1996 Standard contains no direct references to Māori. Section 5.1.8 comes the closest when it suggests the importance of community consent by stating that “it may be appropriate to have consent given by a suitable body within the culture”.

In place of a focus on the production of ethics policy relevant to Māori, the 1996 Standard concentrates on the role of Māori in research oversight. To this end, the 1996 Standard retained the ideal that the principles of the Treaty of Waitangi be incorporated into the processes of the Ethics Committee (sec. 1.5). To aid this partnership it increased the number of Health and Disability Ethics Committee members required to be Māori from the former minimum of one, to two (sec. 2.2). The 1996 Standard also encouraged Health and Disability Ethics Committees to invite nominations from local and national Māori groups. The Standard also explicitly noted that Te Puni Kokiri could assist in this process by providing contact names and addresses (appendix 3) allowing Māori Ethics Committee members to be ‘representatives of Māori’. Additionally, in a shift towards encouraging the

non-Māori members of Health and Disability Ethics Committees to possess the skills necessary to function effectively within a bicultural relationship, the 1996 Standard required that Committee members be trained in the Treaty of Waitangi and an awareness of Māori tikanga (Appendix 3).

The release of the 1996 Standard represented important advancements for Māori involvement in New Zealand research oversight. The level of positive discrimination for Māori on Health and Disability Ethics Committees and the National Advisory Committee on Health and Disability Services Ethics allowed Māori to be present on all future Ministry of Health ethics policy development and ethics committee oversight. Māori enjoyed a degree of participation not seen in Canada or Australia, yet the inclusion of Māori in regimes of research oversight did not occur under the same conditions as those of Canada and Australia. The greater demands of New Zealand bicultural politics required a higher level of Māori involvement to succeed as these ideals wished to influence all New Zealand ethics policy development, and not a discrete Indigenous chapter.

Compared to bicultural ideals of Māori participation in research oversight, Māori partnership in Ministry of Health research oversight lacked equal influence. This is consistent with O'Sullivan's claims that the practice of biculturalism in New Zealand left Māori with symbolic recognition but without substantial influence as 'junior' partners to the state (2007). From this junior position, Māori were unable to develop ethics policy for research with Māori comparable to that found in Canada and Australia.

A further difficulty faced by bicultural ethics in New Zealand was that in the ensuing years, New Zealand politics gradually moved away from the use of the Treaty of Waitangi and its accompanying ideas of mandated Māori inclusion. Consequently, decisions by the Ministry of Health, and its National Ethics Advisory Committee, would undermine gains in Māori

inclusion in the oversight of New Zealand medical and public health research.

New Zealand's political withdrawal from bicultural politics

While government resistance to the use of the Treaty of Waitangi emerged as early as the fourth Labour government (Kelsey 1990), references to the Treaty of Waitangi were not removed from legislation. Perhaps the biggest change away from the use of the Treaty of Waitangi in public life came about during the Fifth Labour government (1999–2008). The Fifth Labour government began its administration supportive of the Treaty of Waitangi, but was forced to backtrack when it suffered a significant public backlash against its Treaty of Waitangi-inspired 'Closing the Gaps' social policy initiative, which it finally abandoned in February 2001 (Humpage 2002, 2006). Adding to the governmental wane was the impact of the 2003 Court of Appeal ruling that allowed Māori to prove in Court their customary ownership of the foreshore and seabed (Meijl 2006). The National party opposition leveraged the public's fears that this ruling would restrict public beach access when it campaigned aggressively against the government giving 'special' consideration to Māori (Gagne 2008). When the party gained power in 2008, it avoided the use of the Treaty of Waitangi (HRC 2013b).

In the context of overall Ministry of Health strategy, the differences between the early period of the fourth Labour government and of the fifth National government are marked. In the case of the former, the *New Zealand Health Strategy 2000* (MOH 2000) gave the Crown's Treaty relationship with Māori a prominent position as the first of its eight key principles. In the later Fifth National government's *Implementing the New Zealand Health Strategy 2009 and 2012* documents, neither the Treaty of Waitangi, nor the particular needs of Māori health are referenced (Minister of Health 2012; see: MOH 2009). Similarly, the Annual Reports of the Health Research Council under the fourth Labour government were required to explain how the Council

responded to Treaty of Waitangi obligations (MHC 2008), while the 2013 Annual Report of the Health Research Council does not reference the Treaty of Waitangi, the work of the Māori Health Committee, or the needs of Māori medical and public health research (HRC 2013b).

As the National Ethics Advisory Committee is directly responsible to the Minister of Health (NEAC 2012a), the committee did not enjoy a buffer between these larger trends and its role in research oversight. This was in contrast to the situation in Canada and Australia in which neither the Tri-Council nor the NHMRC's Australian Health Ethics Committee are directly responsible to government Ministers. Figure 5 (below) reveals that the Ministry of Health's National Ethics Advisory Committee reports directly to the Minister of Health. This direct Ministerial control limited the National Ethics Advisory Committee's ability to voice more concern for the oversight of research within Māori communities.

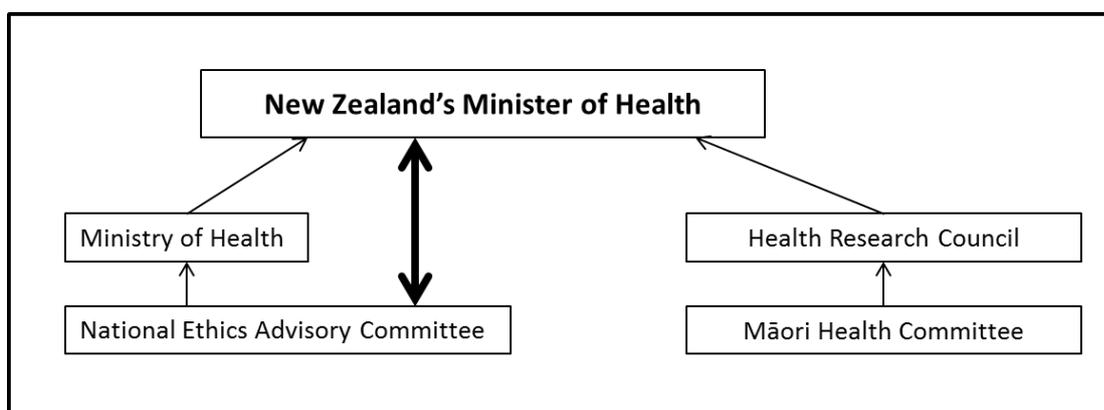


Figure 5, Ministerial distance from the National Ethics Advisory Committee

Consequently, the National Ethics Advisory Committees ethics policy increasingly mirrored government policy that undermined Māori visibility in the public sector, and policies that encouraged the bicultural oversight of medical and public health research in New Zealand were incrementally removed.

In the National Ethics Advisory Committee's 2002 Operational Standard ethics policy, for example, section 174 formally removed Māori as representatives of "particular groups or professional bodies", and the appointments to Health and Disability Ethics Committees were moved to the government's public employment processes (HDEC 2007a). In the 2009 Intervention Guidelines, the National Ethics Advisory Committee made explicit its view that Health and Disability Ethics Committees were not bound by a Treaty of Waitangi partnership when it shifted references to the Treaty of Waitangi into its Justice section. Here it required all researchers (and not the Health and Disability Ethics Committee) to respect the implicit Treaty principles of partnership and 'sharing' (sec 4.7).

The most recent factor in the wane of government support of Māori bicultural involvement in research oversight occurred as a result of the John Key National governments (2008-present) Clinical Trials Inquiry.

The 2010 Clinical Trials Inquiry and the 'cultural turn'

The stated purpose of the Clinical Trials Inquiry was to consider the streamlining of New Zealand's ethical approvals systems to attract international clinical trials to New Zealand (House of Representatives, 2010). The terms of reference of the Inquiry were not directly concerned with Māori involvement, but its focus on speeding up ethical approval processes highlighted that Māori consultation could result in 'significant delays' (House of Representatives 2010, p. 32). The Inquiry Report criticised the current National Ethics Advisory Committee ethics policy advice for research within Māori communities as inadequately defining the purpose of Māori consultation and lacking clarity. It recommended that the National Ethics Advisory Committee "make clear guidelines for ethnic and Māori consultation" to maximise protection, expertise, efficiency, and also to clarify the purpose of Māori consultation (House of Representatives 2010, p. 32).

When the Fifth National government (2008-present) officially responded to the Inquiry Report, it agreed that Māori consultation did not allow the expedient review of clinical trials research, but neither did it recommend any further development of Indigenous ethics. Instead, it noted the existence of the Health Research Council's Māori Health Committee *Guidelines for Research on Health Research Involving Māori* framework (New Zealand Government 2011, sec. 31). Close attention uncovers that the government's reference to the Māori Health Committee Guidelines is disingenuous as the Guidelines are not formally recognised by the Ministry of Health (NEAC 2009) and would not be so in future National Ethics Advisory Committee ethics policy (NEAC 2012b, 2012c).

The government decision not to encourage the development of an ethical framework dedicated to Māori consultation undermined the National Ethics Advisory Committees already-in-motion work as it was seeking to fulfil its mandate to develop ethics policy guidelines relevant for research with Māori (NEAC 2010). If the New Zealand context were to produce an Indigenous chapter similar to Canada and Australia, it would have required the National Ethics Advisory Committee to complete this task as only the National Ethics Advisory Committee guidelines could be used by Health and Disability Ethics Committees. The National Ethics Advisory Committee appeared to persevere with this work against government wishes, as this document was considered forthcoming in a later National Ethics Advisory Committee document (NEAC 2012b, p. 1). However, they would later abandon this task leaving the document unreleased.

Contemporary Ministry of Health research oversight

The most recent work of the National Ethics Advisory Committee demonstrates further the wane in the New Zealand government's interest in Māori involvement in research oversight. Between 2013 and 2015, the National Ethics Advisory Committee requirement to include two Māori

members was removed (NEAC 2013, 2015). In January 2015, no members of the National Ethics Advisory Committee professed iwi affiliations (NEAC 2015). The 2010 Terms of Reference for Health and Disability Ethics Committees also halved Māori representation from two to one committee members (HDEC 2012a, 2012b, 2012c, 2012d). The meaning of this membership also changed away from a bicultural role of partnership in the functioning of ethics committees, to one of possessing a particular skill of the “awareness of te reo Māori and understanding of tikanga Māori” (HDEC 2012a, 2012b, 2012c, 2012d).

The National Ethics Advisory Committee’s 2012 Standard Operating Procedures also undermined the idea that Health and Disability Ethics Committees represented a Treaty partnership with Māori when it stated, ‘Health and Disability Ethics Committee review does not constitute consultation with Māori’ (sec 16). Māori consultation, therefore, must now be addressed at ‘localities’ (sec 18) – a term used to describe District Health Boards, academic institutions, private companies, private hospitals, and other health and disability research centres (sec 169). Health and Disability Ethics Committees now had no role in Māori consultation other than assessing whether consultation had taken place.

The difficulty with this new focus on judging Māori consultation was that the National Ethics Advisory Committee’s 2012 Intervention and Observational Guidelines did not provide clear ethics policy advice on this matter. Instead, the 2012 Intervention and Observational Guidelines are concerned more for what Tolich and Smith (2014) called the ‘cultural turn’. Here, Māori culture, language and tradition are validated in ethics policy but without an equal concern for the nature of a partnership between Māori and researchers (and its associated ideas of power sharing). Both current National Ethics Advisory Committee Guidelines use now familiar phrases to enlist concern for Māori in research when listing among the key objectives a need to

... reflect the principles of the Treaty of Waitangi and protect Māori cultural interests, promote the wellbeing of Māori and ensure mechanisms for Māori participation in both research and ethical review (p. ii & iii – cited page numbers are listed with the 2012 Intervention Guidelines first).

While the above quote hints at bicultural themes of partnership, little policy guidance is given to the practical nature of Māori consultation other than a general statement in section 5.56 of the 2012 Intervention Guidelines that reads

When an intervention study focuses on an intervention for a whole community, rather than on individuals, it is normally appropriate for the community as a whole, rather than individuals, to be consulted about participation in the study.

In terms of ethics policy designed for Indigenous ethics, the National Ethics Advisory Committee lags behind the Canadian Tri-Council context. Unlike the Tri-Council example, the National Ethics Advisory Committee guidelines do not contain further discussions of when consultation is needed, or how to engage in consultation. Also missing is a requirement to become informed about local Māori community practices and world views, guidance on the publication of findings, or how to approach community members who may not have a voice in the formal leadership of a community.

One of the ironies of the lack of Ministry of Health policy development for research with Māori is that during this same period, the Health Research Council produced sovereignty-aligned policy similar to that found in Canada and Australia.

The Health Research Council Māori Health Committee oversight

When the Health Research Council Act 1990 formed the legislative basis for the Māori Health Committee, it created conditions unique to New Zealand as they are aligned to sovereignty politics. In the place of references to the principles of the Treaty of Waitangi that may have implied a bicultural partnership role for Māori in the functions of the Health Research Council, the Act instead defined a discrete role for the Māori Health Committee to,

... advise the Council on health research into issues that affect Māori people, with particular reference to research impinging on cultural factors affecting the Māori peoples... (Health Research Council Act, 1990, section 22).

This legislation placed the Māori Health Committee in a position similar to that of the Tri-Council's Institute of Aboriginal Peoples' Health and the Australian NHMRC Aboriginal and Torres Strait Islander Working Group in that they all focus exclusively on the needs of Indigenous medical and public health. Similar to the Canadian and Australian examples, the Māori Health Committee first concentrated on developing Indigenous public health research strategic plans, before turning to the needs of ethics (Castellano & Reading 2010; NHMRC 1999). There is, however, a fundamental difference between the Māori Health Committee and its Canadian and Australian counterparts: the Māori Health Committee is not directly included in Ministry of Health ethics policy development. The ramification of this lack of inclusion is that ethics policy developed by the Māori Health Committee lacks consistent authority at Health and Disability Ethics Committee level.

The development of the Māori Health Committee mandate

The Health Research Council Māori Health Committee first met on February 1991 and was chaired by Prof Eru Pomare (MRC Committee 2014). Prof Eru

Pomare had a long history of charting Māori health, for example, the *Hauora: Māori Standards for Health iii: A Study of the Years 1970-1984* (Pomare 1988) and *Māori Standards of Health: a study of the 20 year period 1955-75* (Pomare 1980). The method of membership appointments in the Māori Health Committee has ensured the consistent selection of Māori members who presented a concern for the improvement of Māori health. Section 23 of the Health Research Council Act 1990 allows this continuity as it requires that the Health Research Council (not the Minister of Health) appoint the members of the Māori Health Committee. While this does not preclude Ministerial involvement in membership appointments, the structure encourages the appointment of members to the Māori Health Committee to be motivated by the Health Research Council's mandate for Māori health. Under these conditions of relative political autonomy, the Māori Health Committee consistently assembled members who were leaders in the fields of Indigenous public health research and Indigenous ethics. Notable past or present members of the Health Research Council include Professor Mason Durie, Dr Fiona Cram (MHC 1998) and current chair (as of 2014) Professor Linda Tuhiwai Smith (HRC 2013a). Furthermore, all of the current members of the Health Research Council cite iwi associations (HRC 2013a). As the structure of the Māori Health Committee all but guaranteed Māori would dominate membership of the Committee, the Committee did not need to enter into bicultural negotiations over Māori involvement. It concentrated, instead, on developing separate Māori apparatus.

Like Australia's NHMRC Aboriginal and Torres Strait Islander Working Group, the Māori Health Committee began to produce periodical Indigenous public health research strategic plans. In 1998, the Māori Health Committee released the *Pukapuka Tauira Whakamutunga: Strategic Plan for Māori Health Research Development 1998-2002* (MHC 1998). The Strategic Plans goals included improved responsiveness of health research to Māori needs and priorities, the implementation and review of health research, and (most

relevant to Indigenous ethics) a focus on Māori ethical criteria in research design. In 2004, the Health Research Council produced the *Nga Pou Rangahau Kia Piki Ake Te Ora Māori Research Strategic Plan 2004-2008*, and in 2010 this was followed by the *Nga Pou Rangahau: The Strategic Plan for Māori Health Research 2010-2015*. In addition to articulating Māori ethical concerns for health research, the Māori Health Committee released ethics policy guidelines in 1998.

1998 Consultation Guidelines

The 1998 *Guidelines for Research Involving Māori* (1998 Consultation Guidelines) represented a separate ethics policy document dedicated to research with Māori. The 1988 Consultation Guidelines introduced ethical concepts familiar to the Canadian 1998 TCPS and the 1999 NHMRC Indigenous chapters, such as a request that Māori be involved in decisions around the definition of a research topic, research design, participant recruitment, and results dissemination (sec 5 – 5.3.3.). However, as already stated, the Māori Health Committee did not possess the ability to enforce adherence to its guidelines (other than research that it directly funded) (MRC Committees 2014). The Ministry of Health's 2002 Operational Standard, for example, did not formally use the 1998 Consultation Guidelines, but instead noted only that ethics committees should be 'familiar with' the Māori Health Committee guidelines (MOH 2002, sec. 78). As the Health Research Council does not possess a competing set of ethics committees, all medical and public health research in New Zealand would need to pass through ethics committees that used the Ministry of Health Statements, leaving the position of the 1998 Consultation Guidelines unclear.

Despite the shortcomings in the applicability of its Guidelines, the Māori Health Committee emerged as a key site of Māori concern for ethical and public health research oversight in New Zealand. Evidence of the Māori

Health Committee's ongoing involvement in Māori public health research is found in its distribution of Health Research Council research funds. Currently, around 10% of Health Research Council funding is passed through the Māori Health Committee framework (HRC 2014, p. 3). Also in the years following the 1998 Consultation Guidelines, Māori researchers and theorists have emerged as worldwide leaders in the ethics of Indigenous research (Ermine, Sinclair, & Jeffery 2004).

It is here in the Health Research Council frameworks, rather than the National Ethics Advisory Committee ethics policy guidelines, that the broader advances in New Zealand Indigenous ethics are located. The most prominent Indigenous ethics development since the 1998 Consultation Guidelines is kaupapa Māori research. Kaupapa Māori research emerged out of a wider context of Māori rejuvenation (Durie et al. 2012) and is idealised as research conducted 'by Māori, and for Māori' (Walker, Eketone, & Gibbs 2006). Kaupapa Māori moves beyond bicultural arguments that encourage Māori involvement in research oversight and argues for the complete control of research to be held in Indigenous hands.

A fundamental understanding of kaupapa Māori research is therefore that Māori maintain conceptual, methodological and interpretive control over research (Walker et al. 2006). Kaupapa Māori research, in other words, tailors research practices to the needs and aspirations of the participants (Jones, Ingham, Davies, & Cram 2010). In this way, it is considered that Māori are given the space to construct their own reality based on Māori world views and values (Eketone 2008), in what Cram calls a 'community-up approach' (2009).

Kaupapa Māori research has gained a high profile in New Zealand and is used as the basis of university research centres (Canterbury 2011; Otago University 2015) and at least one university postgraduate course paper (University of Auckland 2015). Websites and a DVD series are dedicated to

its evangelising benefits and theories (KM 2007; MIA 2010; Rangahau 2015), and an independent research company uses kaupapa Māori research as its methodology of choice (MIA 2007).

In its next ethics policy guidelines, the Māori Health Committee responded to this trend when it included references to kaupapa Māori research.

The 2008 Consultation Guidelines

The 2008 *Guidelines for Researchers on Health Research Involving Māori* (2008 Consultation Guidelines), like the 1998 Consultation Guidelines, represent separate ethics policy for research that includes Māori. The 2008 Consultation Guidelines maintain an aspiration that researchers consult with Māori on the research design, on potentially contentious issues, and on results dissemination (p. 9–11). For the first time, the Guidelines included a section dedicated to kaupapa Māori research. Kaupapa Māori research was defined as a “philosophy, theory, methodology and practice of research for the benefit of Māori which is also produced by Māori” (P.7).

In 2010, the Consultation Guidelines provided a further forum for the ongoing development of Indigenous ethics in New Zealand when it reissued the Guidelines to include the sovereignty politics-aligned newly created document *Te Ara Tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members* (Te Ara Tika) in its appendices. Te Ara Tika had been funded by (though not officially endorsed by) the Health Research Council (Tolich & Smith 2015). The Te Ara Tika document is organised in accordance with Māori tikanga and, therefore, structures the entirety of its guidance according to Māori concepts and worldviews. The 2010 re-release of the Consultation Guidelines is the most recent policy code by the Māori Health Committee at the time of this study.

The Māori Health Committee is the only New Zealand research oversight mechanism aligned to sovereignty politics. It represents the only separate

ethics policy designed for research that includes Māori, yet it lacks broad applicability. While Māori Health Committee funding requires adherence to the 2008 Consultation Guidelines to grant research funding, other Health Research Council funded research are only required to 'refer' to the guidelines (MHC 2008, p. 2). In the field of the Ministry of Health's Health and Disability Ethics Committee oversight, the position of the 2008 Consultation Guidelines are more tenuous. The National Ethics Advisory Committee does not officially sanction these guidelines. The current Ministry of Health 2012 Intervention Guidelines simply state that researchers should be 'aware' of the Māori Health Committee Guidelines in addition to international documents such as the Declaration of Helsinki (NEAC 2012b). Perhaps the best way to describe the influence of the Māori Health Committee Guidelines in New Zealand research oversight is that it enjoys moral authority as a document that advocates Māori interest in research, rather than as a framework that enjoys substantive authority (outside of the Māori Health Committee funding regime).

The next area of New Zealand oversight of research created policy that enjoyed substantive authority but became fragmented across eight different oversight frameworks.

University oversight of research

When New Zealand universities formed ethics committee following the Cartwright Report, they moved away from centralised research oversight institutions to create separate regimes for each university. The lack of centralised oversight left each university to decide how it would include Indigenous ethics in its policies within the broad framework of the Education Amendment Act 1989.

The New Zealand Education Amendment Act 1989 is silent on the oversight of research ethics but requires in sec. 181 (b) that New Zealand's University

governing Councils must 'acknowledge the principles of the Treaty of Waitangi'. As in the case of the Ministry of Health's 1988 National Statement, the Education Amendment Act 1989 did not advance any arguments as to what it might mean by acknowledging the principles of the Treaty of Waitangi, therefore leaves the practice of the Treaty relationship to be negotiated locally. The most common way in which universities interpreted the Treaty principles was through Māori representation on university Ethics Committee boards (as encouraged by bicultural politics).

The most explicit guidance in the early years of ethical oversight in New Zealand universities came in the form of a recommendation by the Ministry of Health. The Ministry asked that University Ethics Committees include three Māori representatives (Rotondo 1996, p. 103–04). This Ministry of Health recommendation was just that: a recommendation. The Ministry had no ability to enforce its wishes on the university sector. Consequently, as each university created differing protocols of Māori involvement in university-based research all but one of New Zealand universities considered that the Ministry of Health recommendation of three Māori representatives was not practical in their contexts (p. 103–104). Rotondo found, moreover, that three of the universities contained no Māori representation at all (1996). Regarding the inclusion of policy code for researching with Māori, Rotondo is silent. Given the lack of explicit code dedicated to research within Māori communities at this time (the Ministry of Health 1991 Standard for example), it is likely that these policy references did not exist.

The lack of national oversight for university-based research in New Zealand makes charting a history of Indigenous ethics development difficult. Not only must this research spread over eight different fronts, the university ethics committees themselves do not provide readily accessible information such as past or future policy update schedules. This chapter engages with this challenge by measuring a defined outcome linked to the central question of

this thesis: how each New Zealand university policy framework advises researchers to engage in Māori consultation.

In the Auckland University policy code, Māori consultation is required when there is 'clear potential implications of direct interest to Māori or when the research proposal focuses on Māori as a cultural group' (University of Auckland 2013). The Auckland University of Technology directs research projects that 'involve Māori or involves Treaty of Waitangi obligations' to consult the 2010 Māori Health Committee Consultation Guidelines and the 2010 Te Ara Tika Guidelines (AUT University 2014).

Massey University requires that Māori consultation should be considered when 'Māori are involved as participants, or where the project is relevant to Māori' (Massey University 2013). Lincoln University is something of an outlier in this context as the sole reference to Māori in its code is a generic requirement that 'all [research] projects must accord with the Treaty of Waitangi and all other relevant legal requirements' (Lincoln University 2013, sec. 6.1). It does not contain, therefore, any code dedicated to understanding when Māori consultation should occur and what form it might take.

Both the University of Canterbury and Victoria University consider the needs of Māori consultation. The former considers that consultation should result when research involves 'a significant portion of Māori participants or issues... of central concern to Māori', while the latter states that consultation should begin when 'research involves or includes Māori' (University of Canterbury 2014; Victoria University of Wellington 2014). Waikato University makes no reference to Māori or the Treaty of Waitangi in its policy statement (University of Waikato 2008). Regarding consultation, the Waikato policy code does allow for the need of community consultation, but does so in a generic fashion without referencing Māori when it states that 'appropriate consultation is the responsibility of the researcher' (University of Waikato 2014, sec. 4). Otago University provides the most

unique Māori consultation policies of the New Zealand universities. Otago requires that all human research consult with its Māori consultation committee in addition to its ethics committee (Tolich & Smith 2015).

The above examination provides an example of the diversity of policy advice in New Zealand university policy codes. According to this analysis, a researcher based in Auckland University of Technology would require Māori consultation if its participants were likely to include Māori participants. Given that Māori represent approximately 15% of the New Zealand population, any randomly designated population sample over about ten individuals is likely to include a Māori participant. However, a researcher based in Auckland University is required to consult Māori only if the research is of direct interest to Māori. In the case of the Waikato University, its policies do not make it clear when Māori consultation should occur (other than when canvassing a community). The Lincoln University ethics policy is perhaps the least clear of the eight since it does not provide any guidance on when a researcher might engage in Māori consultation. At Otago University, engagement with the Māori consultation committee is considered to constitute consultation (University of Otago 2016). The consultation form requires that researchers demonstrate the relevance of the research project to Māori, but provides no policy code to guide this assessment.

Given that, the New Zealand university oversight of research does not enjoy a centralised structure or substantive guidance in the Education Amendment Act 1989, it is not surprising that New Zealand universities do not provide consistent ethics policy guidance for research that includes Māori. This lack of coherence of New Zealand ethics policy development is underlined further when the Ministry of Health and Health Research Council Māori Health Committee policies are also considered.

Case study summary

The New Zealand development of Indigenous ethics policy lacks the coherence found in Canada or Australia. New Zealand does not provide a unified site of Indigenous ethics advice. The unique contextual features of the three main areas of ethics policy development created differing policy advice. The Ministry of Health and university ethics policy development became subject to the unfulfilled aspirations of bicultural politics leaving Māori without sufficient influence to drive the development of ethics policy. The Health Research Council Māori Health Committee oversight benefited from structural affiliations with sovereignty politics, but its separation from Ministry of Health oversight undermined the application of its policy codes to Health and Disability Ethics Committees. The rise of kaupapa Māori research methodologies maintained interest in Indigenous ethics, but these sovereignty politics ideals only found acceptance in the Māori Health Committee policies. Consequently, the most active field of Indigenous ethical thought in New Zealand has not directly influenced the Ministry of Health policy codes. Māori

The ethics policy outcomes of the fractured development of New Zealand's biculturally-focused research oversight display clear differences from those found in the centralised and sovereignty politics-focused development structures of Canada and Australia. The following chapter will explore these features further when it directly compares the development of Indigenous ethics in Canada, Australia and New Zealand.

10

Negotiating Indigenous resistance and national structures: A comparative analysis of Canada, Australia and New Zealand

The previous three case studies demonstrated *how* Indigenous ethics policy emerged in Canada, Australia and New Zealand. This chapter explains through comparative analysis *why* New Zealand's ethics policy for research with Māori came to lag behind that of Canada and Australia. Punctuated equilibrium was used as a model to compare across both time and the three countries. The analysis in this chapter introduces four factors that explain why the New Zealand outcome was so different to that of Canada and Australia. The first factor is the success or failure of the method of resistance employed by Indigenous political action. The second is the number of research ethics institutions with which Indigenous ethics would need to engage. The third is the coherence of the relationship between the funding of public health and medical research and research oversight, and final factor is the influence of ministerial politics¹⁹.

The shape of Indigenous resistance

The particular form of Indigenous resistance in Canada, Australia and New Zealand guided the demands that each national Indigenous Peoples made to research oversight. The success of sovereignty politics demands in Canada and Australia allowed the formation of separate Indigenous ethical space, while unfulfilled bicultural aspirations left New Zealand without separate policy or the necessary levels of Māori participation to drive Indigenous ethics policy development in New Zealand's policy statements.

¹⁹ This chapter uses a narrative pattern to describe the influence of the four factors. A comparison in table form is produced in Appendix F.

The impetus of sovereignty politics demands in Canada and Australia

Chapter three introduced the national Indigenous political demands of Canada and Australia: an aspiration for the return of control over land, mechanisms of self-governance and culturally relevant means of self-expression. Sovereignty political demands tended not to be concerned with control outside of these areas and instead focused on the production of separate structures dedicated to Indigenous needs. Canadian and Australian sovereignty politics demands described in chapters five and seven aligned with these aspirations and aspired for the creation and maintenance of separate ethics policy. These limited demands do not challenge the larger structures of research oversight. For example, the creation of discrete Indigenous ethics policy did not challenge the wording of national ethics policy other than requiring the formation of discrete chapters or documents dedicated to Indigenous ethics. Likewise, as sovereignty politics made no claim to a larger role in the oversight of research in either Canada or Australia, it did not directly challenge the membership structures of ethics committees or the respective national ethics committees.

The impetus of sovereignty Indigenous ethics was encouraged by the involvement of activism such as was found at the 1986 Alice Springs conference, the 1989 National Aboriginal Health Strategy Working Party and the influence of the Aboriginal and Torres Strait Islander Research Agenda Working Group in Australia. In Canada the direct lobbying by public health researchers at the formation of the Canadian Institutes of Health Research Council convinced the Council to create an institute dedicated to the advancement of Indigenous public health (CIHRC, 2001). Such development of dedicated concern for separate Indigenous public health structures led to support for the creation of dedicated research policy for research with Indigenous communities. In Canada and Australia this impetus is reflected by the current 2014 TCPS2 Indigenous chapter and the 2003 NHMRC Values and Ethics document. Earlier policy documents also followed this

pattern (for example: NHMRC 1999b, 2003, 2013; NHMRC, ARC, & AVCC 2007; CIHR et al. 1998, 2010, 2014).

National research oversight in both Canada and Australia resisted the authorisation of separate Indigenous ethics policy, but the structure of separate Indigenous chapters or documents remained durable over time. In Canada, the most substantial point of resistance to dedicated Indigenous ethics policy was the introduction of the 1996 Draft of the Tri-Council ethics policy statement, which included a collectives chapter (McDonald 2009). The collectives chapter rejected the 'special' relationship between the state and Indigenous peoples found in Indigenous ethics when it merged the ethics policy needs of Indigenous research with those of minority communities.

In Australia, the choice by the NHMRC not to formally validate the 1991 Interim Guidelines (Humphery 2002) did not threaten the structure of Indigenous ethics as separate ethics policy but instead held back its formal introduction into Australian research oversight. The later introduction of a collectivities chapter in the 1999 NHMRC national statement draft conflated the needs of Indigenous communities with those of minority communities in a similar manner to that of the Canadian Tri-Council 1996 draft (Chalmers, Dunne, Finlay-Jones, & Rayner 1996). Despite these threats to the position of Indigenous ethics in Canada and Australia, separate ethics policy dedicated to Indigenous ethics was maintained in both contexts (NHMRC 1999b, 2003, 2013; NHMRC et al. 2007; CIHR et al. 1998, 2010, 2014).

A further feature of Canada and Australia that aided the ongoing development of separate Indigenous ethics policy was an alignment between sovereignty politics and the growing field of Indigenous ethics policy development. In Canada, the continued deployment of Indigenous ethics in research projects (Ermine, Sinclair, & Jeffery 2004; Ten Fingers 2005), Indigenous community desires to be co-creators of research projects (Shore, Wong, Seifer, Grignon, & Gamble 2008), the ongoing development of ethics

policy such as the Association for Canadian Universities for Northern Studies guidelines (Ermine et al. 2004) and community-specific ethics policy (for example: Mi'kmaq Ethics Watch (n.d.), the Auroroa (2011) and Nunavut (2011)) demonstrated continued dedication to the principles of sovereignty politics by arguing for the production of separate ethics policy.

In Australia, ethics policy largely developed within the NHMRC's research oversight frameworks, but the continued presence of Aboriginal and Torres Strait Islander health organisations maintained the capacity of Indigenous proponents who displayed commitment to Indigenous self-determination in health services delivery (NACCHO 2015; Onemda 2016). All of these expressions by Indigenous proponents exhibited a commitment to sovereignty politics as they concentrated on separate structures that considered areas of direct importance to Indigenous peoples.

As of 2014, the national statements of Canada and Australia are mature documents that are unlikely to change significantly in future iterations. The Canadian Tri-Council 2014 TCPS Statement update is the third consecutive document that contains an Indigenous ethics chapter (CIHR et al. 1998, 2010, 2014). The Australian NHMRC decision to update its statements using 'rolling' reviews where one or two chapters are updated at regular intervals instead of the whole structure every five to seven years (NHMRC 2014b) implies that incremental rather than structural changes are envisaged in the future. The likelihood, therefore, of the withdrawal of the Indigenous chapters in the Tri-Council and NHMRC national statements appears to be low.

In contrast to the successful aspirations of sovereignty politics in Canada and Australia, Māori were unable to secure the aims of bicultural politics in the oversight of New Zealand research.

New Zealand's unfulfilled bicultural ethics

New Zealand's Indigenous ethics advocates made bicultural political demands and argued that Māori should gain equal influence at all levels of research oversight. The 1994 Te Puni Kōkiri report, *Ngā Tikanga Pono Wāhanga Hauora*, argued this point explicitly when it recommended that half of the membership of the Ministry of Health national ethics committee and all Health and Disability Ethics Committees be Māori (Te Puni Kōkiri 1994). This focus on Māori representation came at the expense of a concern for the development of policy code because the aspirations of bicultural ethics assumed that the creation of ethics policy sensitive to Māori needs would follow Māori gaining equal participation in New Zealand's oversight of research. This view concentrated attention on participation negotiations rather than policy development.

Te Puni Kōkiri's bicultural demands assumed a radical altering of Māori participation across all levels of New Zealand research oversight. This level of Māori participation did not eventuate (NACHDSE 1996, p. 41). Unlike Canada and Australia where the demands of sovereignty politics were attained, the Ministry of Health's ethics policy rejected the participation demands of bicultural politics and instead introduced Māori as junior partners in New Zealand research oversight. The Ministry of Health's 1988 Standard required the presence of one Māori on each of the Health and Disability Ethics Committees, and therefore falls short of the bicultural aspirations of a 50% Māori and 50% non-Māori membership balance. The 1988 Standard also stated that Health and Disability Ethics Committees should operate according to the principles of the Treaty of Waitangi, but as it did not further define the meaning of partnership, this symbolic policy lacked concrete application. The participation of Māori member on Ministry of Health national ethics committees (where the Ministry developed ethics policy) also fell short of bicultural aims. Chapter nine considered the likelihood that, at best, the Ministry of Health's national ethics committee in

1996 would have contained two Māori members out of total of twelve. The later reformation of the Ministry of Health's national ethics committee (the National Ethics Advisory Committee) did not improve this balance when it required the inclusion of two Māori members on its twelve-member board (NEAC 2007, 2008, 2012a, para. 4).

Given the discrepancies between the bicultural aspirations of Māori participation in research oversight and the practice, it is difficult to argue that Māori were in a position to influence the development of ethics policy for research where Māori are involved as participants. This reduced reality of Māori participation is consistent with O'Sullivan's view that the practice of biculturalism between Māori and the New Zealand state amounts to a 'partnership' where Māori are locked into a relationship where they are junior partners unable to attain meaningful influence (O'Sullivan 2007).

This junior position of Māori in the oversight of Ministry of Health research is further emphasised by the ability of the Ministry to undermine the participation of Māori over time. Early resistance by the Ministry of Health emerged through a lack of commitment to define the Treaty of Waitangi relationship between Māori and non-Māori members of Health and Disability Ethics Committees (DOH 1988, 1991; NACHDSE 1996). Later reactions to bicultural ethics undermined previous bicultural gains, such as the concept that research oversight represented a Treaty of Waitangi partnership between Māori and Health and Disability Ethics Committees (MOH 2012, sec. 16). Also undermined was the required Māori participation on the Ministry of Health's National Ethics Advisory Committee (NEAC 2013, 2015a), while guaranteed Māori membership on Health and Disability Ethics Committees was reduced to a single individual (HDEC 2012a, 2012b, 2012c, 2012d).

In Canada and Australia, the actions of Indigenous ethics proponents aligned with, and gave support for, sovereignty politics when the continued

academic and community development of Indigenous ethics supported separate Indigenous ethics policy. In New Zealand, however, the growing prominence of kaupapa Māori methodologies aligned with sovereignty politics and therefore did not explicitly support bicultural politics in its call for substantial Māori participation in national research oversight. Kaupapa Māori research has gained and maintained a high profile in New Zealand universities and in the wider research context (Canterbury 2011; KM 2007; MIA 2007, 2010; Otago University 2015; Rangahau 2015; University of Auckland 2015). However, in the framing of this thesis, the increased prominence of kaupapa Māori research demonstrates a shift towards sovereignty Indigenous ethics as it emphasises the separation of Māori worlds from non-Māori (Walker, Eketone, & Gibbs 2006). This shift is not given expression in the Ministry of Health statements as references to research with Māori are not included in separate chapters, but instead expressed in sporadic references to Māori in the statements. The last twenty years have also seen the development of dedicated ethics policy for research with Māori outside of the Ministry of Health regime in the Māori Health Committee's 1998 and 2008 Consultation Guidelines. But neither the sovereignty politics calls of kaupapa Māori research, nor the Māori Health Committee ethics policy, bolstered support for increased Māori participation in Ministry of Health research oversight in a manner found in Canada or Australia.

In the almost thirty years since Māori gained junior partnership status in Ministry of Health research oversight, Māori have lost previously gained participation in both Health and Disability Ethics Committees and the Ministry of Health's National Ethics Advisory Committee (HDEC 2012a, 2012b, 2012c, 2012d; NEAC 2013, 2015a). Compared to Canada and Australia's development and maintenance of ethics policy for research that includes Indigenous Peoples, New Zealand's Ministry of Health ethics policy for research involving Māori has been criticised as providing inconsistent

advice (NEAC 2015b) and providing little guidance on how research might partner with Māori (Tolich & Smith 2015).

This does not necessarily mean that bicultural ethical ideals failed in New Zealand. Rather, the aspirations of Māori to gain an equal partnership role in the oversight of New Zealand research was undermined by Ministry of Health decisions to maintain Māori as junior partners in research oversight. From this position of limited influence, Māori did not gain sufficient sway to drive ethics policy development in the Ministry of Health and university ethics committee oversight of research.

The shape of Indigenous resistance to research oversight was brought to this analysis first because it influenced how Indigenous ethics were interpreted in Canada, Australia and New Zealand. However, once Indigenous ethics were introduced to Canada, Australia and New Zealand, the structures of the three research oversight institutions also influenced the development of Indigenous ethics policy. Chapters four, six and eight framed Canada and Australia's regimes as centralised research oversight, and New Zealand's as fractured. The ramifications of these differences inform the final three factors.

The number of research oversight institutions

The number of institutions Indigenous ethics needed to engage with to gain national research oversight coverage impacted Indigenous ethics policy resources. Chapters four, six and eight noted that Canada and Australia developed centralised research oversight, while New Zealand's research oversight fractured into ten different institutions. A comparison of how each case study developed into its current form is provided in Appendix G, leaving this analysis to concentrate on the implications of the number of research oversight institutions to Indigenous ethics.

Canada and Australia's singular research oversight regimes

The release of the Canadian 1998 Tri-Council Policy Statement (TCPS) and the Australian 1999 NHMRC National Statement symbolised the formation of centralised research oversight in Canada and Australia. Both the Tri-Council and the NHMRC were responsible for national research oversight, contained a national ethics committee (the Canadian Interagency Advisory Panel on Research Ethics, and the Australian Health Ethics Committee), produced ethics policy formed as a national statement for all human research (the TCPS Statements and the NHMRC National Statements), and were responsible for ethics committees (Research Ethics Boards and Human Research Ethics Committees).

An outcome of this concentration of research oversight into a single point was that Canada and Australia's Indigenous ethics protagonists could confront a single institution to argue for ethics policy consideration. Before the formation of the Tri-Council, Canadian Indigenous ethics protagonists were required to convince both the Social Science and Humanities Research Council and Medical Research Council of the importance of Indigenous ethics (Scott & Receveur 1995), *and* spread the resources of Indigenous ethics exponents across the development of two different policy documents. Following the release of the Indigenous chapter in the 1998 TCPS National Statement, advocates of Indigenous ethics in Canada could concentrate on aiding the development of the next iteration of the TCPS Indigenous ethics chapter. Indigenous ethics in Australia have benefited from the development of ethics policy within the single institution of the NHMRC since the production of the 1991 *Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* (1991 Interim Guidelines).

A further benefit of the focused production of Indigenous ethics policy in Canada and Australia was that it also allowed the concentration of scarce research oversight resources towards policy development. Canadian Tri-

Council Working Group member Professor McDonald remarked that the development of the 1998 TCPS National Statement operated on a budget of less than 5% of the Royal Commission on Reproductive Technologies (2009). In Australia, the NHMRC allocated only \$25,000 to allow Aboriginal and Torres Strait Islander community consultation to aid in the development of the 1991 Interim Guidelines (Humphery 2002). Within these budgetary constraints, a centralised development of Indigenous ethics policy reduced the potential that institutional capacity would be lost due to duplication. These advantages of centralised research oversight were not found in New Zealand.

New Zealand's ten research oversight regimes

In contrast to Canada and Australia, New Zealand's research oversight is fractured across a total of ten research oversight institutions. Currently, the Ministry of Health maintains a national ethics committee (the National Ethics Advisory Committee) and its own ethics committees (Health and Disability Ethics Committees). In addition, the Health Research Council maintains its Health Research Council Ethics Committee as an accreditor of the Ministry of Health's Health and Disability Ethics Committees and six of the eight New Zealand university ethics committees (AUT University 2014; Lincoln University 2013; Massey University 2013; University of Auckland 2013; University of Canterbury 2014; University of Waikato 2008; Victoria University of Wellington 2014). Finally, the ethics committees of New Zealand's eight universities are guided by ethics policy documents unique to each university (AUT University 2014; Lincoln University 2013; Massey University 2013; University of Auckland 2013; University of Canterbury 2014; University of Waikato 2008; Victoria University of Wellington 2014).

The duplication of research oversight in New Zealand undermines the numerical advantage that Māori enjoy comparative to that of the Indigenous Peoples of Canada and Australia. Māori represent 15.4% of the total New

Zealand population (SATS 2015) compared with the Indigenous Peoples of Canada and Australia representing 4.2% (NHS 2011) and 3% (ABS 2011) of their respective populations. This advantage is negated in New Zealand when Māori are required to spread resources over ten distinct institutions.

The dilution of Māori ethics policy expertise is further undermined in university regimes, as the eight New Zealand universities do not maintain a national ethics committee. Chapter eight explained how Indigenous ethics advocates in New Zealand universities are required to intervene across the eight universities who have no standing committee responsible for ethics policy development and no clear timeline for when each ethics policy would be under review.

From the point of view of research oversight institutions, New Zealand lacks an advantage of scale with which to fund consultation with Indigenous communities to develop ethics policy. The Canadian and Australia health and medical research councils currently control yearly budgets of over \$900 and approximately \$750 million dollars respectively (CIHRC 2015b; NHMRC 2014a). The New Zealand Health Research Council, by contrast, had a budget of \$84 million in 2014 (HRC 2014). From the point of view of institutional scale, New Zealand's smaller funding base is the least likely to be able to absorb the development of Indigenous ethics policy when duplicated over ten different institutions.

Evidence of this discrepancy is found in the funding of Indigenous community consultation where Indigenous ethics policy is developed. The development of Canada's 2010 TCPS2 Indigenous chapter and Australia's 2003 NHMRC Values and Ethics document were the result of extensive Indigenous community consultation (CIHRC 2005; Kishchuch & Gauthier 2009; NHMRC 2003 appendix 1). No New Zealand research oversight institution has provided evidence that it developed Indigenous ethics policy with the aid of widespread Māori community consultation (Auckland

University of Technology 2013; HRCEC 1998; Lincoln University 2013; Massey University 2013; MHC 2008; NEAC 2012b, 2012c; University of Auckland 2013; University of Canterbury 2014; University of Waikato 2008; Victoria University of Wellington 2014).

A further implication of national research oversight structures to the development of Indigenous ethics policy is the position of public and medical research.

The coherence of the relationship between the funding of public health and medical research and research oversight

Medical and public health research funders emerged as cornerstone allies of Indigenous ethics in all three case studies as each research oversight institution dedicated resources to the creation of separate Indigenous ethics policy. For example, the Canadian Institutes of Health Research Council funded and facilitated the production of the 2007 *Guidelines for Health Research Involving Aboriginal People*, the Australian NHMRC's supported the development of the 2003 NHMRC Values and Ethics, and the New Zealand Health Research Council Māori Health Committees produced the 2008 Consultation Guidelines. In Canada and Australia, the formal inclusion of the funders of public health research in national regimes of research oversight allowed the efforts of these two public health research councils to directly encourage the development of Indigenous ethics policy. In New Zealand, the separation between the funders of medical and public health research (the Health Research Council) and the research oversight of medical and public health research (the Ministry of Health) undermined the influence of the Māori Health Committee's 1998 and 2008 Consultation Guidelines in Ministry of Health national statements.

Canada and Australia's public health support of Indigenous ethics

Canada and Australia's medical research councils symbolically recognised the needs of public health research at the Canadian Institutes of Health Research Council's reformation in 2000 (Canadian Institutes of Health Research Act 2000) and the reformation of the NHMRC in 1994 (1994 NHMRC Act). Both the Canadian and Australian Institutes of the Health Research Council and the NHMRC were required by law to fund research that would ensure national public health gain (1994 NHMRC Act, sec 4; CIHRC Act 200, preamble).

In aid of this requirement, each was able to be convinced of the need to directly address Indigenous public health. In 2001, the Canadian Institutes of Health Research Council created the Institute of Aboriginal Peoples' Health Research as one of its 13 core initiatives (Castellano & Reading 2010), and in 1997 the NHMRC directly addressed Indigenous public health by forming the Aboriginal and Torres Strait Islander Agenda Working Group (NHMRC 1999a). To gain an ethical consensus on Indigenous public health research, both the Institute of Aboriginal Peoples' Health Research and the Aboriginal and Torres Strait Islander Agenda Working Group prioritised the formation of Indigenous ethics policy (IAPH, 2002; NHMRC & RAWG 2002). To fulfil this mandate, the Canadian Institutes of Health Research Council funded and facilitated the First Nations, Inuit and Métis consultation that led to the 2007 CIHRC Guidelines (Reading & Dean 2005), which in turn directly informed the later 2010 NHMRC national statement Indigenous chapter (Onyemelukwe & Downie 2011). In Australia, the Aboriginal and Torres Strait Islander Agenda Working Group facilitated a meeting of Aboriginal and Torres Strait Islander representative to mould these frames into a draft document (HREC 2003) that would later form the 2003 Values and Ethics document.

Both the Canadian Institutes of Health Research Council and the NHMRC evidenced their support for these ethics policy documents when they formally accepted their relevance to each national statement (Castellano & Reading 2010; NHMRC 2003). The Canadian Institutes of Health Research Council is a founding member of the Tri-Council, and the NHMRC is the regime responsible for research oversight in Australia. Consequently, both of these policy documents formed the basis of Indigenous ethics policy in the respective national policy statements of Canada and Australia (NHMRC et al. 2007, Chapter 4.7; CIHR et al. 2010, Chapter 9).

New Zealand public health research funders were separated from research oversight

Like the Canadian and Australian case studies, the Health Research Council's Māori Health Committee funded the production of Indigenous ethics policy documents (HRC 2008; HRCEC 1998). Yet even as the Māori Health Committee possessed an ability to develop and recommend Indigenous ethics policy, it lacked an authority to demand Ministry of Health recognition of its policy Guidelines.

Under the conditions of New Zealand's fragmented oversight structures, the Health Research Council lacked direct influence in Ministry of Health ethics policy development (NEAC 2012d). Consequently, although New Zealand does possess dedicated Indigenous ethics policy similar to that of Canada and Australia, it has no formal position in the Ministry of Health's Health and Disability Ethics Committees research oversight (NEAC 2012d). This lack of inclusion in Ministry of Health oversight limits the direct applicability of the 2008 Consultation Guidelines to research that is directly funded by the Māori Health Committee (MHC 2008, p. 2; NEAC 2012b).

The influence of Ministerial politics on research oversight is a final factor that explains the difference between the production of Indigenous ethics policies in New Zealand from Canada and Australia.

The influence of Ministerial politics

The relationship between Ministerial politics and research oversight in Canada and Australia did not negatively affect the development of Indigenous ethics policy, while this relationship in New Zealand undermined the development of Indigenous ethics policy.

Canada and Australia's indirect relationship with Ministerial politics

Canada and Australia research oversight maintained a consistent and indirect relationship with Ministerial politics. None of Canada's three Councils or the Tri-Council itself report directly to government Ministers (Rolleston, Armour, & Stipich 1997). The three Councils do enjoy a legislative basis (CIHRC 2015a; NSERC 2015; SSHRC 2015) but these frameworks do not directly consider research oversight. The Australian NHMRC is controlled by the National Health and Medical Research Council Act 1992. Section 35 of the Act requires the formation of the Australian Health Ethics Committee (which is responsible for the production of ethics policy). Section 35, 3, (C) of the Act does allow the Minister to direct the Australian Health Ethics Committee, but successive Ministers have chosen not to use this feature.

Given this structure, Ministerial input to the Canadian Tri-Council is reduced to issue-specific advice or concerns, and not day-to-day oversight. Here, the Canadian Ministry of Health and the Ministry of Industry and Commerce encouraged the three Councils to set up the Tri-Council policy Working Group that was responsible for drafting the 1998 TCPS Statement. Likewise, the Department of Justice recommended that the communities section of the TCPS be withdrawn as the Tri-Council working group had not sufficiently consulted with First Nations, Inuit and Métis communities (McDonald 2009). Following the Department of Justice recommendation, the communities' chapter of the TCPS draft was no longer tenable.

Like the Tri-Council, the NHMRC's Australian Health Ethics Committee is distanced from day-to-day Ministerial oversight of its activities. The Australian context was defined by indirect Ministerial involvement in the related area of Aboriginal and Torres Strait Islander medical and public health research. These indirect involvements gave legitimacy to Indigenous research ethics.

An example of such indirect Ministerial involvement was the Minister of Health demands to the 2002 115th session of the NHMRC that it should increase its concern for Aboriginal and Torres Strait Islander medical and public health research (NHMRC 1993). Significantly, this Ministerial intervention was not directed at research oversight but towards the funding of public health research. The report of the 115th session does not record the Minister of Health referencing Indigenous ethics. However, as the NHMRC sought to heed the Minister's intent in creating the Aboriginal and Torres Strait Islander Agenda Working Group, it enabled the formation of a committee that directly supported the development of the 2003 Values and Ethics document (Castellano & Reading 2010).

New Zealand's uneven relationship with Ministerial politics

The Ministerial relationships to research oversight present in Canada and Australia are not found in New Zealand. Within the fractured nature of the New Zealand context, the nature of political autonomy in the ethical oversight of research depends on the institution concerned.

In the case of New Zealand's eight universities, there does not exist a direct political relationship with research oversight. Rotondo (1996) found that before 1996, the Ministry of Health encouraged university ethics boards to contain three Māori members. However, the lack of political capital behind this request can be seen in the fact that none of the university ethics committees complied with this request (Rotondo 1996). Likewise, the Health

Research Council Ethics Committee desire to accredit university ethics committees is not fully subscribed (HRCEC 2013). An important outcome of this unsubstantial Ministerial involvement is that the eight universities did not enjoy the benefit of either an encouragement to form a national ethics committee or, more importantly, the funding to do so. By contrast, the development of Indigenous ethics documents in Canada and Australia benefited from the dedicated resources of the Canadian Institutes of Health Research Council and the NHMRC respectively. This institutional support in Canada and Australia allowed the formation of literature reviews (Ermine et al. 2004; McAullay, Anderson, & Griew 2002) and facilitated substantial Indigenous community consultation to aid the drafting of ethics policy (Humphery 2002; Kishchuch & Gauthier 2009; Weijer 1999). It is difficult to imagine how each of New Zealand's eight universities could have completed these tasks, as they do not enjoy the institutional support that Ministerial or legislative oversight might bring.

Ministerial influence over New Zealand's Ministry of Health research oversight created limits that excluded the development of ethics policy code designed for research with Māori communities. Such Ministerial control undermined the National Ethics Advisory Committees ability to create policy code for research with Māori, even though its Terms of Reference required that it 'promote national ethical guidelines relevant to Māori health research' (NEAC 2008, para. 10).

Chapter nine's discussion of the development of New Zealand Indigenous ethics policy revealed how the wane in government interest in bicultural politics, coupled with the direct reporting relationship between the National Ethics Advisory Committee and the Minister of Health, encouraged the development of Indigenous ethics to mirror the larger political wane. Since the political withdrawal from bicultural politics following the 2000 Closing the Gaps initiative and the 2003 Court of Appeal ruling (Humpage 2002, 2006; Meijl 2006), Māori have lost guaranteed inclusion on the National

Ethics Advisory Committee (NEAC 2013, 2015a), the number of Māori members of Health and Disability Ethics Committees has halved from two to one (HDEC 2012a, 2012b, 2012c, 2012d), and the justification of Māori inclusion on Health and Disability Ethics Committees has fallen from ideals of a bicultural partnership to that of holders of expertise in Māori tikanga (HDEC 2012a, 2012b, 2012c, 2012d). Similarly, Indigenous ethics policy in the Ministry of Health statements diminished the role of Māori communities in research over time. Tolich and Smith have described this shift as a 'cultural turn' where ethics policy increasingly emphasises the ethic of avoiding offence rather than creating supportive environments where partnership can occur between researcher and Māori communities (Tolich & Smith 2015).

This analysis has revealed characteristics that explain why the ethics policy outcomes of the three countries are different. These factors are the different methods of Indigenous resistance, namely sovereignty and bicultural politics, and the form of research oversight institutions. Sovereignty politics, in negotiation with a central research oversight institution, direct public health research support and indirect Ministerial involvement, fostered the development of separate national ethics policy for research with Indigenous Peoples in Canada and Australia. Bicultural politics, in negotiation with New Zealand's multiple research oversight institutions, without the support of the public health research council, and influenced by uneven Ministerial involvement, produced a very different outcome: New Zealand has no nationally recognised chapter or document dedicated to research with Māori communities.

Chapter 11 focuses solely on how New Zealand might align itself with the Canadian, and to a lesser extent the Australian, model.

This chapter makes specific recommendations intended to address New Zealand's failure to create robust Indigenous ethics policy development. Robust Indigenous ethics policy has been defined here as policy that can withstand threats to its existence; allow widespread community consultation in its development; support ongoing policy development; be relevant to all human research; and consistently require researchers to consult with Indigenous communities.

Chapter ten introduced four explanatory factors that showed why New Zealand failed to match Canada and Australia. Broadly speaking the first factor relates to the impact of Indigenous ethical aspirations, and the final three factors to overarching structures of research oversight. I will address the final three factors first.

The fragmentation of New Zealand's oversight of research diluted both the bureaucratic and human resources of ethics policy development. This suggests that a transfer of research oversight to a centralised research oversight body would allow Māori to engage a single institution to press for ethics policy consideration. It would also encourage the creation of nationwide policy code designed for research with Māori that is relevant for both medical and non-medical research. All other New Zealand research oversight bodies would be required to either disband or come under the direct authority of the new national body. Tolich and Barry (2015) have put forward the Royal Society of New Zealand as a suitable body. The Royal Society of New Zealand is an independent statutory organisation whose purpose is to advance and promote science, technology and the humanities in New Zealand (RSNZ 2016a, 2016c). Similar to the three

Councils of the Canadian Tri-Council and the Australian NHMRC, one of the ways the Royal Society advances its aims is to fund research (RSNZ 2016b). Another potential oversight regime is the Health Research Council. The Health Research Council Act 1990 includes a provision for a national research oversight committee, but under the current political climate the authority of this committee is undermined²⁰.

The creation of a national oversight institution would likely enfranchise the institution responsible for public health research (the Health Research Council) with the oversight of research ethics for the first time in the New Zealand context since the Cartwright Inquiry. The previous chapter described how these conditions in Canada and Australia allowed the needs of public health research to convince research oversight regimes of the need to create substantive policy for research within Indigenous communities. This is a feature that is lacking in the New Zealand context.

²⁰ While the transfer of research oversight responsibility to the Royal Society of New Zealand or the Health Research Council would allow important advantages to the development of ethics policy for research with Māori, recent history suggests little room for optimism. Following the Cartwright Inquiry the oversight of medical research has been entangled with the oft-restructured public health sector. Beginning in Health Research Council Act 1990, subsequent governments have used their own legislative frameworks to oversee research with little concern for creating cohesive national research oversight apparatus. The later Health and Disability Services Act 1993 and the New Zealand Public Health and Disability Act 2000 simply created national ethics committees that operated in addition to the work of the Health Research Council. The creation of national research oversight mechanisms has been lost in larger government priorities for the public health sector. While this research shows the advantages of centralised research oversight for Indigenous ethics policy development, there is little to suggest that the current New Zealand government is sufficiently motivated to nationalise the oversight of research.

The creation of a national research oversight institution should enjoy a distance from day-to-day Ministerial involvement. This institutional structure would encourage the oversight of research ethics to develop according to the needs of the 'stakeholders' (such as New Zealand Universities and the Health Research Council) as opposed to the political needs of the Minister of Health. These three features would afford Māori a level of structural support comparable to that which allowed advocates of Indigenous ethics in Canada and Australia to develop cohesive policy for research involving Indigenous communities when aligned with the aspirations of sovereignty politics.

In the interests of ensuring Māori influence in New Zealand policy development, this thesis recommends the creation of a separate ethics policy chapter for research with Māori in a national research oversight structure. There are currently separate chapters for research with Māori, but these policies are not formally included in the Ministry of Health statements and therefore lack bureaucratic support and legitimacy in Ministry of Health ethics committee rulings.

The creation of a separate chapter addresses an ongoing difficulty in New Zealand, namely the lack of influence of Māori in Ministry of Health research oversight. If the national oversight regime were to function in a similar manner to that of the Tri-Council and NHMRC it would form a dedicated working committee to drive the development of Indigenous ethics policy. This Māori ethics working group would likely be dominated by Māori ethicists and researchers and therefore allow Māori to escape the junior partnership role experienced under the Ministry of Health research oversight. Creating a separate chapter would also align ethics policy with the development of kaupapa Māori research since both argue for the creation of separate ethics policy space for Māori.

The formation of a chapter in a national statement dedicated to research with Māori could allow the Māori ethics working group to leverage the national oversight institutional mechanisms to conduct extensive consultations with Māori to inform the drafting process. This could lead, for the first time in New Zealand, to the development of a nationally recognised ethics policy for research with Māori that is based on the outcome of extensive consultation with Māori communities.

In Canada and Australia the creation of separate policy chapters in national ethics statements created robust policy that withstood threats to its existence, allowed widespread community consultation in its development, supported ongoing policy development, covered all human research, and consistently required researchers to consult with Indigenous communities.

The recommendation to create separate structures within national research oversight for Māori is not a critique of the wish for Māori to maintain interest in all research conducted in New Zealand. Instead it is simply a recommendation based on what has worked in Canada and Australia, and what has lessened Māori influence over ethics policy development in New Zealand. With this in mind, future research may extend the findings of this thesis by exploring the means by which Māori may gain influence over research oversight in addition to the creation of separate structures for ethics policy development.

This research may benefit from further clarification of Māori interest in all New Zealand research. If, for example, an answer to this question is that Māori wish to capture the benefits/knowledge of public health research regardless of whether Māori are involved as participants, involvement in the development of national ethics policy may not benefit this end. Likewise, if Māori involvement is encouraged by a desire to see that all human research should seek to benefit communities, direct engagement

with funding councils such as the Royal New Zealand Society may be more profitable.

It is the intentions of these recommendations to encourage the creation of ethics policy development in New Zealand to match or exceed those found in Canada and Australia and in doing so bring truth to the aspirations of bioethicist Alistair V. Campbell who considered that

... if New Zealand has something special to offer [the world] it must surely be in terms of a genuine willingness to go beyond colonialism to a rediscovery of the strength and ethical relevance of Indigenous cultures (Campbell 1995, p. 153).

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Appendices

Appendix A

Way Back Machine

Way Back Machine is a non-for-profit digital archive of the World Wide Web and has been in operation since 1996. Its intent is to capture and archive the entire Internet and allow users to view archived versions of webpages across time. To build this archive, Way Back Machine revisits webpages every few weeks or months every few weeks and adds each new 'web capture' to the archive (source: http://en.wikipedia.org/wiki/Wayback_Machine).

This thesis used Way Back Machine to visit earlier versions of websites in the following manner:

First, the following the web page location is inserted into a web browser such as Google Chrome: <http://archive.org/web/>

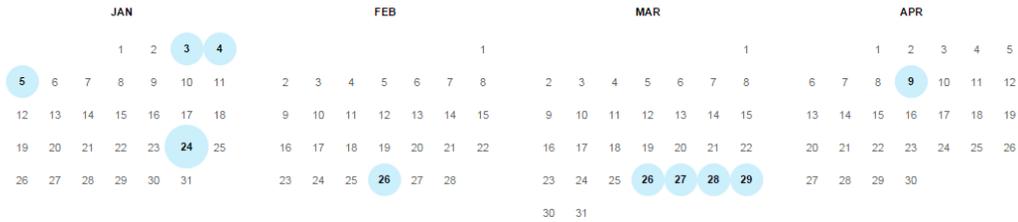
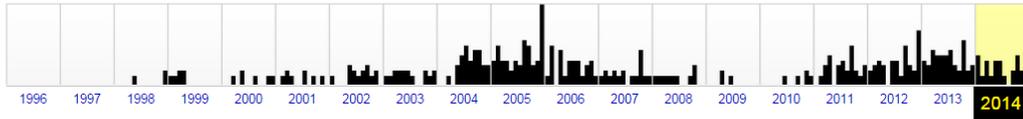
Next, the address of the desired webpage is inserted into the Way Back Machine search engine – in this case the New Zealand Human Rights Commission: <http://hrc.co.nz>.

As illustrated below, way back machine organises it's 'web captures' of the site according to year and month.

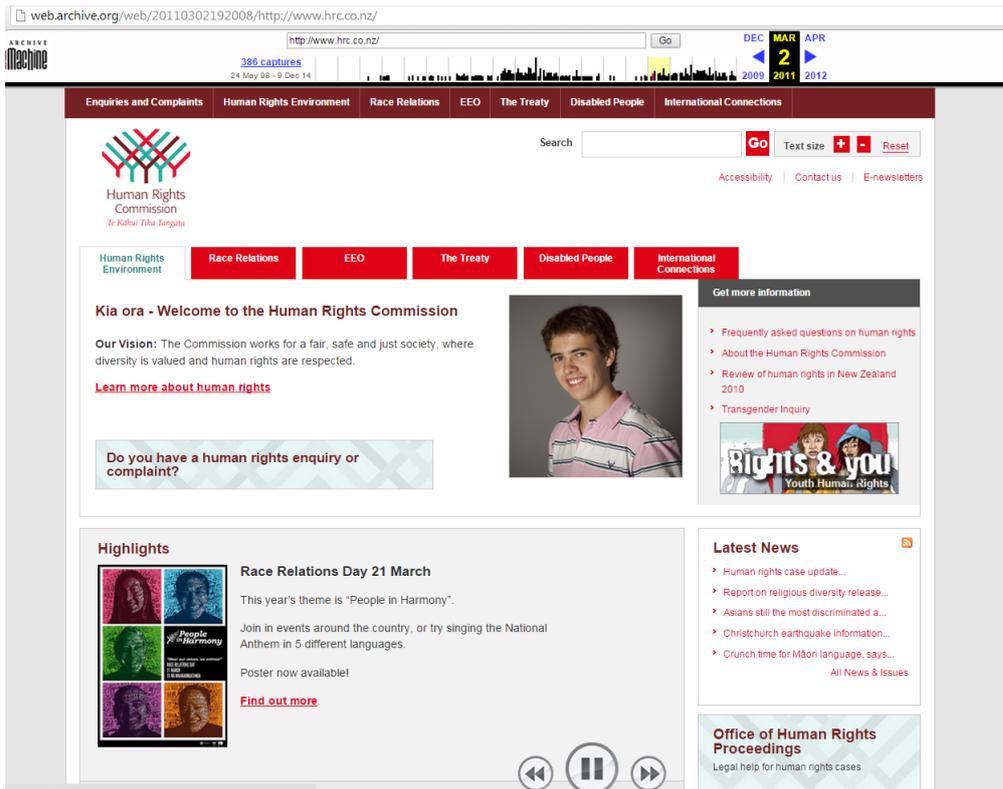
<http://hrc.co.nz>

Saved **386 times** between May 24, 1998 and December 9, 2014.

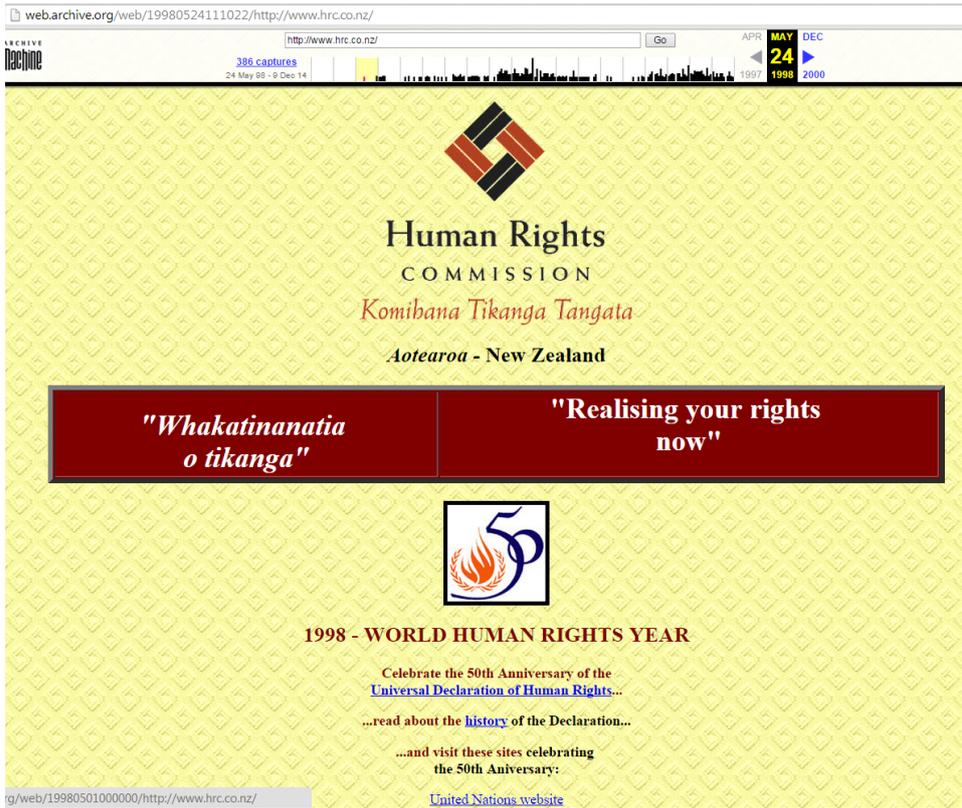
PLEASE DONATE TODAY. Your generosity preserves knowledge for future generations. Thank you.



Choosing a relevant web capture is accomplished by clicking the desired year on the above column (for example 2011), and then clicking on a relevant month and date web capture (shown by the circles above). If chosen as above, the following page will be produced:



Likewise, choosing the May 1998 chapter would gain this website capture:



Depending on the particular web capture, it is possible to enter the various sections of a website and download documents that may have been withdrawn from the future website iterations.

Appendix B

The Treaty of Waitangi

The Treaty of Waitangi, signed in 1840, formed a partnership between Māori and the Crown (Durie, 2002). As early as the 1870s, however, the Treaty had fallen into irrelevance to New Zealand's colonial society (Orange, 2011), and out of New Zealand's constitution (R. G. Mulgan, 2004).

One of the hallmarks of the Treaty of Waitangi is that it has two versions: a version written in English, and a version written in Māori. Significantly, there are serious discrepancies between the Māori and English versions which make direct application of the Treaty of Waitangi in law problematic (R. Walker, 1989). Biggs considered that these differences resulted from the translation of crucial terms in the two Treaty versions that are,

... not equivalent, either because they mean something else, or because the Māori words are more general and less precisely defined than the English" (1989, p. 310).

When the fourth Labour government began to introduce the Treaty of Waitangi into legislation in the mid-1980s, it chose to use the concept of the 'principles of the Treaty of Waitangi' in legislation and policy documents. The concept of the Treaty principles had first appeared in the Treaty of Waitangi Act 1975 – though the Act did not define them (Hudson & Russell, 2009).

The use of the principles of the Treaty of Waitangi by the fourth Labour Government allowed a move away from the pursuit of reconciliation between the two non-equivalent versions Treaty, and towards a search for

the 'intent' of the Treaty as found in Māori and English versions (T. J. Wright, 2006). Perhaps more importantly, the use of the principles of the Treaty provided a more flexible legal framework within which to consider Treaty-related concerns and obligations (Kingi, 2007). Professor Mason Durie explained the advantages of the elastic nature of the Treaty principles in the following way:

The good thing about that Treaty is its vagueness and that means you can negotiate it. If an issue comes up, Māori and the Crown talk about, and eventually after a decade or so reach the position they can both live with (Mason Durie cited in: Durie, Hoskins, & Jones, 2012, p. 28).

Appendix C

Glossary

The term **Indigenous ethics** is used to explain the research demands of Indigenous communities in Canada, Australia and New Zealand. Chapter 3 explores the history and arguments of Indigenous ethics further, but for now Indigenous ethics is considered to represent a call to move away from research *on* Indigenous communities to research conducted *by* or *with* Indigenous communities. Indigenous ethics argues that Indigenous worldviews, social practices, and community affiliations be respected in any research involving Indigenous individuals. Indigenous ethics argues further that research projects should ideally engage Indigenous communities in all stages of research: from the choice of research subject, to actual research itself and the dissemination of results. The importance of the definition of Indigenous ethics is underlined by the main aim of this thesis: to explain how the demands of Indigenous ethics were translated into ethics policy code in Canada, Australia and New Zealand.

Research oversight refers to the formal process of gauging the ethical suitability of research projects. **Centralised research oversight** must contain the following features,

- A **national oversight institution** tasked with the overall responsibility to maintain ethical standards in all human research. In Canada this organisation is the Tri-Council, in Australia it is the National Health and Medical Research Council (NHMRC). New Zealand does not have one national oversight institution, but many research oversight institutions; the Ministry of Health, the Health Research Council and eight unique university ethics committees.
- **Ethics committees** are charged with measuring the ethical suitability of research projects. It is ethics committees that weigh the ethical

suitability of individual research projects. Ethics committees are termed Research Ethics Boards in Canada, Human Research Ethics Committees in Australia, and Health and Disability Ethics Committees and university ethics committees in New Zealand.

- **Ethics policy** refers to national policy documents designed to guide both ethics committees and researchers to gauge the ethical suitability of research projects.
- **National ethics committees** or national standing committees are formed to provide ongoing development of ethics policy. The presence of a national ethics committee tends to ensure that ethics policy development is considered in a regular, as opposed to ad hoc, fashion. A national ethics committee may also maintain documentation that guides the procedures and membership requirements of ethics committees.

The term **National Statement** refers to an ethics policy document designed to consider all human research within a national context. A national statement should consider and be applicable to the ethics policy needs of the following research disciplines:

- **Medical research** is defined here as research that involves patients in intervention-based research designed to inform medical knowledge. Medical research can test standards of medical care, experiment with treatment practices or involve the clinical trial of pharmaceutical medicines. Medical research interventions are most often targeted at individual patients.
- **Public health research** is considered here to be distinct from medical research²¹ as it moves away from individual approaches to health in favour of a focus on social and environmental determinants of health. A focus on public health research encourages research projects to engage directly with communities to gain health information. In focusing on

²¹ Public health research is often considered as a sub discipline of medical research, but this thesis finds it useful to delineate this distinction.

communities, public health research aligns with Indigenous ethics demands to be considered as communities of affiliation.

- **Social science research** refers to the research that is operationalised in the social science and humanities disciplines. Of the three research disciplines, social science research embraces qualitative research more fully. Qualitative research critiques the empirical foundations of medical research and considers that ethics policy that is formed within empirical assumptions is inappropriate for the oversight of qualitative research. In the Canadian and Australia National Statements, a separate qualitative chapter was included to give consideration to social science concerns.

Health services are non-experimental health interventions such as hospitals and health clinics provide.

Hapu: 3. (noun) kinship group, clan, tribe, subtribe - section of a large kinship group and the primary political unit in traditional Māori society.

Iwi: 1. (noun) extended kinship group, tribe, nation, people, nationality, race - often refers to a large group of people descended from a common ancestor and associated with a distinct territory.

Koha: 1. (noun) gift, present, offering, donation, contribution - especially one maintaining social relationships and has connotations of reciprocity.

Tangata whenua: 1. (noun) local people, hosts, indigenous people - people born of the whenua, i.e. of the placenta and of the land where the people's ancestors have lived and where their placenta are buried.

Tikanga: 1. (noun) correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol - the customary system of values and practices that have developed over time and are deeply embedded in the social context.

Tino rangatiratanga: 1. (noun) self-determination, sovereignty, autonomy, self-government, domination, rule, control, power.

Māori translations retrieved from the *Māori dictionary: Te Aka Māori-English, English-Māori Dictionary*. <http://www.maoridictionary.co.nz/>

Appendix D

New Zealand governments

Some of these governments contain coalition partners, but this thesis borrows from Roper's terminology of New Zealand governments and cites the major political party in a coalition government as it allows for the recognition of the dominant party in any ruling coalition (Roper, 2011).

Second National	1960–1972
Third Labour	1972–1975
Third National	1975–1984
Fourth Labour	1984–1990
Fourth National	1990–1999
Fifth Labour	1999–2008
Fifth National	2008–present

Appendix E

New Zealand university ethics committee establishment

Table 2, List of New Zealand's university ethics committees and year of establishment (source: Rotondo, 1996)

University	Committee name	Established
Auckland	University of Auckland Human Subjects Ethics Committee	1988
Canterbury	University of Canterbury Human Ethics Committee	1992
Lincoln	Lincoln University Human Subjects Review Committee	1994
Massey	Massey University Human Ethics Committee	1987
Otago	University of Otago Ethics Committee	1980
Victoria	Victoria University of Wellington Human Ethics Committee	1991
Waikato	University of Waikato Human Research Ethics Committee	1993
Auckland University of Technology	Auckland University of Technology Ethics Committee	2000

Appendix F

Table 3, Summary of the factors driving the development of research oversight in Canada, Australia and New Zealand

National factors

National Factors	Canada	Australia	New Zealand
1. Research oversight drivers	<ul style="list-style-type: none"> 1. Funding pressure 2. The rise of public health 3. Fear of U.S style legislation 4. Research scandal 5. 3 funding Councils 	<ul style="list-style-type: none"> Institutional creep One ethics council... 	<ul style="list-style-type: none"> Scandal One ethics council...
2. Centralised research oversight	Yes	Yes	No: Ministry of Health; University: each separate; Health Research Council:

			funding control
3. Guiding legislation	No	Yes	Yes, but overlapping Acts
4. Political influence	Not direct	Not direct	Direct over the National Ethics Advisory Committee; not direct over universities

Indigenous factors	Canada	Australia	New Zealand
5. Formative Indigenous ethics drivers	Calls of Sovereign Pre-existing code development Royal Commission	Calls of Sovereign Growing funding of community controlled health organisations Royal Commission; Alice Springs	Biculturalism the leading organiser; Ethics as oversight, not policy code Criticism of research 'on' Māori
6. Research oversight resistance	Multicultural	Multicultural	Lip service bicultural; wane over time
7. Allied structures	Social science	Public health	Public health:

	(initially) Public health (Canadian Institutes of Health Research Council)	(NHMRC) – politics Roadmaps I & II	Health Research Council Māori Health Committee unable to influence the Ministry of Health
8. Ongoing Indigenous ethics drivers	Continued growth • Ethics policy development Indigenous research capacity	AIATSIS Continued existence of Aboriginal and Torres Strait Islander health organisations	Kaupapa Māori (separation) Te Ara Tika Indigenous research capacity growth
9. Availability of research oversight structures	• Yes: Aboriginal and Torres Strait Islander Research Ethics Initiative (p. 7)	Yes: Aboriginal and Torres Strait Islander Research Agenda Working Group (p. 10)	No: Ministry of Health Lacked influence: Health Research Council Māori Health Committee
10. Political influence	Positive/slight: Department of Justice advice	Positive: Ministry of Health pushed the NHMRC towards Indigenous public health research	Negative: Ministry of Health moved against Indigenous ethics None: New Zealand's eight Universities
11. Current ethics policy position	One policy code for all human research:	Two policy codes for all human	Not clear: Indigenous

	A separate chapter in the national statement	research: A separate document for medical research, and chapter in the national statement for non-medical	ethics sprinkled through the Ministry of Health codes; a dedicated document in the Health Research Council; mixed in the eight university codes.
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Appendix G

Comparison of the development of Canada, Australia and New Zealand's national research oversight institutions

Chapters four, six and eight described how Canada and Australia developed centralised research oversight, while New Zealand's research oversight fractured across multiple institutions. The paths to these outcomes were each unique in each country.

The development of contemporary research oversight in Canada was a reaction to the four factors of research funding pressure (McDonald, 2009), the undermining of former distinction between medical and social science research due to the rise of public health research (Rocher, 1999), fear of U.S style legislation (Kinsella, 2010) and research scandal (McDonald, 2009). The confluence of these factors encouraged the three government research funding Councils to act cooperatively to form the Tri-Council. An additional feature unique to Canada was the prior existence of the three funding Councils. The Canadian Institutes of Health Research Council (formerly the Medical Research Council), Social Sciences and Humanities Research Council and the National Science and Engineering Research Council had shared histories by Act of Parliament, were given responsibility to manage research funding within their remit (Rolleston, Armour, & Stipich, 1997), and were each formed before 1979 (CIHRC, 2015; NSERC, 2015; SSHRC, 2015).

Tri-Council-developed centralised research oversight comprised a national oversight institution (the Tri-Council), a national ethics committee (the Interagency Advisory Panel on Research Ethics), ethics policy that formed a national statement for all human research (the TCPS Statements), and

Research Ethics Boards that are required to follow the TCPS statements (TCPS2, 2014).

Australia developed its research oversight in a contrasting manner to Canada in that a single Council, the National Health and Medical Research Council (NHMRC), dominated its development (Chalmers, 2001; Israel, 2015). The factors present in Canada did not converge on the NHMRC in a fashion that forced the disruption of NHMRC research oversight.

As the NHMRC broadened its reach and regulatory intensity, it gradually added all the features of centralised research oversight. The NHMRC was designated as the institution responsible for national research oversight (NHMRC, 2015b), formed a national ethics committee (the Australian Health Ethics Committee) (Chalmers, Dunne, Finlay-Jones, & Rayner, 1996; Humphery, 2002; NHMRC, 2007, p. 1), developed ethics policy as a national statement for all human research (the NHMRC Statements), and Human Research Ethics Committees that are required to follow the NHMRC Statements (NHMRC, 1999b, 2013).

Unlike Canada, the Australian context did not contain three legislatively-backed Councils during formative points in its development. When, for example, the Australian Research Council (the Australia equivalent of Canada's Social Science and Humanities Research Council) was created by the Australia Research Council Act 2001, it was three years after the 1998 NHMRC statement had required all human research to be subject to NHMRC oversight (NHMRC, 1999b) and the NHMRC had already formed the features of centralised research oversight. The Australian Research Council was involved in the production of the 2007 NHMRC statement (NHMRC, ARC, & AVCC, 2007), but following this short period of inclusion, the Australian Research Council's involvement in NHMRC research oversight did not extend to an ongoing role (NHMRC, 2013, 2015a).

Despite the differing research oversight drivers in Canada and Australia, the development of centralised research oversight by both reveals a high degree of similarity. Both have a dedicated national ethics committee, ethics committees, and ethics policy as a national statement for all human research. The main difference between Canada and Australia, is that the national oversight institution of Canada formally includes the three funding Councils. In doing so, it enfranchised the medical and public health, social science and humanities, and natural science and engineering research Councils (Onyemelukwe & Downie, 2011). The Australian national oversight, by contrast, is directed singularly by the NHMRC.

Of the three contemporary structures, New Zealand's development was most influenced by research scandal. The 1987-8 Cartwright Inquiry radically altered New Zealand's research oversight (Tolich, 2001), but it did so in a manner that reflected its previous focus on the needs of medical and public health research. Between 1969 and 1983, the Medical Research Council introduced ethics policy, ethics committees, and a national ethics committee (Chalmers et al., 1996; Collins, 1992; McNeill, 1993; MRC, 1986). These same committees were also established in Australia. However, where pre-Cartwright Inquiry New Zealand research oversight differed from Australia in that it did not extend its ethics policy to formally include social science research (HSRC, 1983, p. 1, 13; MRC, 1986). The Australian NHMRC, by contrast, stated that its ethics policy was relevant for both medical and social science research in 1976 (Dodds, 2000; Humphery, 2002), and in 1985, required that all human research submit to NHMRC Institutional Ethics Committee review (Humphery, 2002; McNeill, 1993).

Consequently, when the Cartwright Inquiry focused attention on the needs of government health services (Douglass, 1993; McNeill, 1993), New Zealand had not gained Australia's level of experience in considering the ethical needs of all human research. The first ethics policy following the Cartwright Inquiry, the 1998 *Standard for Hospital and Area Health Board Ethics*

Committees Established to Review Research and Treatment Protocols (1998 Standard) reflects this focus on the needs of medical research (DOH, 1988). Likewise, the government's transfer of research oversight responsibilities for the Medical Research Council to the Ministry of Health (Douglass, 1993; McNeill, 1993) did not represent a concern to expand ethics policy to all human research.

Also implicated in the fracturing of New Zealand research oversight was the government's aborted plan for the Health Research Council Ethics Committee. Chapter eight uncovered how the incoming government chose not to use the Health Research Council Act 1990 as the sole institution responsible for research oversight. Instead, the New Zealand government both maintained the dominance of the Ministry of Health in research oversight, and also retained the existence of the Health Research Council Ethics Committee. New Zealand's research oversight was further fractured when New Zealand universities came to create research oversight regimes of their own in response to perceptions of legal vulnerability (Rotondo, 1996).

The ramifications of the differences between the centralised research oversight found in Canada and Australia, and fragmented oversight in New Zealand to Indigenous ethics are numerical. Advocates of Indigenous ethics in Canada and Australia would only need to confront a single institution to argue for ethics policy consideration. New Zealand's fractured research oversight requires that resources be split over ten different points of engagement.

Appendix E

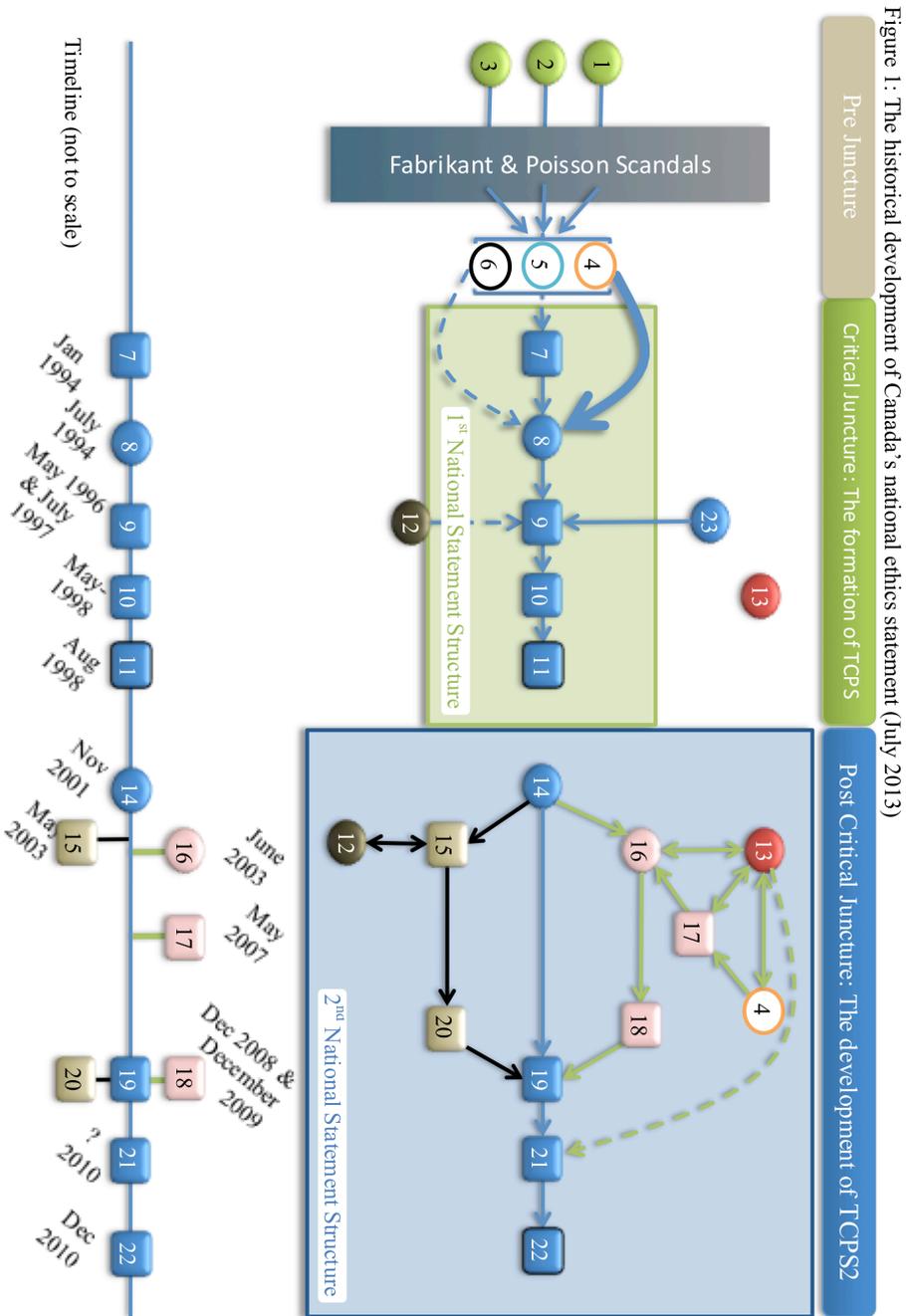


	Figure 1 Legend		
	<p>Square boxes such represent written processes such as might be found in a the release of a significant report, draft codes or final policy code</p>		
	<p>Round boxes represent either influential groups or large effects such as Indigenous authorities and community groups and the formation of a working group in order to form a national ethical statment</p>		

1	Neoliberal change in university and research funding regimes	13	Indigenous groups
2	Health research extends into the social sciences	14	Formation of PRE
3	Emergent ethical understandings of research ethics: inclusion, communities and Indigenous groups	15	Giving Voice to the Spectrum report
4	MRC – <i>Medical Research Council</i>	16	PRE Guiding Consortium (Indigenous)
5	NSERC – <i>National Science and Engineering Research Council</i>	17	Release of the CIHRC guidelines for health research within Indigenous communities
6	SSHRC – <i>Social Science and Humanities Research Council</i>	18	Indigenous chapter (9) intended for TCPS2
7	The 1994 tri-council statement in response to the Fabrikant scandal	19	Draft TCPS2
8	The Formation of the Tri-Council Working Group	20	Qualitative chapter (10) intended for TCPS2
9	1996 & 1997 Tri-Council Working Group drafts	21	Final TCPS2 write-up by the tri-councils (blind)
10	Final write-up by tri-council (blind)	22	Release of the 2010 TCPS2

11	Release of the 1998 TCPS code	23	Department of Justice intervention
12	Social Scientists		