

When the numbers do not add up:
Health research and health disparities
in Aotearoa New Zealand

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Abstract

Decisions about health policy and services are, in part, informed by research. In this thesis, I argue health research and the systems which generate and then use it, fail to consider marginalised populations. As a consequence, decision-makers in service and policy settings lack appropriate information to address health inequity and in fact contribute to it through their regard for these marginalised populations.

To support this argument, I draw on a range of empirical work. I review public records for evidence of marginalised groups' inclusion in research and the activities that use research to decide policy or service provision. I then examine the role of ethics committees in reviewing justice and the systems and structures that researchers who work with marginalised populations navigate. Using this information, I then look at reasons and potential solutions to this injustice.

I scrutinised public records for representation of three case populations considered marginalised in Aotearoa New Zealand (NZ) in evidence-generating activities and evidence-using activities to establish a lack of inclusion. Based on the data available, representation was found to be lacking.

In NZ, approved ethics committees have the task of ethically assessing health research that has the potential to create evidence. The National Ethical Advisory Committee (NEAC) of NZ sets out what justice entails in the review and practice of research. I surveyed committee members to understand their views on justice requirements and their review of them. The survey response rate was too low to be representative but provided starting points for discussion.

Using an institutional ethnographic method, I analysed interviews with senior researchers (informants) who work with marginalised populations alongside institutional texts to understand informants work and how it sits within the larger system of health research. I theorise that the marketisation of the university and health system within a neoliberal knowledge economy, along with an emphasis on the biomedical, direct research practices in ways counter-intuitive and counter-productive to those working with marginalised groups. Not only that but these

research systems create what Miranda Fricker calls an ‘epistemic injustice’ by their privileging of certain kinds of research work over others.

Moving from the empirical, the thread of epistemic injustice is then taken up and elaborated. Epistemologies in health research– their foundations, the information they provide, and their limitations are laid out. I argue that the privileging of one kind of knowing is in part based on our established theory of justice narrowing our perspective (especially within a neoliberal environment). Then, I put forward the claim that a shift in justice theory to a Capabilities Approach (CA) that reframes the questions that we need to address and therefore the methods needed to address them, might be more effective in acknowledging health inequity and creating a fairer health research environment.

Sen’s CA takes as its foundation the equalising of people’s capabilities to achieve their preferred functionings, recognising the diversity of these functionings and does this on the basis of public discourse and decision-making. This approach to justice in health research requires a more inclusive and patient-centered framework than the current model which in practice is often disease-centric and generalising. I argue a CA framework is likely to not only change the informational environment required to make decisions but liable to improve inequity because it more explicitly asks us to notice it.

Acknowledgements

A doctoral candidacy is in reality a selfish endeavour, it is a period of time in which you tell the people in your life you are going to be absent, in which you want your supervisors and others to have the same sense of interest in your topic that you feel, in which you want the world to stop while you figure something out – it does not. And yet the goal is often other-directed – the process is begun in the hopes of making something better or clearer, of creating something new or making something make sense. The candidacy is paradoxically a form of hermitship and exposure, as it requires introspection and extroversion in understanding your thoughts and their limits and engaging with others to expand and test them. My candidacy has at times seemed like a baptism by fire, full of stress and pressure, insecurity and doubt, sleepless nights and exhaustion; but equally has included some of my most proud and intellectually challenging moments, as well as some of the most collegially enjoyable. This would not have been the case if it were not for some important people.

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Ehara taku toa i te toa takitahi, engari he toa takitini ke

(Translation from Māori to English: My strength does not come from me alone but also from others)

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Abbreviations

| | |
|---------|--|
| ACC | Accident & Compensation Corporation |
| ANZCTR | Australia New Zealand Clinical Trial Registry |
| CA | Capabilities Approach |
| CBA | Cost Benefit Analysis |
| CEA | Cost Effectiveness Analysis |
| CT | ClinicalTrials.org |
| DHB(s) | District Health Board |
| EBM | Evidence-Based Medicine |
| ERA | Excellence in Research for Australia |
| HDEC | Health and Disability Ethics Committee |
| HRC | Health Research Council |
| HTA(s) | Health Technology Assessment |
| MBIE | Ministry of Business, Innovation and Employment |
| MoH | Ministry of Health |
| MRC | Medical Research Council |
| MSD | Ministry of Social Development |
| NEAC | National Ethics Advisory Committee |
| NGO(s) | Non-governmental organisations |
| NHMRC | National Health and Medical Research Council (Australia) |
| NIH | National Institutes of Health (USA) |
| NIHR | National Institute of Health Research (UK) |
| NZ | Aotearoa ¹ (New Zealand) |
| OMERACT | Outcomes Measures in Rheumatology |

¹ I refer to New Zealand as Aotearoa in recognition of the Tangata Whenua (People of the Land), but it is abbreviated throughout as per international usage.

| | |
|---------|----------------------------------|
| PBRF | Performance Based Research Fund |
| PHARMAC | Pharmaceutical Management Agency |
| PHO(s) | Primary Healthcare Organisation |
| PIS | Participant Information Sheet |
| RCT(s) | Randomised Controlled Trial |
| REF | Research Evaluation Framework |
| UK | United Kingdom |
| USA | United States of America |
| WHO | World Health Organisation |

Research Outputs during PhD Candidacy:

Journal publications (letter and articles) related to PhD:

1. **Tumilty, E.** (2013) Letter to the Editor: Leading the way with a health research repository. *The New Zealand Medical Journal*; 126 (1386).
2. Weale, A., Kieslich, K., Littlejohns, P., Tugendhaft, A., **Tumilty, E.**, Weerasuriya, K., Whitty, J. A. (2016) Introduction: priority setting, equitable access and public involvement in healthcare, *Journal of Health Organisation and Management*, 30 (5):736 – 750 <http://dx.doi.org/10.1108/JHOM-03-2016-0036>
3. Hunter, D. J., Kieslich, K., Littlejohns, P., Staniszezwska, S., **Tumilty, E.**, Weale, A., Williams, I. (2016) Public involvement in health priority setting: future challenges for policy, research and society, *Journal of Health Organisation and Management*, 30(5): 796 – 808 <http://dx.doi.org/10.1108/JHOM-04-2016-0057>
4. Slutsky, J., **Tumilty, E.**, Max, C., Lu, L., Tantivess, S., Curi Haeugen, R., Whitty, J.A., Weale, A., Pearson, S.D., Tugendhaft, A., Wang, H., Staniszezwska, S., Weerasuriya, K., Ahn, J., Cubillos, L. (2016) Patterns of public participation: opportunity structures and mobilization from a cross-national perspective, *Journal of Health Organisation and Management* , 30(5): 751 – 768 <http://dx.doi.org/10.1108/JHOM-03-2016-0037>

(Based on a presentation I gave (No.8. below) I was invited to a workshop at the Brocher Foundation on public participation in priority setting exercises for better health equity, publications 2.-4. above and 6. below are related to this workshop).

Presentations related to PhD:

5. **Tumilty E** (2016) *Battling Upstream: An Institutional Ethnography of Researchers working with Disadvantaged Populations suffering Health Inequity in the Aotearoa New Zealand Health Research Setting*, Feminist Approaches to Bioethics, (13-15th June), Edinburgh, UK
6. **Tumilty E** (2015) *New Zealand Case Study – Public Involvement in Prioritisation Decisions*. Workshop 13: Improving equitable access to healthcare through increasing patient and public involvement in prioritisation decisions (10-13th November). Brocher Foundation, Geneva Switzerland
7. **Tumilty E** (2015) *When evidence leads us astray: evidence generation, health inequity and theories of justice*. Australasian Association of Bioethics and Health Law, Wellington, New Zealand.
8. **Tumilty E**, Walker S, McMillan J (2014) *Priority Setting & the Capabilities Approach*. Priorities 2014, Melbourne, Australia.
9. **Tumilty E**, Walker S, McMillan J (2014), *When the numbers don't add up: Health inequity and research practice in Aotearoa New Zealand*. University of Otago Health Science Research Forum 2014 - Learning Different Research Languages, Dunedin, New Zealand.

Chapter 1: Introduction

“The world as we have created it is a process of our thinking. It cannot be changed without changing our thinking.”
Albert Einstein

1. Background

This thesis grew out of intuitions in practice. While working in research governance, I became aware that those people who took part in trials were always quite similar. The literature that informed funding applications often described trial cohorts (if articles reported demographics beyond age) as quite homogenous. Furthermore, the people I knew that worked with those who suffered the most health inequity, always seemed to struggle to get their research funded, approved, and recognised. This lack of inclusion of both particular populations in individual projects and projects of interest to these communities in the greater research landscape seemed wrong to me. I wanted to know if it was a national problem in Aotearoa New Zealand and if so what factors contributed to the phenomenon so that change can happen.

This thesis presents a new way of thinking about the problem; connecting issues previously dealt with separately. The core idea here is that the way we think about health and health inequity determines our ability to affect and change it. Justice theories require an informational base; a defined space in which to evaluate options. Our epistemologies determine, what is ‘information’ in that space. The dominant ideas about what is fair (justice) and what is evidence (epistemology) in their current combination funnel our problem-solving and thinking into an effective dead-end. This dead-end forces us to:

- think of people generically, creating a mismatch between theory and reality;
- think mainly of health from a disease-centric perspective, which fails to inform interventions adequately for all.

We have set up structures and practices that consistently reinforce this thinking and undermine our ability to be helpful to those in need.

In this chapter, I describe health inequity and make the connection between health inequity and health research inequity, before explaining the objective and aims of the work in this thesis.

1.1. Health Inequity

The New Zealand Public Health and Disability Act clearly states that the purpose of the Act is to ensure provision of funding, services and the creation of organisations with the objective (amongst others) of reducing disparities (NZ Public Health & Disability Act 2000). Health Research Council Annual Reports and various documents from the Ministry of Health continue this thought – describing health equity as a goal.

Health inequity² is a dire and immediate problem globally, both across and within nations. Health inequity is multi-causal and complex (Chandrasekhar, 2009; Preda & Voigt, 2015; Smith, Bamba, & Hill, 2016). The definition of health inequity is an unfair inequality; that is, a difference in health that occurs because of practices or circumstances that are unjust towards a specific group based on that group's social characteristics (Braveman & Gruskin, 2003; Braveman, 2006; Smith et al., 2016). These inequities can be due to a complex interplay of social conditions and service access or delivery. Social conditions are the fundamental conditions for health, including but not limited to clean water, shelter, food and education. Access is the direct ability to receive healthcare. Delivery specifies the acceptability of its form (Smith et al., 2016).

Health inequity in Aotearoa New Zealand (NZ) is a very real phenomenon. For example, amenable mortality rates (i.e. avoidable deaths before the age of 75) vary considerably between different groups of the population. Amenable mortality rates are three times as high for Māori, twice as high for Pasifika peoples, and there are significant differences related to deprivation status. These rates are mainly attributable to diabetes and cardiovascular disease (McCormack, Yeh, Braybrook, & Clyne, 2012; Talamaivao et al., 2010). This thesis aims to provide a foundational

² Inequity and disparities are seen as moral terms referencing justice, whereas inequality is seen as simple difference. (Carter-Pokras & Baquet, 2002) These three terms can be used interchangeable in different settings based on the common usage within that setting (i.e. North America can differ from Europe). For this thesis, inequity is used as an indicator of unfair circumstances.

argument for change. The work draws on interdisciplinary knowledge and research across economics, politics, policy analysis, data management, bioethics, and more.

Health equity is a complex goal to obtain and is influenced by healthcare policy, provision, research, and social conditions (Braveman, 2006; Kawachi, Subramanian, & Almeida-Filho, 2002; Smith et al., 2016). Evidence-based policy and provision (services) depend on health research to provide the necessary “evidence” for decision-making. Current health research does not inform policy and services appropriately or adequately to change health inequity dramatically. Various factors influence the research endeavour and thereby distort evidence. These factors are in the selection of what research we fund and prioritise, as well as how we conceptualise issues and how relevant research is to real life and its diversity. To better understand health inequity and improve it, a shift in focus is needed to change research processes and the resultant information that feeds into decision-making.

In this thesis, the focus is on health research and health research practice, i.e. the means of informing decision-making. I will not be discussing the socio-economic factors that influence health in any depth, nor the social reform that may be necessary to ‘even the playing field’ (Kawachi et al., 2002; Marmot, 2007), although these issues arise periodically in setting context and deliberating forms and types of changes. I will also not touch on institutional/structural racism, even though this is a very real factor in the Aotearoa New Zealand health environment (Harris et al., 2006). Structural racism is a macro-level phenomenon that shapes civil society in such a way as to be discriminatory, although not overtly so, through institutional philosophies, policies, and practices (Gee & Ford, 2011). This kind of racism (as well as overt racism) affects the indigenous population of NZ, despite NZ’s Treaty with Māori guaranteeing certain rights and defining obligations on the part of the Crown (Harris et al., 2006; Kearns, Moewaka-Barnes, & McCreanor, 2009; Human Rights Commission, 2012; Came, 2014). However, it also affects populations who identify ethnically with the Pacific, Asia, the Middle East and Africa (Human Rights Commission, 2012). It is my belief that the problem addressed in this thesis is broader than structural racism as it affects other groups not only those ethnically-

defined. By this, I mean to say that structural racism, can explain some of the disparity, but not all, and equally, if we were to fix the issues outlined in this thesis, it may not fully eliminate this type of discrimination.

While many an argument abounds about *means* and *ends* and their relative worth to each other, this work takes as its point of interest *means*, based on the assumption that the *end* of health equity is agreed (Daniels, 2007; Riddle, 2017).³ These *means*, i.e. health research and all the associated, intertwined practices and mechanisms that foster and support it, should be changed for their sake, as well as achieving the desired *end*. This reform is desirable and necessary because the changes proposed aim to make research more efficient and effective (Cochrane, 1972), which in and of itself is a matter of social justice given the massive public investment carrying the health research endeavour directly and indirectly (projects, institutions, and infrastructure).

Current health services and policy are ill-equipped to deal with a person's individuality, and this would be the case whether the social determinants of health in society were addressed or not. Health research practice provides evidence for interventions about indeterminate masses. Evidence takes a broad scatter gun approach. The assumption is that because this works for a large part of one group (the trial cohort), it will work for a large proportion of another group (the population). Little work is done after this initial step to consider the variety of people and situations in which any given intervention needs to be effective. Our frameworks fail to think about, how we may better design and target interventions to those affected, seeing them as people with characteristics and contexts that require attention. At present health practitioners are left to address the specific needs of a wide variety of patients in practice, adapting evidence ad hoc to suit patients. Health professionals do not have any apparent tools to do this in a robust way. This adaptation in practice ignores two important factors. Firstly, a health

³ Norman Daniels, among others, has noted that health holds a special place in our considerations of priorities and is crucial for wellbeing in other domains. It is this recognition that underpins such things as "Health in all Policies" (Pinto, Molnar, Shankardass, O'Campo, & Bayoumi, 2015) and why NZ's legislation and commitment to human rights obligates us to address health and health inequities.

practitioner other than through experience or self-teaching is not automatically prepared to deal with the complexities of various people's social, cultural, economic, educational or other influences on their health. Secondly, necessary interventions or ways to manage within certain circumstances are not even in existence because of the perceived difficulty in researching them under current conditions.

1.1.1. Relationship between research and inequity

Little work has been done exploring the relationships between health inequity and health research practices in comparison to the work done for other causes of injustice.

Prominent indigenous researchers have written extensively on the lack of consideration for indigenous worldviews and knowledge in conducting research generally, and more specifically for health (Durie, 1985; Dyck & Kearns, 1995; Guillemin et al., 2016; Hudson & Russell, 2009, 2009; Smith, 1999; Walter & Andersen, 2013).⁴ Overlooking indigeneity is evident in the lack of consideration of cultural safety or appropriateness when designing research projects and interventions or services. It is also apparent in the dismissal of indigenous health and medical knowledge (Cram, Smith, & Johnstone, 2003; Durie, 1985; Hudson, 2004). Compounding this issue is a (historical) narrative of exploitation or abuse in research (Smith, 1999). Stories of researchers "researching on" rather than for, or with indigenous communities are common, and examples across both indigenous communities and other marginalised groups contribute to a sense of distrust in an environment where "authority" is mostly not responsive to needs.

Echoes of this fraught relationship also exist in the disability community. The community voices their need for disability specific outcome measures and research, where this means both considerations of what research is needed, how research is designed considering people with disability, and what outcomes measures are valid. (Andresen, 2000; Björnsdóttir & Svendsdóttir, 2008; Charman & Campbell, 1997; Cohen & Marino, 2000; Leeder & Dominello, 2005; Pendo, 2016; Shakespeare,

⁴ These are but a selection of references for the Māori perspective but excellent texts exist from all over the world exploring the ways in which indigenous and aboriginal world views are silenced in the defining of health and healing (Bartlett, Madariaga-Vignudo, O'Neil, & Kuhnlein, 2007; Humphery, 2001; Turton, 1997; Waldram, Herring, & Young, 2006)

1996). Again as a community, people with disabilities (both physical and learning disabilities) have had a difficult relationship with institutions and research groups. These groups and organisations have failed to acknowledge people with disabilities as equal. Authorities whether research organisations or not often consider disability as an inferior state. Alternatively, they classify people with disability as vulnerable by definition rather than by situation (Bickenbach, 2013; Borsay, 2005; Gustafson & Brunger, 2014; Horner-Johnson & Drum, 2006; Longmore, Gallagher, Lane, Tyor, & Bell, 1987; Melbøe et al., 2016).

Others have written about the lack of representation in studies. Trial populations are often white and male (Bartlett et al., 2003; Burchard et al., 2003; Oh et al., 2015; Rogers, 2004b; Rogers & Ballantyne, 2009). As we will see in Chapter 5, this is problematic. It means that the research that tests diagnostic parameters, disease characteristics, interventions and outcome measures, uses samples that lack representation. Evidence, on which we then base decisions, is only evidence of illness presentation or interventional effect as it applies to one group within the population. The differences between a generic trial cohort (which might be white, middle-aged males for example) and other groups can be remarkable. These differences can include genetics (Mays, Ponce, Washington, & Cochran, 2003; Pearce, Foliaki, Sporle, & Cunningham, 2004), metabolic variation (in relation to medications)(Burroughs, Maxey, & Levy, 2002; Kalow, 2012), characteristics of disease presentation (Chaturvedi, 2003; Collins, Vitale, Spoletini, & Barbaro, 2011; Shavers, Harlan, & Stevens, 2003), or other things such as acceptability of intervention. We use best evidence for one group and assume that the differences between groups will not be so significant. The reasons for this homogeneity are discussed further in Chapters 4 and 5. Homogeneity is caused partly by:

- the evidence environment, i.e. regarding what we can and cannot count as evidence;
- the research environment, due to funding, performance measures, incentives; and
- the way researchers run trials, including recruitment methods, intervention ancillaries related to intervention delivery, service environment, staffing and the like.

There are not only problems of representation in the sense of trial participants but also representation in the disease and interventions that are chosen to investigate in the first place. Research activity rarely focuses on the issues that concern those marginalised groups in society. The exception to this is when the disease creates severe consequences, and this is still not necessarily sufficient, or the disease creates a significant economic burden.

Rheumatic fever would be an obvious example in NZ of a condition with severe consequences that received attention. However, the prominence of rheumatic fever in health policy (Ministry of Health, n.d.-j) is in large part due to the advocacy of then Associate Minister Tariana Turia (Māori Party) in the Ministry of Health. This prominence was not due to general recognition by the Ministry of Health of the problem and its ethical implications. By this I mean, that it is not clear that this funding/strategy would be in place without the advocacy of M. Turia (O'Sullivan, 2015).

Economic burden, as a reason for attention, rarely occurs for something that solely affects a marginalised or minority population. Therefore, when such a disease becomes the focus, interventions are not necessarily designed with these populations in mind. Interventions are not planned considering their needs, and trials do not necessarily recruit relevant subgroups. Exceptions of course exist, but there are noticeable examples that confirm this case, diabetes and cardiovascular disease being the obvious ones.

1.2. Research Questions and Aims

As mentioned, this thesis began in observed practice, a practice that was limited in scope. Therefore, the growing intuition that a problem of injustice might be occurring on a larger scale required verification, if the problem was to be solved.

The questions I, therefore, set out to address, in their simplest form were:

Q1: Is the principle of justice, defined as (at minimum) both the fair distribution of benefits and harms and fair representation, evident in the Aotearoa New Zealand health research environment?

Q2: If not, why not?

Q3: What can we do about it?

To answer these questions, I required information about the reality of the NZ situation, and from that information, I could identify where problems lie and consider solutions. The aims of this thesis, therefore, were to:

- Aims 1 Seek information on the representation of marginalised groups in health research and explore what information decision-makers use.
- Aim 2 Seek information on the review of justice at ethics committees
- Aim 3 Seek information about conducting research with marginalised groups
- Aim 4 Use the information from Aims 1-3, to theoretically explore the problem and potential solutions

1.3. Chapter Outline

As indicated, I needed empirical as well as theoretical work to address these goals.

In Chapter 2, a description of three case populations is given, as well as a scoping of their representation in public records. The three case populations, Māori, Pasifika and the learning disabled⁵, are described demographically and in terms of the health inequity they suffer. I explain the justification for this selection and then provide a survey of their representation in public records, which included clinical trial registry data, ethics committee data, and Health Research Council records (primary NZ health research funder). This review of public documentation for representation is the first of its kind in New Zealand and while limited to three case populations provides new information on research equity. There is an indication of non-proportional representation of all three groups in all sources, comparative to their population size within the limitations of information available; and this despite the fact that their need is greater and so representation should conceivably be higher. I also undertook a further survey of representation in guideline documents for the conditions causing the largest degree of morbidity and mortality

⁵ The term used up until 2014 was intellectual disability, but based on the advocacy of People First NZ (a New Zealand non-governmental organisation advocating for those with learning disabilities) this has now been changed to learning disability.

for these groups. This review was to understand the extent to which guidelines include relevant evidence, research or expert opinion for three case populations. Again, representation was relatively weak. Finding a lack of representation in this sort of documentation further supports the work of Dr Heather Came who reviewed public health policy documents between 2009-2011 for Māori scholarship and input and found a similar dearth of material (Came, 2014). Came theorises this as institutional racism and suppression of Māori knowledge within a model that favours the epidemiological and biomedical without acknowledging and acting on the commitments the Crown has to Māori as Tangata Whenua⁶ (Came, 2012, 2014). My work adds to this, by showing that the lack of representation occurs much more widely (i.e. in other types of documentation and activity) and the focus on the epidemiological and biomedical is not only disadvantaging Māori but also other groups within society.

Part of ethics committees' remit is to review justice, which in the NZ context (and more widely) includes reference to not only the fair distribution of benefits and risks but also representation (NEAC, 2012a, 2012b). It, therefore, seemed necessary to question how committees understand and review justice, as no-one has done this work yet in NZ. In Chapter 3, I report on a survey of accredited NZ ethics committees.⁷ This study did not reach a high enough response rate to be conclusive. Questions took the form of both quantitative Likert scales and tick-box formats, but also asked for comments on some issues. The limited responses provided a mixed picture of the understanding of the guidelines that prescribe justice review, as well as differing opinions on ethics committees' role in the consideration of justice. The survey included questions regarding research methodologies and practices that are thought to be able to help address some issues of health inequity. Again from the small sample, that responded, views on these matters were mixed.

⁶ Indigenous population, translated as "People of the Land"

⁷ Approved ethics committees are those who met the criteria of robust ethics committees as judged by the Health Research Council of New Zealand under its mandate in the Health Research ACT 1990 to approve ethics committees. This is explained in full in Chapter 3.

After finding a lack of representation in the research activity within the reference period (2006-2013)⁸, and exploring the role of ethics committees in promoting justice, an understanding of the research environment was necessary to be able to draw conclusions about what the likely causes of this research inequity might be. I explored a new avenue of enquiry to achieve this. Using an institutional ethnographic method, I talked to researchers working with marginalised populations. In Chapter 4, I report on these interviews with senior researchers and their experiences which I analysed alongside the institutional texts that are part of their research environment. This institutional ethnographic method aims to find the “ruling relations” of a given problematic; this being the context or setting in which the informants⁹ experience their “everyday”, in our case senior researchers for marginalised populations (Smith, 1987). A research environment ruled by neoliberal educational policy and managerialism¹⁰ combined with a biomedical bias, served to marginalise the researchers themselves and I argue, creates an epistemic injustice.

The underlying cause of the epistemic injustice that occurs for marginalised researchers is a two-part problem. On the one hand, it is a failure of the prevailing theory of justice in health, that fails to value topics addressing marginalised populations when weighing priorities. On the other, it is a problem of epistemology, with the current dominant epistemology dismissing types of research (those often used with marginalised populations) based on a conflation of objectivity in theory and objectivity in practice (Chapter 5). This application of epistemic injustice is entirely novel. Others have explored epistemic injustice within the academy (Wylie, 2011) or have related it to evidence-based medicine in the healthcare setting (Ho, 2011; Hutchison & Rogers, 2012; Kidd & Carel, 2016; Carel & Kidd, 2014; Loughlin et al., 2015; Wardrope, 2015) but no-one has examined how an evidence-based

⁸ This period was chosen as this was the period available within the Health Research Council funding records. All other sources were then searched between this period even though some had greater reference periods for record-keeping.

⁹ This is the terminology of an institutional ethnography – informants are the experts within the problematic, i.e. those living that particular reality. Triangulating their reports of their experience with institutional texts and discourses provide the material for analysis (M. Campbell, 2002).

¹⁰ Is also described in Chapter 4, but is: a professional practice and ideology that through the use of management tools and techniques removes decision-making power from all other parties (owners, workers, civil society) other than management by arguing for the superior knowledge/ability of managers to run any kind of organisation based on management knowledge rather than organisation-specific expertise. (Klikauer, 2013).

health research environment affects researchers working in health research and specifically those working with marginalised populations.

In Chapter 6, I put forward the original argument that a shift in justice theory is needed to reform the evidence and research environment linking the informational base of a justice theory to the epistemological environment. The Capabilities Approach (CA) as described by Amartya Sen provides a framework that connects well with the issues raised and is, I suggest, a solution to the problems identified. Sen's CA is a framework that evaluates justice by determining people's actual well-being and freedom by focusing on the capabilities they have to achieve valuable functionings that they have reason to value (Sen, 1992). Key elements of the CA are its person-centredness, the focus on intrinsic goods, and use of democratic public discourse. I argue that a CA in health would require a broader informational base for decision-making while ensuring an emphasis on freedom and well-being when addressing capability deficits. All justice theories have an informational base (Sen, 2011). This informational base is the space in which one evaluates options as fair, based on the information about the effects of various options measured, i.e. option x increases capabilities or utilities, for example, over option y .

Finally, in Chapter 7, I summarise the new information gleaned from the empirical work along with the original argument made in the theoretical work in the context of the NZ research environment. Likewise, I outline the limitations of the work, as well as put forwards what future work, would be of interest; specifically around funding frameworks, research evaluation exercises, ethics committee standards and review processes, and big and open data practices. I argue that this thesis adds to the NZ research setting by providing information not previously available and making a case for the reform of the research and evidence environment using Sen's Capabilities Approach.

These chapters together make the argument that:

- 1) Representation of marginalised groups in information that determines health policy and services is poor, where that information is sourced from research and service data.

- a. Research shows a lack of representation of marginalised groups in overall research topics and general research sub-analysis.
 - b. Data from services, etc. is lacking in representation due to both less service use by marginalised groups and poor data classification and collection methods according to literature.
- 2) Representation in research is not easily supported or reviewed by ethics committees (definitive statements cannot be made) and their views of potential big data/open data practices as well as co-design/engagement models are not clear.
 - 3) Researchers working with marginalised populations experience the system in a way that suggests an epistemic injustice occurs.
 - 4) This epistemic injustice is related to the evidence-based medicine epistemology and related evidence-based frameworks in policy and decision-making settings (within a neoliberal political environment), creating a narrow informational base for decision-making.
 - a. This narrow informational base necessarily creates an injustice for marginalised populations by restricting the ability of decision-making to be responsive to diverse needs.
 - 5) To change this injustice, a framework for justice using Sen's Capabilities Approach (CA), which requires a broadening of the informational base, public deliberation, and prioritising those with the least well-being and freedom is put forward.

This CA-related extension of the informational base and need for public deliberation, prioritising those with the greatest capability deficits will require new processes, systems, and tools. I make some suggestions as to the change needed, which includes changes to prioritisation exercises in research, policy, and services, data practices, the academic environment, health research funding and ethics committees.

By describing the problem, addressing why we should care and what particular form that care should take (justice), refocusing what evidence is required to address health inequity (informational base – what counts) and identifying what reform might require in Aotearoa New Zealand, this thesis provides a new approach to

improving a contributing factor of health inequity from the bottom up, i.e. through the research that informs both policy and practice.

Chapter 2: Representation in Aotearoa New Zealand Health Research

Activity

The best way to show that a stick is crooked is not to argue about it or to spend time denouncing it, but to lay a straight stick alongside it."

D. L. Moody (1894)

2.1. Introduction

The disparity in health experienced by particular groups in Aotearoa New Zealand (NZ) is blatant. One can easily compare the straight stick of the general population's health statistics (life expectancy, morbidity/mortality) to the crooked stick of marginalised groups, and observe the deviations (Blakely, Soeberg, & Sarfati, 2012; Hill, Sarfati, Robson, & Blakely, 2013; Jeffreys et al., 2009; Linton, Maskill, & Wright, 2011; McCormack et al., 2012; Talamaivao et al., 2010). The factors that go together to create these deviations, however, are not as obvious and require something more than a superficial comparison.

Certain causal factors of inequity are socially determined; these are poverty and the associated poor housing, or education and access to healthy food and services to name a few (Chandrasekhar, 2009; Preda & Voigt, 2015). These are the social determinants of health (Chandrasekhar, 2009; Preda & Voigt, 2015) and they exist in NZ. These factors tell only one part of the story (Marmot, 2007; Neckerman & Torche, 2007; Rogers, 2004a). This thesis is an exploration of the existence and magnitude of structural causes of health inequity in the ways the system currently prioritises, conducts, and utilises health research; arguing that this is another source of disadvantage for marginalised groups and that is open to change.

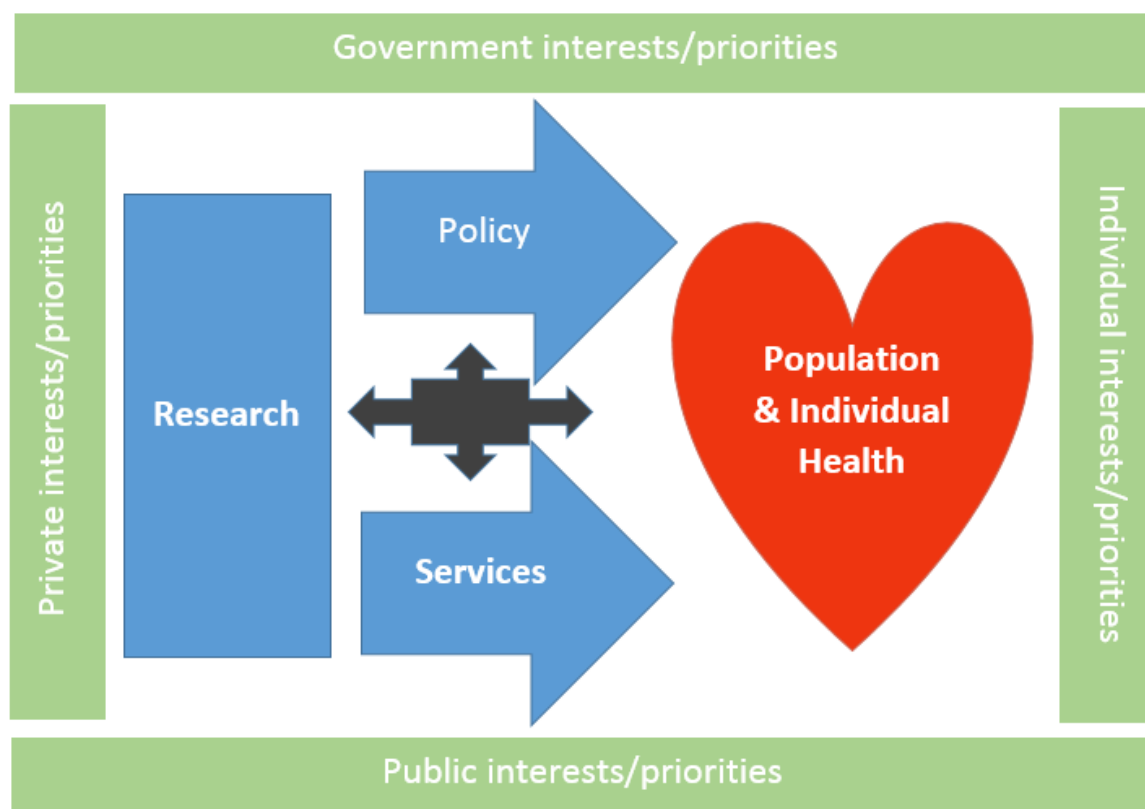


Figure 1 - Relationships between research, policy, services and equity

Research is one of the elements in a complex environment that informs health policy and service decision-making, which then affects health (Figure1): if the research used to make decisions ignores the complex reality in which people strive for health, then it hampers our ability to make truly relevant and applicable decisions about the systems that support the achievement of health.¹¹ Structural inattention to complexity and context have the potential to worsen health inequity. This potential for worse inequity is especially urgent given the phenomena of growing income inequality (Piketty, 2014; Stiglitz, 2012), chronic and multi-disease (Agborsangaya, Ngwakongnwi, Lahtinen, Cooke, & Johnson, 2013; Caughey, Vitry, Gilbert, & Roughead, 2008) and ageing populations (Beard et al., 2016). As these three things collide in the 21st century, they will increasingly create more complex needs.

¹¹ It is acknowledged that research could ignore complexity, if complexity was considered in the decision-making itself in conjunction with the research evidence. It will be explained in Chapter 5 & 6 that there are different models capable of including complexity through the evidence>decision-making>implementation chain.

This chapter describes health inequity in the context of NZ and explores the inequity in research evidence. Health inequity in NZ is seen most starkly in the management of cardiovascular disease and diabetes. For some these conditions can mean death before retirement age and severe morbidity, while for others, these are conditions to be managed well into their late 70s or 80s (Chen, Eggleston, Li, Shah, & Wang, 2014; Talamaivao et al., 2010). Similarly, cancer rates (Jeffreys et al., 2009; Blakely, Soeberg, and Sarfati 2012; Hill et al., 2012), mental illness management (Gone, 2015; Ministry of Health, 2013), and public health issues (Blakely et al., 2011; El-Khorazaty et al., 2007) show disparities between some groups and the general population. It is not easy to pinpoint the cause of these differences to a lack of service access or specific social determinants. As we will see, differences between some groups and the general population even exist when controlling for socio-economic status (Hill et al., 2010, 2013).

I described the distinction between health inequalities and health inequities in Chapter 1. Health inequalities are differences in health outcomes that occur without unjust causes, such as breast cancer rates by sex.¹² Health inequities or disparities are differences in clinical outcomes based on an unfair distribution of the means of health (in their broadest sense), such as differences in breast cancer survival based on ethnicity (Hofrichter, 2003; Marmot, 2010). The latter indicates at minimum some form of inaction; some passivity to the needs of those suffering the inequity and this is what is unjust. At maximum some action that leads to worse outcomes for one group over another based either on a lack of knowledge or lack of consideration, which is unjust. The distribution of the means of health in this broadest sense addresses not only accessibility but acceptability and applicability of healthcare options. What does this mean? Prohibitive costs of accessing some services and complying with interventions (such as the ongoing cost of medication or travel for treatments) are not the only causes of health inequity. Inequity occurs because of the absence of fit between interventions and people, where those with access to the social determinants of health have more options to benefit from healthcare, and those with less struggle to convert health services into well-being.

¹² Based on American Cancer Society, Statistics: New Cancer rates and Deaths by Sex for 2016, available from:
<http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047070.pdf>

The argument in this part of the thesis is that the foundations of our systems (concerning both epistemology and justice) that generate health evidence from research, which then informs policy and services, create implicit injustice and this injustice is manifest in three specific ways:

- 1) Evidence used for decision-making is not generalizable to those that are marginalised.
- 2) Research addressing the needs of those who are marginalised is relatively rare or is of a type that is unlikely to meet the grade of “evidence” and therefore be included in decision-making processes.
- 3) The mechanisms by which decisions are made, priorities set (including research priorities), are largely circular, i.e. are informed by the research and data¹³ generated by the epistemology and practices mentioned in 1) and 2) and therefore closed. Politics and advocacy can sometimes push these beyond their narrow purview, but in general, they are unavailable or beyond the scope of influence of those who suffer health inequity and their advocates.

Certain terms in this analysis require clarification. Firstly, “marginalised” and “disadvantaged”¹⁴, within the context of this thesis, will be used interchangeably to describe those who suffer health inequities. These “marginalised” people can be different groups within various discussions, i.e. a group identified by culture, socio-economic status or conditions, for example, and where this is the case, this will be made explicit. In general, they are any group, who based on a particular characteristic(s), recognising that people are more than one specific identifying characteristic and that the intersection of different characteristics can be further marginalising, fare worse than others. They fare worse in disease manifestation, outcomes, or health status, in a way that is considered unjust (Hofrichter, 2003).

¹³ Data from systems that are underutilised by certain groups fails to adequately capture the realities of those groups’ health and well-being, i.e. primary care use, etc. Not only that, but research has shown that ethnicity data for example, collected within the system is not always accurate (Bramley & Latimer, 2007; Swan, Lillis, & Simmons, 2006).

¹⁴ The term vulnerable population has been avoided, as I wanted to place the emphasis of these groups’ disadvantage on something that is being actively done to them; vulnerable as a word, does not impart this. While vulnerability has in recent times been discussed as social process rather than necessarily a group or individual characteristic (people are not inherently vulnerable, social factors and situations create vulnerability for different people based on their characteristics (Fineman, 2008; Mechanic & Tanner, 2007), it still remains somewhat passive in its description.

“Evidence” will be used throughout this thesis to denote information ranked as useful within the dominant epistemology. This dominant epistemology is promoted through the Evidence-Based Medicine (EBM) hierarchy of evidence and similarly in policy-making exercises through the use of grading tables and the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) tool.¹⁵ Within these ranking exercises, valuable evidence is the information gained from randomised controlled trials and systematic reviews. A discussion of the validity of this ranking forms part of the conversation in Chapter 5, but for clarity, I use the term “evidence” to represent information graded as strong or robust evidence in typical grading exercises. It is of note, that epidemiological and some pathophysiological research can also be used as evidence, which is beyond the scope of “evidence-based” in its traditional form and this is part of the expansion of the term of “evidence-based” and its sphere of influence discussed in Chapter 5.

Policy and services are in part determined by research evidence. Research evidence informs the identification and understanding of the problem, as well as the scoping and evaluation of solutions (regarding efficacy, effectiveness, and cost-effectiveness) (Figure 2) (Andermann, Pang, Newton, Davis, & Panisset, 2016; Majone, 1989; Oliver, Innvar, Lorenc, Woodman, & Thomas, 2014; Samson, van Katwyk, Fröling, & Ndoro, 2015). For policy, this may be about what a government will or will not fund, for services it may be what is best practice or considered the usual standard of care. Research alone does not inform decisions, but within an evidence-based decision-making and practice framework, research evidence is a crucial factor in identifying issues and justifying an argument for or against something. Arguments for a particular decision are also made based on the values of the group making them, their constraints (financial or otherwise) and their goals regarding the outcome of their decision-making (Fisher, 2014; Glied & Miller, 2015; Majone, 1989).

¹⁵ The most popular form of this is GRADE which helps policy-makers, guideline creators and those undertaking health technology assessment, organise and rank appropriate evidence. <http://www.gradeworkinggroup.org/>

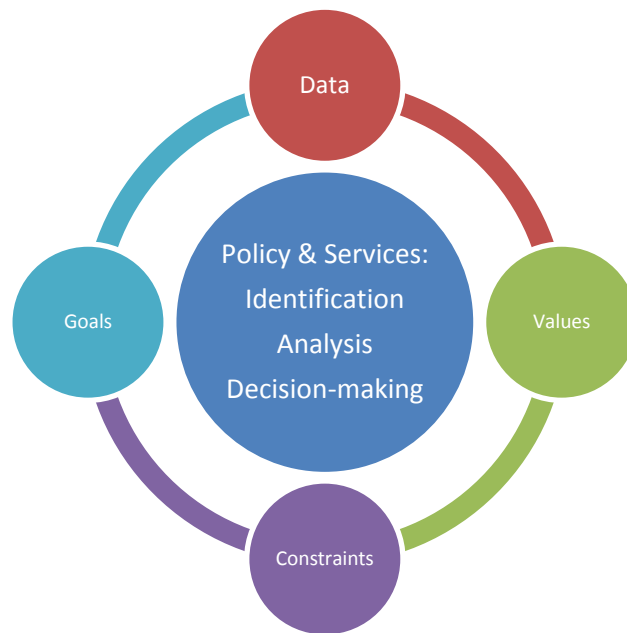


Figure 2 - Elements influencing process of policy & service setting

If the research used within these frameworks is not representative of the society, they are meant to serve, and especially not representative of those who fare worst then this is an injustice. If no additional work is done to address the information gap between the non-representational research and the real world need for the diversity of people present in society, then this is an injustice. This gap means that we are failing to make informed decisions for all people and especially those who need it most. Failing to make relevant decisions for all is a compounded injustice. By this I mean, that this situation marginalises people, i.e. those who cannot either adapt or overcome the lack of applicability research (and therefore policy/services) has to them. This disadvantage is further exaggerated by the fact that it occurs to people who are often already disadvantaged within society based on geography, culture, socio-economic position for example.

The outcomes of the three premises above would suggest that interventions are therefore not designed with those who need them most in mind and may be less effective or potentially harmful depending on the nature of the intervention. This lack of appropriate or responsive interventions means that their health status is unlikely to improve or equal the wider population, maintaining the current injustice. Even if the social determinants that affect their health were to improve without addressing this problem, and consequently, their health status improved;

lack of representation and consideration within the evidence-generating system is still problematic.

Three groups are used here as valuable test cases within the NZ context to consider this issue: Māori, Pasifika peoples, and those who have a learning disability. These groups are representative of health inequity in NZ. Each suffers worse outcomes across most health domains. Each is the subject of some attention, and therefore some statistics and information are collected and reported by the government on the health status of these three groups. Each suffers health inequity for reasons that are complex and in some ways similar, though in other ways distinctly different.

The aim of this chapter is, therefore, to:

- 1) State the current degree of health inequity for three groups identified.
- 2) Relate this inequity to the premises listed above by:
 - a. Surveying representation in funding, trial registry, and ethics records. Providing an overview of inclusion in the research conducted in NZ most likely to feed into decision-making.
 - b. Describing the evidence used to make policy and guidelines for disease/conditions where the three groups are known to suffer poor outcomes.

This review then sets the scene in such a way as to allow critical reflection on where the gaps occur – these deficiencies are between the ideal and the reality (policy), theory and practice (research), and planning and implementation (service). They occur both on the micro- and macro-level insofar as problems are not conceptualised adequately, investigated effectively, and implemented appropriately across policy, research, and services.

2.2. Current Health Disparities in Aotearoa New Zealand

2.2.1 Background

In this section, I outline inequalities for Māori, Pasifika and learning disabled groups based on Ministry of Health reporting.

2.2.2. Māori

Māori are the indigenous population of NZ. There is a long and tragic history, mirrored in many other countries with indigenous peoples, of the effects of colonisation on their cultural, economic, and social sovereignty. Māori are a heterogeneous ethnic group, being comprised of many iwi/hapu (tribes/families) that have different cultural practices (Tikanga) and dialects (Te Reo Māori) as part of their world view or Māori world (Te Ao Māori¹⁶). Recognition of this Te Ao Māori is relatively new within the social and health systems, and responsiveness to it is still developing or missing.

There are approximately 700,000 Māori living in NZ (Ministry of Health, n.d.-k). More than 50% of Māori live in the lowest (most deprived) three deciles of social deprivation (total of ten deciles), compared to only 24% of non-Māori (Ministry of Health, n.d.-h). Regarding health literacy, 80% of Māori males and over 70% of Māori females had a “poor” health literacy score (Talamaivao et al., 2010.). Māori reported a higher rate of having an unmet need to see their GP in the past 12 months, despite the fact that their rates of having a usual health practitioner, and having seen a general practitioner (GP) in the last twelve months were equivalent or similar to non-Māori (Ministry of Health, n.d.-h). The most cited reason for not seeing a GP was cost (Ministry of Health, n.d.-h). Māori were also twice as likely to have uncollected prescriptions due to cost than non- Māori (Ministry of Health, n.d.-h).

Māori statistics for hospitalisation and mortality were worse than those of non-Māori for all diseases noted. These disparities were present for cardiovascular disease, cancer, respiratory disease, diabetes, infectious disease and mental health (Gillies, Tomlin, Dovey, & Tilyard, 2013; Hill et al., 2010, 2013; Ministry of Health, n.d.-g). Overall life expectancy at birth for Māori is around seven years less than non-Māori for both males and females (Ministry of Health, n.d.-e). Leading causes of

¹⁶ Te Ao Māori – means “Māori world” which generally encompasses three main things: Te Reo Māori (the language), Tikanga (protocols and practices) and the Treaty of Waitangi. However, more broadly it includes whānau, hapū, iwi (familial and tribal connections) and the Marae (the community focal point), whakapapa (genealogy) and Waahi Tapu (sites of importance)

death for Māori are different to non-Māori. For Māori ischaemic heart disease, lung cancer, diabetes, cerebrovascular disease, chronic obstructive pulmonary disease (COPD), suicide, and motor vehicle accidents are the leading causes of death (Ministry of Health, n.d.-f). The reports do not list diabetes as one of the leading causes of death for non-Māori; COPD is also not listed (breast cancer and colorectal cancer replace these in the list for non-Māori) (Ministry of Health, n.d.-f).

When examining diseases individually within the data provided by the Ministry of Health, the pattern is often of higher prevalence, but also much higher rates of poor outcomes. For example, diabetes prevalence was twice as high for Māori as for non-Māori, but related renal failure was five times as high (Ministry of Health, n.d.-d). Māori also had poorer outcomes for cancer, total cancer registrations for Māori were 503.6 per 100,000, while those for non-Māori were 405.8 per 100,000 and yet mortality was closer to twice the ratio: 215.6 per 100,000 for Māori and 120.3 for non-Māori (Ministry of Health, n.d.-a). The same kind of disparities exists across other conditions reported (Ministry of Health, n.d.-g).

The picture we get from this information allows us to draw inferences on how to address health inequity. Management of chronic disease is poorer for Māori than non-Māori, hence the higher rates of hospitalisation and mortality for Māori, especially when bearing diabetes in mind. This inequity is obviously in part due to healthcare access, i.e. costs of GP visits and prescriptions. However, other factors must also play a role, including health literacy, but also research for each disease regarding treatment design/delivery, adherence, and acceptability, as well as work mitigating the effects of living in social deprivation and public health measures.

2.2.3. Pasifika Peoples

The Pasifika population in NZ initially began emigrating here after World War 2 but were encouraged to emigrate during the 1960s and 1970s to address worker shortages (Hill, 2010). Today the population consists of 1st, 2nd, and 3rd+ generation immigrants. The population much like Māori is heterogeneous having originated from many Pacific Nations, with various languages and cultures. Their history in NZ is similarly one that includes racism and oppression: when the need for extra workers passed, their welcome in New Zealand waned. Stories of the

“Dawn Raids” in the mid-70s (Anae, 1997; Pearson, 2005) are prevalent in popular culture where “over-stayers” were forcibly removed from their family homes in the early hours of the morning, causing distress and terror in the community. There is some recognition of Pasifika peoples’ cultural and social needs within health services, systems, and research, but much like the situation for Māori, it is often, underdeveloped, minimal, and sporadic.

Tupu Ola Moui- Pacific Health Chart Book 2012 states that 7% of the population of NZ identify as Pacific Islander (in comparison to 15% Māori (Ministry of Health, n.d.-k)) and of these more than 50% live in the two lowest deciles of social deprivation (McCormack et al.,2012). Nearly 90% of Pasifika peoples have poor health literacy (McCormack et al.,2012). Life expectancy was slightly better for Pasifika peoples when compared to Māori, but rates of independent living (i.e. free of functional limitation) were lower in comparison to the total population (McCormack et al.,2012). Again, while the rates for having seen a GP in the last twelve months were equivalent to the total population, rates of having an unmet need for seeing a GP in the past 12 months were higher (McCormack et al.,2012). Primary reasons for visiting a Pacific Health Provider¹⁷ were the need for having someone who understood their culture, then, the proximity of provider, and cost; in contrast to Māori, where cost was a primary reason for visiting a Māori Health Provider (McCormack et al.,2012).

As with Māori, rates of hospitalisation and mortality for cerebrovascular disease, ischaemic heart disease, diabetes, and asthma, among others were higher than for the total population (McCormack et al.,2012). Unlike, Māori whose primary reason for unintentional injury was road accidents (McCormack et al.,2012), for Pasifika peoples, the leading causes of unintentional injury are entirely different. Leading causes of unintentional injury for Pasifika peoples were split between falls and “*drug, medicaments and biological substance causing adverse effects in therapeutic use* - * assigned for adverse effects of drugs properly administered (e.g. allergic reactions)*” (p54, McCormack et al.,2012). This cause of injury is curious, as this is potentially a sign of the lack of transferability of general pharmaceutical

¹⁷ Pacific Health Providers and Māori Health Providers are health practitioners who generally also identify as Pasifika or Māori (not always the case for all staff in a given centre), who provide care in a culturally more responsive fashion.

interventions to this specific population or the need for ancillary elements to the encounter apart from the standard prescription and application of a general remedy.

Again, we can infer from this picture what might be fruitful directions for investigations to improve health inequity for the Pasifika population. Chronic disease management, health literacy, culturally-appropriate healthcare and suitability of treatments are obvious avenues of inquiry.

2.2.4. People with Learning (Intellectual) Disabilities

People with learning disabilities represent another population for whom health is poor and research attention is minimal. Unlike Māori and Pasifika peoples, who may be included in “mainstream” research and have some targeted funding, those with a learning disability are unlikely to be included in clinical trials at all and have less research and funding focused on their needs.

Based on a report written for the Ministry of Health only 0.7%¹⁸ of the population has a learning disability (Linton, Maskill, and Wright, 2011). However, this group incurred almost three times as many costs in primary/secondary healthcare than the general population (not counting non-health related care, such as in-home help, or educational support) (Linton et al., 2011). This group is more likely to be enrolled with a primary healthcare organisation, more likely to visit their GP within a three month period, and their health practitioners are more likely to prescribe twice as many drugs than the total population (Linton et al., 2011). Again, those with a learning disability were highly represented in the most socially deprived deciles (more than 50% in points 4 & 5 on a 5-point scale, where 1 is least deprived and 5 is most deprived)(Linton et al., 2011). Their life expectancy is lower than not only the total population but each of the groups considered so far, with a gap of 18 and 23 years for females and males respectively to the total population (Linton et al., 2011).

For the chronic conditions, coronary heart disease, respiratory disease, diabetes, kidney disease, cancer and morbid obesity, the learning disabled had higher rates

¹⁸ This figure is however presumed an underestimation due to issues of classification and recording both in the report itself (Linton, Maskill, and Wright, 2011) and in the community.

across the board (Linton et al., 2011). Those with learning disability showed lower numbers in participating in screening for both breast and cervical cancers (Linton et al., 2011). They were also more than four times more likely to have an avoidable hospital discharge (i.e. avoidable injury, or something that could have been prevented by a primary health intervention, or public health measures) (Linton et al., 2011). These disparities exist, although the learning disabled are more likely to access healthcare regularly (Linton et al., 2011).

Again, we see the same issues related to the management of chronic disease (regardless of higher contact with health professionals), health literacy, and speculatively the suitability of treatments to their specific situations.¹⁹

2.2.5. Other Groups

Why are other groups not chosen for these case studies? The simple answer is that for other groups the ability to map their disadvantage is limited. NZ has no mandatory reporting in trial research of ethnicity data, socioeconomic status or education level, unlike for example, the NIH, which requires at least ethnicity data (on top of sex and age) (National Institutes of Health, n.d.). Also, reporting of some of these factors is not necessarily routinely collected in health services data (Douglas, Dawes, Holden, & Mack, 2015; *The use of routine healthcare data in New Zealand*, Gurney, 2012). Data collection within the New Zealand health system is limited (Bramley & Latimer, 2007; Swan, Lillis, & Simmons, 2006) and so the ability to even take stock of where certain groups with vulnerability within the population might be regarding their health is difficult. The Ministry of Health commissions reports for various groups as they become priorities. Reports for some other groups exist such those for the Asian population (Ministry of Health, 2006a) and the elderly (Ministry of Health, 2006b).²⁰ The Ministry does not update these reports on a regular cycle while tracking their measures over extended periods of time, to establish a true picture of the health of particular groups. In addition to the groups

¹⁹ It is noted that people with some learning disabilities have shorter life expectancy due to the condition that causes their learning disability. However, much of the data presented in the Linton report (Linton, et al., 2011) available in NZ showed that much of their disparity in mortality is related specifically to chronic disease management and an averseness to screening, and therefore amenable – their life expectancy and quality of life can be improved. This is confirmed by work in the UK (Bittles et al., 2002).

²⁰ There are also a variety of reports from different times regarding young people and specifically Māori or Pasifika young people. These can be found at: <http://www.health.govt.nz/publications>

mentioned, groups that would be of interest are those in the lowest social deciles for example or those suffering mental health issues. In the literature, there is speculation that these groups fare worse in their encounters with health services and much like the case populations struggle to manage their chronic illnesses (Ashworth, Medina, & Morgan, 2008; Cabassa, Siantz, Nicasio, Guarnaccia, & Lewis-Fernández, 2014; Kawachi & Kennedy, 1999; Stafford & Marmot, 2003).

2.2.6. *Why is there a difference?*

What all of these group descriptions suggest is that there is something outside of the general biomedical view of health that influences health outcomes. Why is this conclusion drawn? Because for those people who are not Māori, Pasifika, or do not have a learning disability, life expectancy and hospitalisations for the same conditions are more favourable, and mortality is not related to things that are avoidable or at least manageable (like diabetes). This discrepancy in outcomes means that interventions are working for some. We can see that aside from social deprivation; other factors are influencing the health outcomes for these groups, which means that addressing health inequity is not just a matter of improving access (regarding individual financial barriers). For example, avoidable injury, in the form of adverse drug reactions, (noted in Pasifika peoples) is not likely to be reduced by providing free access to primary healthcare and cheaper prescriptions. Those with learning disabilities have access to healthcare, and yet, the management of their chronic illnesses is still poor.

This chapter will explore the representation of these groups in research activity to try and understand these disparities. Research activity informs what we know about health conditions and the people that suffer from them and helps us to decide what to do for people. If we do not have knowledge of these groups and their needs, then the services we design and provide are potentially unhelpful for some groups.

2.3. Representation in Health Research Council of New Zealand Funding

Health research funding was an obvious place to start this exploration of representation. How are the case populations represented in the activity that the government pays for to improve the health of those living in Aotearoa New Zealand? The Health Research Council of New Zealand (HRC) is NZ's major health funder,

similar to the Medical Research Council (MRC) in the United Kingdom, the National Health and Medical Research Council (NHMRC) in Australia and the National Institutes of Health (NIH) in the United States of America. I chose the HRC records, because 1) they were public, 2) they are NZ's largest health funder, and 3) they are the funder specifically mandated by the government under the Health Research Council Act of 1990 to fund research that contributes to the health of New Zealanders.

The HRC has an annual funding round that calls for investigator-led proposals. These proposals can be Feasibility Studies (limit \$150,000 over two years), Project grants (limit \$1.2 million over three years maximum) and Programme Grants (limit approx. \$5million over five years maximum, although applications for extensions are an option through the annual process). In addition to this round, HRC has multiple career awards for various levels of career achievement (Summer Studentships, Masters, PhD and Postdoctoral grants). There are targeted career award categories such as Māori and Pasifika, but also awards aimed at specific types of researchers (for example clinicians, those interested in health policy, or delivery). There was previously a Disability Placement scholarship programme, but this was discontinued. The HRC also funds partnership programmes which are not investigator-led but driven by a specific government priority or sector need. These require partners in the health sector that will ensure the successful translation or implementation of the research results into policy or practice.²¹

Other funders naturally exist. For example, the Lottery Health Grant round funded by lottery income and managed by the Department of Internal Affairs is more community focused. However the full details of Lottery Health grants are not publicly available, and their funding is limited both in terms of duration (no more than two years) and budgets (no more than \$120,000).²² These budgets do not include overheads, like the HRC, making their budgets even more limiting.²³ These

²¹ Information on HRC funding opportunities can be found here: <http://www.hrc.govt.nz/funding-opportunities>

²² Information on Lottery Health grants can be found here: <http://www.communitymatters.govt.nz/Funding-and-grants---Lottery-grants---Lottery-Health-Research>

²³ Overheads are a line within a budget, generally based on percentage of the staffing budget within the grant that recognises the infrastructure cost of running any particular project. Few grant bodies

restrictive funding opportunities mean that what research is possible with a community focus is limited and less financially attractive to tertiary institutions (due to the lack of overheads). Disease or cause-based funders, such as the Heart Foundation, Neurological Foundation, Arthritis New Zealand also exist. The Royal Society of New Zealand offers Marsden grants, but these are with the express purpose of supporting “blue skies” research, and so any health research projects awarded under this scheme are often lab-based or at a purely theoretical level.

The HRC as the funder with the explicit mandate of contributing to the health of New Zealanders was the clear choice for this review.

The records available were limiting, in that they only provided a title for investigation. Titles were checked for descriptions of Māori, Pasifika, or learning disability projects.²⁴

Table 1 - Summary of Research Funding by Case Groups

| | 2006-2013 | Total | Māori | Pasifika | Learning Disability | Mixed/ Equity |
|---|-----------|---------------|--------------|-------------|---------------------|---------------|
| 1 | Total \$ | \$618,182,308 | \$53,232,138 | \$7,449,037 | \$2,025,241 | \$10,469,653 |

in New Zealand offer overheads, other than the HRC grants, the Ministry of Business, Innovation and Entrepreneurship grants, and any private research funding contracts with industry.

²⁴ A full description of methodology used is available in Appendix A along with a full list of the applications selected for inclusion.

| | | | | | | |
|---|---|---------------------|--------------------|------------------|-----------------|------------------|
| | | | (8.6%) | (1.2%) | (0.3%) | (1.7%) |
| 2 | Total no. of Grants | 823 | 127 (15.4%) | 32 (3.9%) | 6 (0.7%) | 15 (1.8%) |
| 3 | Average \$ | \$751,133 | \$405,981 | \$180,639 | \$337,540 | \$697,977 |
| 4 | Annual Funding Round Grants/Group Total Grants | 476/823 (57.4%) | 47/127 (37.0%) | 4/32 (12.5%) | 3/6 (50.0%) | 9/15 (60.0%) |
| 5 | All Career Development Awards /Group Total Grants | 172/823 (20.9%) | 60/127 (47.2%) | 24/32 (75.0%) | 1/6 (16.7%) | 2/15 (13.3%) |
| 6 | Grants under \$100,000//Group Total Grants | 111/823 (13.5%) | 37/127 (29.1%) | 20/32 (62.5%) | 2/6 (30.0%) | 3/15 (20.0%) |
| 7 | Grants over \$1.3mill.//Group Total Grants | 101/823 (12.27%) | 2/127 (1.58%) | 1/32 (3.12%) | 0/6 (0.0%) | 1/15 (6.67%) |
| 8 | Average Duration | 29.8 months | 27.1 months | 14.1 months | 19 months | 23.3 months |
| 9 | Grants 12 months or less//Group Total Grants | 151/823 (18.35%) | 33/127 (25.98%) | 20/32 (62.5%) | 3/6 (50.00%) | 6/15 (40.00%) |

As can be seen, the representation of the case groups in the total funding pool is not proportional to their representation in society (Table 1 - row 1) despite there being a specific Investment Stream for Māori research and specific career awards.²⁵ Māori and people with learning disabilities do reach some degree of proportional representation in the total number of grants awarded (i.e. 15% and 0.7% respectively), but Pasifika barely reach half (Table 1 - row 2). This discrepancy between the amount funded and the number of grants awarded, is discussed further

²⁵ The HRC asks applicants to align their projects within four Investment Streams in the Annual Funding round (Health and Well-being in New Zealand, Improving Outcomes for Chronic Conditions, Health Service Delivery, and Rangahau Hauora Māori)

in Chapter 4, where researchers explain the perception of having to limit the money they ask for so that they can get funding. One can see clearly (Table 1 – row 3) that the per-grant-cost across the groups is quite different from the total group average. It is not immediately clear why clinical projects for marginalised populations would cost less, in fact, they are likely to cost more given the geographical spread of small populations within the country. Therefore, the assumption is that these projects with less funding are unlikely to be either technically sophisticated (requiring expensive laboratory equipment) or clinical interventions (requiring sample sizes sufficient to power studies). This assumption is explored further within this chapter and Chapter 4. Rows 4-5 (Table 1) show the degree to which career awards represent the share of funding that each group receives. Career awards are necessary for workforce development but are also limited in the scope of what they can achieve – Masters’ projects and summer studentships are unlikely to lead to immediately translatable knowledge or evidence. Of the 111 grants under \$100,000, the three case groups combined received 55% of them. These smaller grants represented a significant portion of the case groups’ overall grant lists (especially for Pasifika – 62.5%) (Table 1 – Row 6). Grants under 12 months also represented a significant proportion of these case groups funding success (i.e. case groups received 41% combined of all grants under 12months) (Table 1 – row 7). This prevalence of shorter and smaller grants shows that the work done with these case groups is of a different nature. The average duration of each groups’ grants was significantly less than that of the total group average except for Māori (27.1 months versus total group average of 29.8 months). There were 101 grants of \$1.3million or more, which are generally programme grants but can also be partnership grants. Of the 101 grants that were larger than \$1.3million in funding, so those grants that represent a significant investment over a longer period, only four were for the case groups of interest (combined), and not one of these was for people with learning disabilities.

I cannot speak to the numbers of grants submitted. For example, an objection might be that no-one has ever submitted grants to the Health Research Council within the programme grant section for the people with learning disabilities. Part of the criteria for applying for a Programme Grant is that you have already been successful

in HRC funding to a certain extent before your application to receive programme funding. Given the low numbers of grants awarded to learning disability projects in these records and the years of those grants, none of the investigators working with people with learning disabilities are eligible for programme funding. Furthermore, no new investigators would be eligible to apply without showing equivalent level experience somewhere else. In other words, the lack of representation for research for people with learning disabilities at the programme level is a direct reflection of their lack of representation at project level, despite informants (in Chapter 4) reporting that grants have been submitted at the project level annually.

As mentioned above there are some limitations to this analysis. I cannot compare what was submitted, and its evaluation to those projects that the HRC funded. The review of titles alone does not guarantee that efforts were not made within funded projects to recruit or consider diverse populations. Moreover, some information is missing from the publically available list, based on a researcher's ability to embargo their publication. This embargoing of information is more likely to occur for commercially sensitive research rather than the research that occurs for marginalised populations, however.

Overall, what this information points to is that there is significant support for research workforce development by earmarking career awards for Māori and Pasifika, and there is a specific Investment Stream for Māori. However, grant funding for the health needs of populations that suffer the greatest health disparities are lower than their representation in society and arguably than their need, and this is especially the case for the people with learning disabilities.

Funding records from the HRC do not provide a full picture of health research activity occurring in NZ. Therefore other sources were necessary. The use of clinical trial registries (described below) is growing in NZ (Jull, Wills, Scoggins, & Rodgers, 2005; Currie & Jull, 2012) and the information is publically available, so these too, seemed like a useful source of information.

2.4. Representation in Trial Registries

2.4.1. A Brief History of Trial Registration

Efforts on both sides of the Atlantic in the 1970s led to the creation of the first clinical trial registries. In the United States of America (USA), Nixon's "War on Cancer" and the resultant National Cancer Act (Steinbrook, 2004) specified the need for sharing of trial information to speed up efforts to address research gaps and avoid publication bias. Similarly, in the U.K., Iain Chalmers, an ardent follower of Archibald Cochrane²⁶ and later creator of the Cochrane Collaboration and Library, helped advocate for and set-up a perinatal medicine registry (Chalmers et al., 1986).

Advocates of registries saw a key factor impeding progress in research development was the lack of information sharing, in particular for trials that had not been published (Chalmers et al., 1986; Chalmers, Gray, & Sheldon, 1995; Simes, 1986; Steinbrook, 2004). Trial registries were designed to not only provide a way of knowing what activity was occurring but also to provide a way of sharing the outcomes of activity regardless of whether the research was published in academic journals or not. In the USA, legislation in 1997 required the NIH to create a database for trial registration (FDA Modernisation Act of 1997). This database came to fruition in 2000, when NIH created the ClinicalTrials.gov registry. Efforts were occurring globally, albeit without coordination, to create trial registries. In 2004, at a Ministerial Summit on Health Research, the WHO was asked to monitor this activity and provide access to it, to make the use of registries more amenable (WHO, n.d.-a).

The WHO created standards for clinical trial registry creators and administrators, the clinical trial registry data set, and a portal for searching all trials registries classified as primary (i.e. meeting WHO criteria)(WHO, n.d.-b). The WHO Trial Registry Data Set (TRDS) specifies what a registration must include to meet their standards of reporting (WHO, n.d.-c). These reporting standards include specification of funders, sponsors, inclusion/exclusion criteria, primary outcome measures, study type, among others (20 items in all).

Also in 2005, the International Committee of Medical Journal Editors (ICMJE) released a statement saying that they would only publish research that had been registered in a clinical trial database (De Angelis et al., 2004). This policy was

²⁶ Archibald Cochrane called for randomised controlled trials in medicine post World War 2 to bring methodological rigour to health research.

supposed to provide motivation to researchers to prospectively register their work in accordance with what was considered best practice.

Despite all these efforts, many trials are still not being registered prospectively, and many of the registrations are incomplete and/or inaccurate (Currie & Jull, 2012; Goldacre, 2012; Jull et al., 2005; Mathieu, Boutron, Moher, Altman, & Ravaud, 2009; Wood, 2009).

2.4.2. Trial Registrations and Our Premises

Given that trial registration was introduced in 1997, endorsed by the International Committee of Medical Journal Editors (ICMJE) initially in 2005, and embedded in their policies in 2007, registries were thought to be a good source of information for further establishing the premises of this project, namely that:

- the majority of research conducted is not for, or generalizable to various subgroups in the population

While the HRC data provided in the previous sections shows what work and types of work are funded (from the main health research funder in NZ), this by no means provides a complete picture of research activity and provides little information on methodologies used. It was therefore thought prudent to investigate trial registries relevant to the NZ context to examine:

1. What research has been/or is being undertaken for the three case groups identified in this work as examples of those suffering health inequity (Māori, Pasifika, and people with learning disabilities)? This question concerns both research specifically with these groups in mind, and research in areas of particular interest to these groups (i.e. based on disease prevalence or poor outcomes for example)
2. For all research, what kinds of subgroup analyses have been/or are being done and how was/is external validity considered, as this would make the work more likely to be generalizable across the population?

I chose the ClinicalTrials.gov, Australia New Zealand Clinical Trial Registry (ANZCTR) and ISCRTN²⁷ Registry as sources of information likely to contain the majority of registered interventional and observational studies occurring in NZ. This choice was related to the fact that previous work by Jull examining the increasing use of trial registries by NZ researchers in two studies (Currie & Jull, 2012; Jull et al., 2005) included these registries.

Our general search criteria to get an initial list of interest²⁸ from each registry were:

Table 2 - Search criteria across all three registries

| Factor | Search Value | Reason |
|-----------------------------|-----------------------|---|
| Time period | 01/01/2006-31/12/2013 | To align with the data used from the HRC |
| Trial Status | Completed | This criterion would increase the likelihood of information regarding publication or results being available for earlier studies within the group (i.e. those registered from 2010 onwards, depending on their duration would be unlikely to include publications). |
| Location of data collection | New Zealand | This criterion definition could mean either as a main site of collection or as an “arm” of an international trial. This was chosen to identify trials that had chosen a New Zealand population as relevant. |

A search of each of the three sites resulted in the identification of 646 relevant trials. These relevant trials were spread across the sources as follows:

²⁷ ISCRTN is not spelt out as its original definition as 'International Standard Randomised Controlled Trial Number' is stated on the registry website as no longer applying because the scope has broadened, so they just use the acronym.

²⁸ The list of interest was a list of all research being conducted during the reference period that may include projects that either directly or in subgroup analysis focused on the case populations. More details are available in Appendix A-1

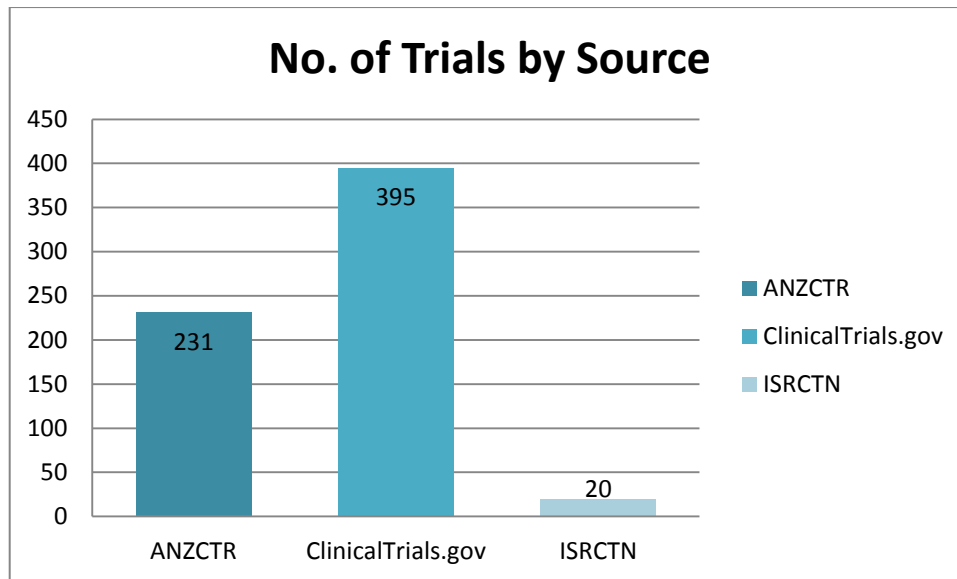


Figure 3 - Search Results by Source

It is important to note that the trial registries were not as complete or as informative as anticipated. As outlined above, trial registries were designed to provide transparency and information to the public and professionals on clinical research work being conducted at any given time (Chalmers et al., 1986; Steinbrook, 2004; Wood, 2009). By posting detailed and accurate accounts of protocols and research activity people can investigate researchers and hold them accountable for what they said they would do and what they then later publish.

The ANZCTR specifies that it meets the data requirements of the WHO. However, information that could have led to an analysis of how externally valid a trial was, was largely not available and information regarding internal validity was varying in its standards in the records found. Best practice which includes prospective registration and full and clear descriptions within entries in the registries was not evident, based on the following factors:

1) Retrospective registrations

Trials are ideally registered before the commencement of work so that the intended outcomes to be measured and the analysis are recorded and researchers cannot change these after they have collected data. There is evidence in the literature of the switching of the secondary and primary outcome when primary outcomes show no result (Goldacre, 2012; Mathieu

et al., 2009). This switching is problematic: most studies are powered²⁹ off the primary outcome and so generally have insufficient numbers to assess the efficacy/effectiveness of the secondary outcome. Retrospective registration while not necessarily the result of wilful misdirection undermines the purposes of the registry (as outlined above). Less than half of the trials meeting our search criteria were registered prospectively in the ANZCTR (98 of 231, 42.42%) or ISRCTN (6/20, 30.0%) (see Figure 4), while the ClinicalTrials.gov registry showed somewhat better practices (275/395, 69.62%, Figure 4).

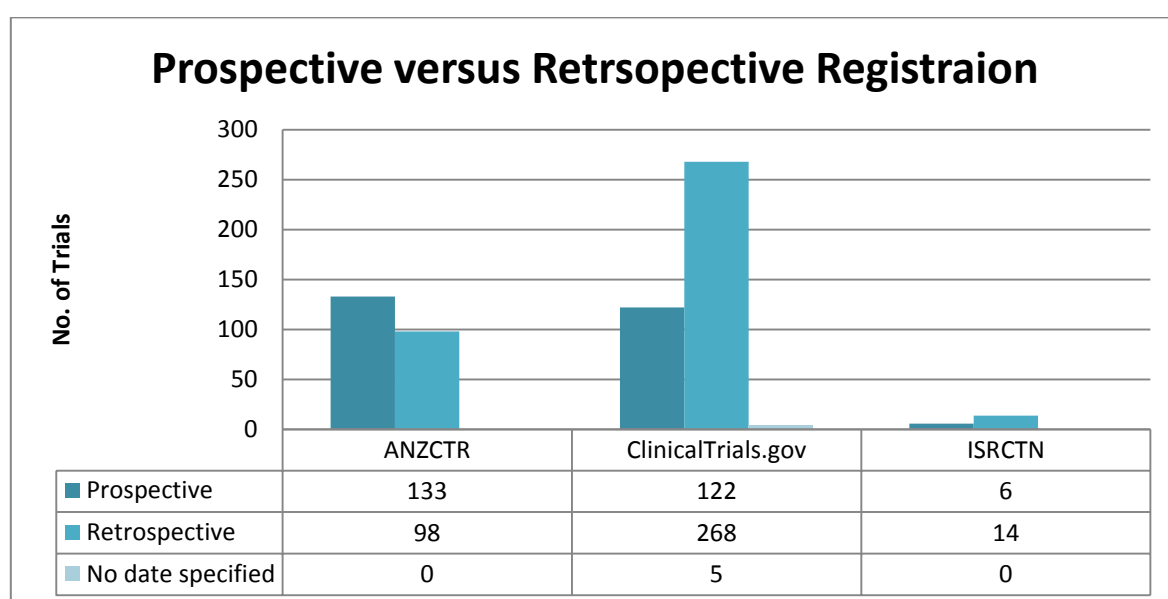


Figure 4 - Registration Timing

2) Minimalist descriptions of outcomes

Descriptions of outcomes in the registries ranged from detailed descriptors that included considerations of minimally important clinical difference (MICD) or clinical significance measures, to those that simply stated a category of outcome such as “pain”. What this vague specification of outcomes means is that researchers can, if they feel pressure to, redefine what a significant outcome is in their trial after the fact. Others have done research scoping the size of this issue. (Chan, Hróbjartsson, Haahr, Gøtzsche,

²⁹ To power a study, is to complete a calculation that informs you how many participants you need to be able to make statements about the significance of results, given the variables identified. Power calculations can vary depending on your statistical preferences and are dependent on the outcome measure you have chosen and the size of change you need in that outcome for it to be classed as significant.

& Altman, 2004; Goldacre, 2012; Mathieu et al., 2009; Prayle, Hurley, & Smyth, 2012). The switching of outcome measures after analysis is comparable to taking a test and deciding what the passing grade is after you know your grade. What is also worrying about the lack of detailed information in this category is that to calculate correct sample sizes requires specific outcomes measures. If therefore, trial teams have not determined specific outcomes measures, they cannot calculate robust sample sizes. Alternatively, if the teams have calculated specific outcome measures, why are they not being shared? Interestingly, the WHO TRDS (WHO, n.d.-c) does not make explicit the level of detail required and has “accredited” the ClinicalTrials.gov registry, ISRCTN, and the ANZCTR through their inclusion in the primary registries group. So, despite the serious problems just described, it could be claimed that these practices are “acceptable” according to current WHO requirements.

3) Incomplete records (no description of statistical analysis)

All trial records had insufficient information about the statistical analyses used to determine their sample or to analyse their outcomes. For example, of the 231 records matching our criteria in the ANZCTR, only 19 specified their statistical methods (Figure 5).³⁰ Most users provided no information, and where information was provided it varied in detail. Again, while WHO TRDS does not specify the level of detail (WHO, n.d.-c), this lack of information clearly undermines the purposes of the registry. Sample size calculations are powered from the primary and sometimes also the secondary outcome. Deciding what a significant difference in outcome might be is used to calculate sample sizes. Researchers should have determined this significant difference and the sample size to proceed with a trial, meaning that the information should be available. Therefore, where this omission occurs in the registry, the information is either a) available and the researcher is not providing it; or b) it is not available in which case the researcher is conducting a trial without a scientifically valid sample size.

³⁰ Less than 10% specified an intention-to-treat analysis. An intention-to-treat analysis is one where statistical analysis is done on the whole cohort including drop-outs. This allows for an analysis that can make claims about treatment adherence, as well as efficacy of intervention and is therefore more externally valid in its claims, because one could presume if adherence is low in a trial situation; it is likely to be lower still in a “real life” situation, where treatment effects generally drop.

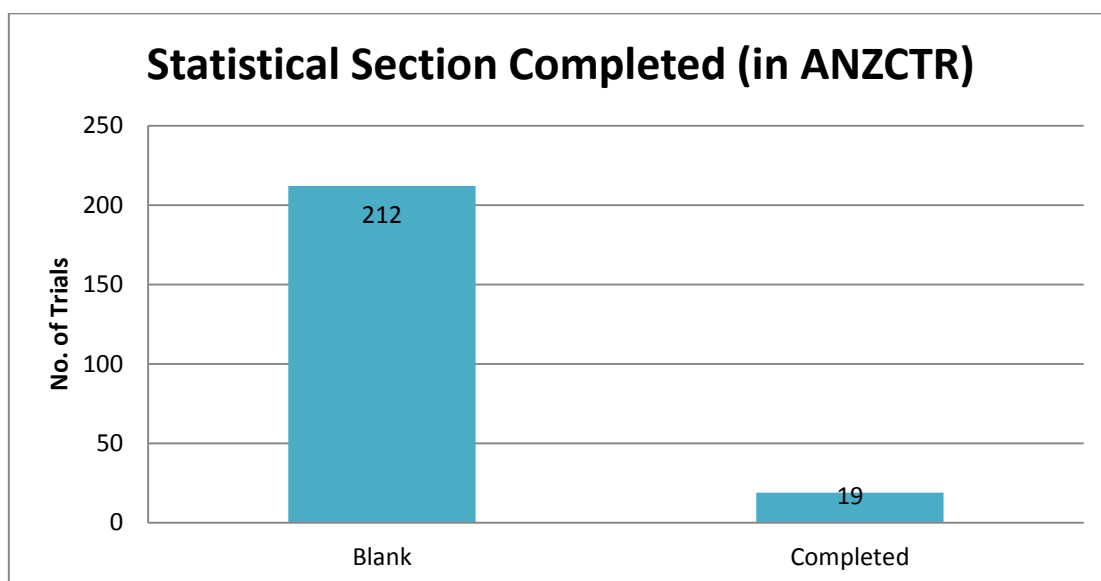


Figure 5 - No. of Trial Registrations with Statistical Methods Section

What this shows is that trial registries are at present only partly fulfilling their purpose in providing accountability. While they do allow clinicians, researchers, the public, and other interested parties to find out what work is going on to some degree (insofar as researchers use them), they do not consistently provide enough information to ensure research conduct (for this particular aspect) is acceptable.

To investigate how much work is done specifically for or with the groups identified in our work as disadvantaged, we searched our results for the occurrence of the case groups within protocols. We did this for each trial registry separately given the differences in their formats and search functions.

The following search terms were used to identify population-specific work:

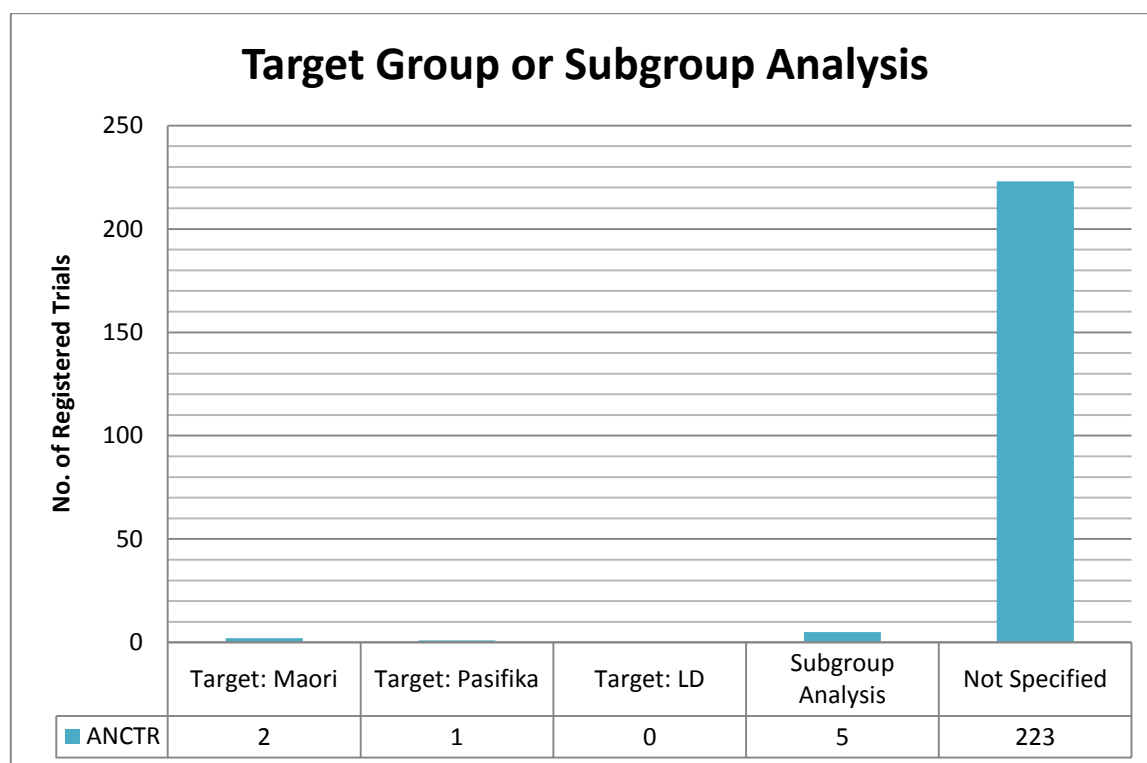
Table 3- Population Search Terms³¹

| | |
|----------|---|
| Māori | “Māori”, “indigenous”, “Tangata Whenua”, “whanau”, “hauora” |
| Pasifika | “Pasifika”, “Pacific Islander”, “Tongan”, |

³¹ For all three categories terms were used that cast the net wide (i.e. Pac* or disability) to ensure a comprehensive search; this resulted naturally in more results than were relevant – irrelevant results were removed on reading of trial descriptions.

| | |
|---------------------------------------|---|
| | “Samoaan”, “Cook Islander”, “Cook Island Māori” “Fijian”, “Niuean”, “Rarotongan”, “other Pacific Peoples”, “Pas*”, “Pac*.” |
| Intellectually Disabled ³² | “intellectual disab*”, “Downs syndrome”, “Prada-Willi syndrome”, “f* alcohol syndrome”, “FAD” also “disability” and “development” were included |

In the ANZCTR, the research summary and inclusion/exclusion criteria sections provided the information regarding target population. I found subgroup analysis information in inclusion/exclusion criteria, secondary outcomes measures, randomization process (specification of stratification by subgroup) and statistical methods (where these were complete) sections. The results provided in Figure 6 regarding subgroup analysis could, in fact, be larger, though we cannot confirm this due to the incompleteness of records.



³² This terminology was used in the search as it pre-dated the use of learning disability. The search terms, do not provide a full profile of the learning disabled population and underestimation of population size is an ongoing issue for this group based on classification and diagnosis issues (Leeder & Dominello, 2005; Linton et al., 2011). Added to this, we excluded SOTOS (generally considered an intellectual disability) due to its rarity. After the change of name from intellectual to learning, other disorders such as dyslexia, could have been included, but were not based on adhering to the chronologically accurate definition.

Figure 6 - ANZCTR Registered Trials with Target Group or Subgroup Analysis of Target Group

In the ClinicalTrials.gov registry, as with ANZCTR, target group information was found in the research summary and inclusion/exclusion criteria sections. However, for the subgroup analysis, two methods were used. Of the 395 trials that met the search criteria on ClinicalTrials.gov, 120 had study results available. These results include a “baseline measures” section where registrants specify their baseline measures for each participant including demographic details. For the 120 trials with results, I checked their baselines measures for a specification of ethnicity/race data collected. For the remaining 275 trials, I checked their inclusion/exclusion criteria, secondary outcome measures and any publications listed. Of the 275, none specified anything related to relevant subgroup analysis. As with ANZCTR however, this could mean the 275 collected ethnicity/race data but did not report it. No studies targeted any of our groups specifically and only 39 of 395 trials reported the collection of ethnicity data (Figure 7).

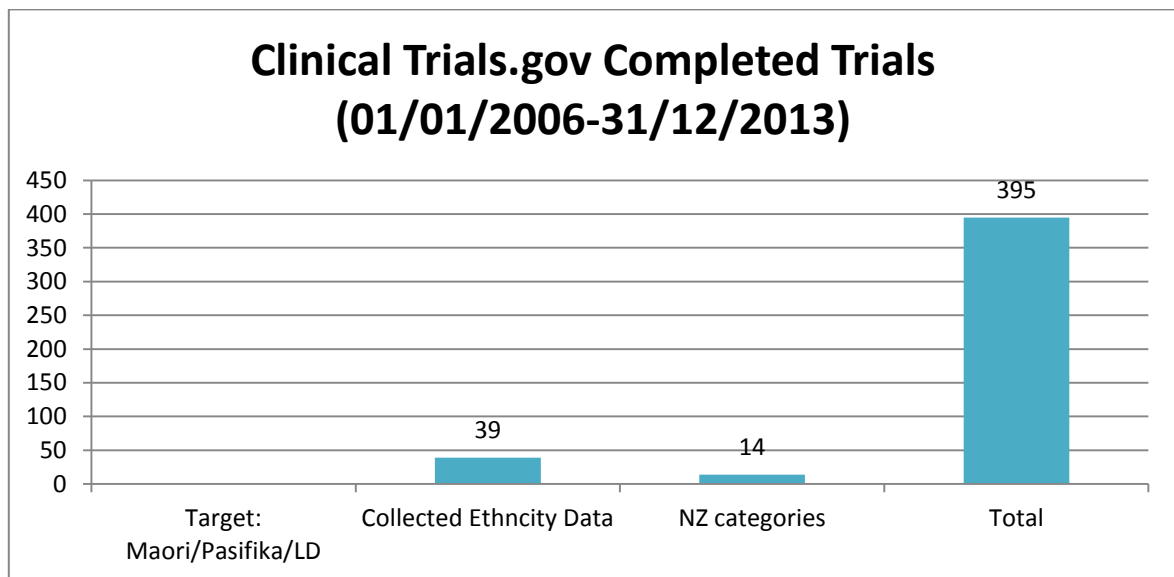


Figure 7 - ClinicalTrials.gov Trials with Target Group or which specified collection of ethnicity and included NZ relevant categories

It is significant that of the 120 studies with results in the ClinicalTrial.gov registry, the 14 that collected New Zealand specific data included one study that had the category “Māori” and thirteen studies with the category “Hawaiian/Pacific Islander”. Of these 14, none had recruited anyone to those categories, i.e. in their study results, numbers next to these categories were “0”. Of 120 studies that could potentially

lead to changes in services or policy³³ none could report the inclusion of a single participant of Māori or Pasifika ethnicity. This lack of participation by the case groups speaks to the premise that evidence generation is not generalizable or externally valid to our setting.

Based on the Māori Health Chartbook (Talamaivao et al., 2010), I also decided to investigate the research activity around the leading causes of death in this population. The “Pasifika Health Chartbook” and “Health Indicators for Intellectually Disabled New Zealanders” did not specify leading causes of death (Linton et al., 2011; McCormack et al., 2012) and so an equivalent analysis could not be undertaken. Of the 231 trials found on the ANZCTR, the following studies related to leading causes of death for Māori (Total: 60/231) (Figure 8).

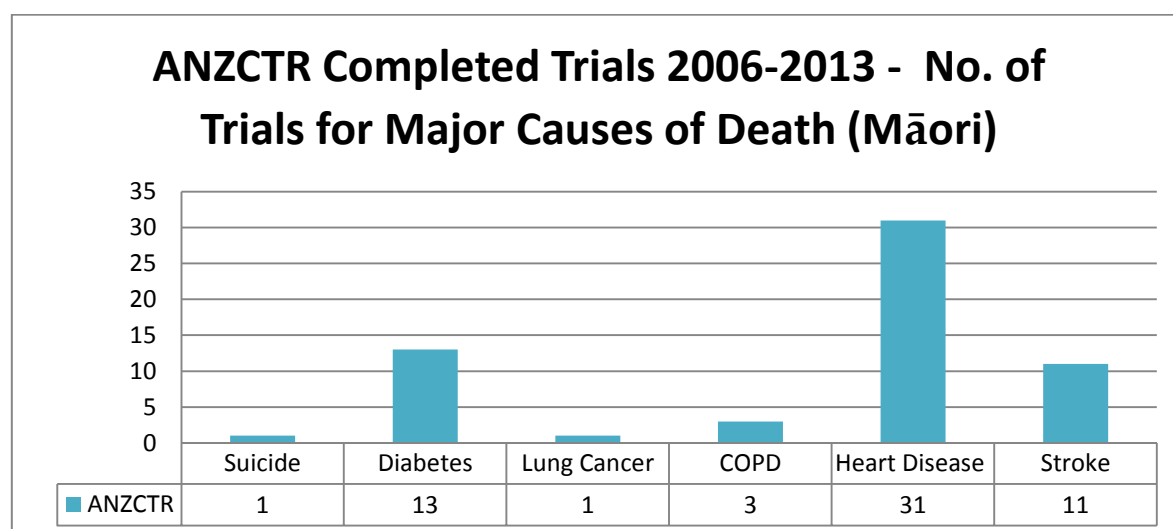


Figure 8 - Major Causes of Death, Māori Health Chartbook (2010)

Given the trials sourced in the ClinicalTrials.gov registry only listed New Zealand as a secondary site for research and rarely collected ethnicity data relevant to our population, I did not complete a similar analysis of disease type in this registry.

The ISRCTN registry sample covered cancer (breast, gastro-intestinal, colorectal, gynaecological) (7), kidney disease, flu vaccinations, blood pressure during pregnancy, cardio- pulmonary or vascular related interventions (5), faecal incontinence, pelvic floor prolapse, patient reassurance intervention, infantile spasms and traumatic brain injury.

³³ It acknowledged that a trial’s ability to affect services or policy depends on the outcomes of the trial, its dissemination, and the implications.

Of the 20 trials in the ISRCTN, six primarily recruited in New Zealand. Of these, three had information on ethnicity data:

- one trial recruited one participant;
- one trial had two ethnicity categories, “European” or “Other”, and in the “Other” category recruited 29 participants;
- one trial collected full ethnicity data and recruited 41 Māori participants and 19 Pasifika participants in a total participant pool of 113.

None of the trials registered in the ISRCTN specifically targeted Māori, Pasifika, or people with learning disabilities.

Regarding this inquiry, what do these findings mean for representation? While research activity relating to diseases of interest to the case populations is occurring (Figure 8), little research is being done specifically for them (Figure 6). I cannot conclude that much work is being done to recruit or undertake subgroup analyses within the research activity recorded (Figures 7) keeping the limitations of the information described above in mind.

Information provided in trial registries was more limited than expected.

Representation appeared superficially to be weak. This weak representation was both in relation to numbers of trials registered where Māori, Pasifika or people with learning disabilities were the main focus, but also regarding subgroup analysis and recruitment of Māori or Pasifika participants. Subgroup analysis for people with learning disabilities is not specified and people with learning disabilities are very rarely included in trials that are not specifically for them (McDonald & Keys, 2008; Puyalto, Pallisera, Fullana, & Vilà, 2015). There are barriers to recruiting people with learning disabilities into research (and especially research directed to the wider public). On the one hand, designing recruitment activities, research procedures and interventions that are user-friendly for those with learning disabilities requires more care and consideration so that information is conveyed appropriately, interventions are suitable and practicable, and processes include guardians where necessary (Iacono, 2006; Iacono & Murray, 2003; Lennox et al., 2005). On the other hand, ethics committee review can be more challenging and lengthy (Lennox et al., 2005) with some committees’ attitudes being classed as

overprotective (this also is mentioned in Chapter 4). Both of these factors require time which researchers sometimes perceive to be lacking. Knowing that people with learning disabilities are not generally recruited into total population trials means that these results for this group specifically can be taken at face value, i.e. if they are not the primary focus of the trial then they are unlikely to have been included at all. For Māori and Pasifika peoples, we can assume that reporting may well have been lower than practice and that therefore, aside from research directed towards them specifically, and the research where we found some subgroup analysis, figures for this subgroup analysis are probably somewhat higher. Overall, however, representation was still not proportional to either demographic representation or need.

Given the use of registries was not 100%, a review of a further source of research activity made sense.

2.5. Representation in Ethics Committee Records

Health researchers in NZ complete ethical review for their work and therefore ethics committee records provided another avenue for investigation. Actual regulation in New Zealand is somewhat odd, in that no one piece of legislation prescribes ethical review, but a collection of legislation ensures the rights of participations/patients, these include: Protection of Personal and Property Rights Act 1988, New Zealand Bill of Rights Act 1990, Privacy Act 1993, Health and Disability Commissioner Act 1994, Accident Compensation Act 2001, Human Tissue Act 2008, and the Treaty of Waitangi. The HRC stipulates that ethics review is compulsory for funding, and universities enforce a compulsory ethics approval for research undertaken, as do hospitals. There are however gaps in this system for research undertaken outside of universities that do not involve hospitals or patients recruited from hospitals.

An approved ethics committee is one that has been through the HRC process for accreditation³⁴. The HRC is the main funding body for health research in New Zealand, and under the Health Research Act (1996) is mandated to accredit ethics

³⁴ The approval process asks committees to demonstrate their members mix (in terms of gender/ethnicity), their expertise (capability to robustly review) and annual training, their procedures and review processes, and commits them to reporting, and maintaining standards <http://www.hrc.govt.nz/ethics-committee-approval-and-annual-reporting>

committees on the basis that it cannot award funding to an investigator who has not undertaken robust ethical review. In addition, to the HRC, there is a National Ethics Advisory Committee (NEAC). This committee creates reports and guideline documents for clinical and research ethics matters but has no oversight responsibilities for research ethics review. Accredited committees are currently of two kinds: Health and Disability Ethics Committees (HDECs) and various Institutional Ethics Committees.

HDECs are Ministerial Committees (Ministry of Health) tasked with the review of all health and disability research. Their scope was restricted and their structure changed in 2012, to minimise review times within committees and make them more efficient, in the hopes of making the clinical trial environment more welcoming and productive (Tolich & Smith, 2015).³⁵ All clinical (interventional, all risk; observational, high risk) research is supposed to be assessed by an HDEC. Where a researcher requires approval from an accredited ethics committee as part of their funding arrangements, but their projects falls outside of this HDEC scope, they would apply to an appropriate accredited Institutional Ethics Committee. Some universities and polytechnics have applied to have their Institutional Ethics Committees accredited and these committees review research work of all levels and kinds at the institution that fall outside of the scope of HDEC review. Other Institutional Ethics Committees at universities and polytechnics are non-accredited and largely assess student work of a non-health nature (i.e. sociological research for example). District Health Boards³⁶, where they have their committees, still require HDEC approval, but their committee will approve the research to go ahead within their facilities specifically. The New Zealand Ethics Committee is non-accredited independent/private committee reviewing non-clinical research from the government/third sector/industry and is not related to our inquiry. Historically, NZ also had one accredited industry committee. This committee was a committee at a

³⁵ While Tolich and Smith discuss this reform, full documentation regarding the enquiry and the various submissions made by pharmaceutical companies, concerned citizens, ethics committee chairs, academics, the Law Foundation, Women's Health Aotearoa, and many more can be found here: https://www.parliament.nz/en/pb/sc/submissions-and-advice/document/49SCHE_ADV_00DBSCH_INQ_9752_1_A146217/summary-of-submissions

³⁶ District Health Boards are regional governance and service structures for the provision of secondary and tertiary care and public health in NZ, which also distribute funding through Primary Health Organisations to primary care.

Drug-Trial Company that trialled generics. This committee is no longer in existence (Figure 9).

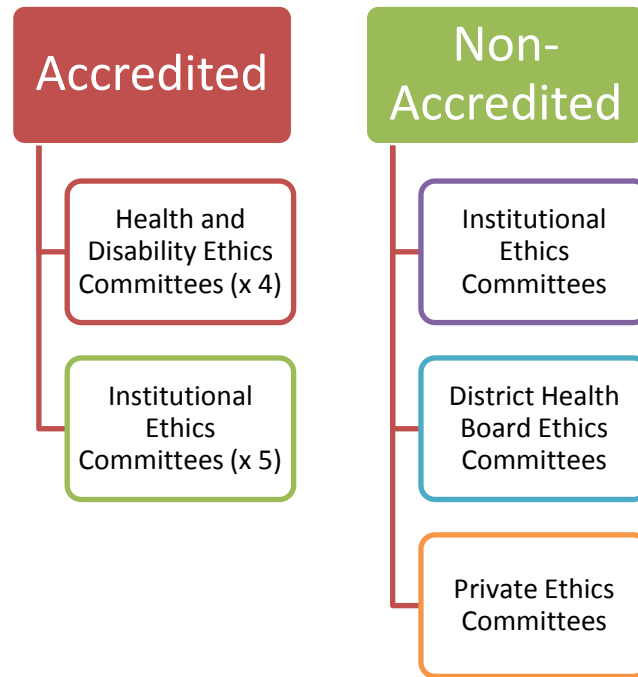


Figure 9 - Ethics Committees in Aotearoa New Zealand

For this analysis, I took the records of HDECS, which are publically available, as a representation of clinical research work occurring in NZ, i.e. work likely to generate 'evidence'. Records before 2012 are more comprehensive in that their review scope was broader at that time and therefore more diverse kinds of research were considered by the committees. Records post-2012 are less comprehensive of the total view of health research occurring in NZ but can be seen as more relevant in that the work reviewed is much more likely to be work that leads to 'evidence' within current ranking/evaluation systems. This difference post-2012 is based on the 2012 reforms which limited the committees' review scope, but in doing so focused it more clearly on clinical work (likely to be classed as evidence).

A limitation of this study was that I had to rely solely on the project title and this may not have accurately reflected the content of the project as a whole. I and one other (as described in Appendix A-2) went through all titles for descriptions of

Māori, Pasifika, or learning disability projects, as well as projects that referred to multiple ethnicities, comparisons or disparities.³⁷

Table 4 - Breakdown by year total for all Health and Disability Ethics Committee applications and proportion for groups of interest

| | 2005 | % | 2006 | % | 2007 | % | 2008 | % | 2009 | % |
|---|------|------|------|------|-------|------|-------|------|------|------|
| Total no. of applications | 848 | | 939 | | 1186 | | 1176 | | 1035 | |
| Withdrawn | 14 | | 25 | | 15 | | 20 | | 11 | |
| Declined | 9 | | 11 | | 24 | | 18 | | 18 | |
| Total no. of applications considered | 825 | | 903 | | 1147 | | 1138 | | 1006 | |
| Combined - case populations | 47 | 5.70 | 42 | 4.65 | 40 | 3.49 | 52 | 4.57 | 43 | 4.27 |
| Māori | 24 | 2.91 | 20 | 2.21 | 10 | 0.87 | 24 | 2.11 | 20 | 1.99 |
| Pasifika | 8 | 0.97 | 8 | 0.89 | 13 | 1.13 | 18 | 1.58 | 3 | 0.30 |
| Learning/Intellectual disability | 2 | 0.24 | 6 | 0.66 | 8 | 0.70 | 4 | 0.35 | 5 | 0.50 |
| Ethnicity/Disparities | 13 | 1.58 | 8 | 0.89 | 9 | 0.78 | 6 | 0.53 | 15 | 1.49 |
| | 2010 | % | 2011 | % | 2012a | % | 2012b | % | 2013 | % |
| Total no. of applications | 1322 | | 1409 | | 578 | | 262 | | 562 | |
| Withdrawn | 15 | | 10 | | 3 | | 1 | | 0 | |
| Declined | 14 | | 13 | | 2 | | 6 | | 16 | |
| Total no. of applications considered | 1293 | | 1386 | | 573 | | 255 | | 546 | |
| Combined - case populations | 69 | 5.34 | 68 | 4.91 | 27 | 4.71 | 11 | 4.31 | 20 | 3.66 |

³⁷ A full description of methodology used is available in Appendix A-2 along with a full list of the applications selected for inclusion.

| | | | | | | | | | | |
|---|----|------|----|------|----|------|---|------|---|------|
| Māori | 34 | 2.63 | 30 | 2.16 | 14 | 2.44 | 6 | 2.35 | 5 | 0.92 |
| Pasifika | 9 | 0.70 | 8 | 0.58 | 3 | 0.52 | 1 | 0.39 | 3 | 0.55 |
| Learning/Intellectual disability | 4 | 0.31 | 10 | 0.72 | 1 | 0.17 | 1 | 0.39 | 5 | 0.92 |
| Ethnicity/Disparities | 22 | 1.70 | 20 | 1.44 | 9 | 1.57 | 3 | 1.18 | 7 | 1.28 |

Table 5 -Summary of HDEC Application Numbers 2005-2013 (inclusive) and proportion of applications for groups of interest

| | Total | % |
|---|--------------|----------|
| Total no. of applications | 9317 | |
| Withdrawn | 114 | |
| Declined | 131 | |
| Total no. of applications considered | 9072 | |
| Combined - case populations | 419 | 4.62 |
| Māori | 187 | 2.06 |
| Pasifika | 74 | 0.82 |
| Learning/Intellectual disability | 46 | 0.51 |
| Ethnicity/Disparities | 112 | 1.23 |

As with the trial registries, it is apparent that based on research titles alone less than 5% of research is conducted with our case populations combined.

Numbers before 2012, when the HDEC review was regional³⁸ show no difference in representation despite Māori and Pasifika populations being larger in some regions, such as Central Regional Ethics Committee, Northern X and Northern Y.

To be clear, the information available in the ethics committee reports does not provide information as to a researcher’s intention to conduct subgroup analysis. However, it is fair to assume none completed subgroup analysis specifically for

³⁸ post-2012, while each committee has a name identifying it geographically, applications are submitted through a portal and then distributed to committees based on monthly capacity to review

those with learning disabilities as this is not common practice in NZ and most trials would exclude those without the capacity to consent independently.

2.6. Representation in Government Strategies and Guidelines

2.6.1. What Evidence?

It is important to understand what information is used to guide decision-making in health. To this end, I collected all relevant guidelines from the Ministry of Health website and discussion documents for Health Technology Assessment in NZ. These are two areas of decision-making that have open documentation available for scrutiny, one relating to healthcare delivery and the other to its provision.

Guidelines for conditions that the three case populations fare worst in based on the health statistics in 2.1 of this thesis were the obvious choice. These guidelines especially should take account of the case populations based on their need. I used guidelines that included either a specific reference to evidence grading, expert review or included a full reference list. Guidelines for each condition were not available, but guidelines for related management were included (this included the Primary Care Handbook). I then reviewed each guideline for the following, where available:

- 1) Specific sections for Māori, Pasifika or learning disabled populations
- 2) Specific inclusion of Māori, Pasifika or learning disabled experts on the review or advisory panels
- 3) Grading of evidence in recommendations specifically related to Māori, Pasifika or learning disabled populations
- 4) Number of references included for Māori, Pasifika or learning disabled populations.³⁹

Table 6 - Government documents for the major causes of mortality and morbidity⁴⁰

| | Specific Sections | Evidence & References | Expert Consultation/ Review |
|---------------------------|--------------------------|----------------------------------|--|
| New Zealand | Māori section | No evidence/grading | No information provided. |
| Suicide Prevention | Pasifika section | information provided. | |

³⁹ Appendix A-3 includes full lists of the references referred to.

⁴⁰ Full citations for these documents are available in Appendix A-3

| | | | |
|--|--|--|--|
| Strategy 2006-2016 | + other sections for other minority groups (but not the learning disabled) | However, calls for the inclusion of broader types of research evidence in future including comparative and qualitative studies. 46 References, 7 Māori, 7 Pasifika, 2 covering both | |
| Stroke Guidelines (2010) | Māori Pasifika Younger Adults | All recommendations for Māori and Pasifika are “consensus/best practice point” grade level – lowest grade. 1107 references, 20 Māori, 11 Pasifika, 14 covering both | Specific subgroup for Māori section development. No mention made of Pasifika section subgroup. |
| Background information and recommendations for Stop Smoking Guidelines (2014) | Māori Pasifika As well as a number of other groups including Asians, mental healthcare consumers, etc. but no reference to learning disability | Māori – Grade C and consensus/best practice point Pasifika – Grade C and consensus/best practice point 68 references – 4 Māori, one of which includes Pasifika peoples. | Pasifika representative on guideline group, no specific Māori representative. |
| Clinical Guidelines for Weight Management in New Zealand Adults | Māori Pasifika South Asian | States no evidence found for Māori, uses best practice points (GRADE Scale) derived | One Māori and one Pasifika expert in peer review panel. |

| | | | |
|--|---|---|---|
| (2009) | | <p>from expert input. States no evidence found for Pasifika except two RCTs, uses good practice points derived from expert input.</p> <p>Similarly, expert input used for South Asian population</p> <p>199 References, 5 for Māori, 3 for Pasifika, 7 for Asian populations, plus 7 covering mix</p> | |
| New Zealand Primary Care Handbook (2012) | None | References and grading not supplied. | Pasifika team member included in guidelines group, no specific Māori representative. |
| Assessment and Management of Cardiovascular Risk (2003) | Māori section and Pasifika section (including discussion of disparities and institutional racism) | <p>Recommendations for Māori included one of c-grade, all others “key messages”.</p> <p>Recommendations for Pasifika all best practice points.</p> <p>One combined recommendation C-grade.</p> <p>705 References, 5 Māori, 2 Pasifika, 12 covering both</p> | 2 Pasifika experts were included in subgroup membership. Māori experts were thanked for their contribution but were not formal members. |

This table shows that guidelines and strategies include little in the way of high-quality evidence as judged on the GRADE scale to support the case populations with some guidelines specifically stating the difficulty in making recommendations due to lack of available health data or research evidence (Ministry of Health, 2009). This lack of relevant evidence for the case groups is further emphasised by Collings and Beautrais when referring to suicide, who state:

“Unfortunately, in regard to individual risk factors there is no published research that rigorously compares the profiles of Māori and non-Māori. Neither is there robust research that examines risk and protective factor profiles among Māori with the same explanatory power as has been used in studies of the wider population.” (Collings & Beautrais, 2005)

Where the guidelines do reference relevant research, it is mostly epidemiological or theoretical, and only refers to Māori and Pasifika peoples, those with a learning disability being entirely invisible. Most of the intervention studies listed in reference lists were completed internationally and so the generalisability to Māori and Pasifika groups, and even the NZ population is unknown. The Suicide guideline⁴¹ in the table above makes specific reference to including broader types of research in the generation of guidelines: *“There is an urgent need to increase and build on existing evidence-based research relating to Māori suicidal behaviour, and the inclusion of other forms of evidence is seen as critical by Māori.”* (Ministry of Health, 2006c), something we will discuss further in Chapter 5.

Guidelines were one source of information, which relate to service delivery. Health Technology Assessments (HTAs) undertaken by governments determine health service provision. The National Health Committee (NHC) of New Zealand (recently made defunct) was the main body that undertook HTA in NZ. These kinds of assessments inform governments on appropriate services to fund (or more rarely de-fund) when determining the limits of the health budget. The other government agencies that currently undertake these kinds of assessment are PHARMAC⁴² which

⁴¹ An excellent Suicide Prevention Toolkit for DHBs has also been created (Ministry of Health, 2015). This document references Māori and Māori resources specifically and includes a section for consideration of diverse populations.

⁴² The Pharmaceutical Management Agency, for more information, see their website: <https://www.pharmac.govt.nz/about/>

does them solely for pharmaceutical products, although the government has recently added medical devices to its remit; and the Accident & Compensation Corporation (ACC)⁴³, which is NZ's no fault injury insurance.⁴⁴

HTAs undertaken by the NHC that are publicly available are those for aortic stenosis and low back pain management. Aortic stenosis is not highly prevalent in the Māori population according to the documents related to this HTA. Of note, however, is the Tier 2 and 3 assessments documents as well as the decision paper which includes more than 140 references, one of these references relates to Māori, and none relate to the other populations (National Health Committee, n.d.-c). The low back pain document is similarly sparse (one mention of obesity in Māori in the text, no references unique to Māori in the list of 76 references). The omission of relevant work is despite the fact that prevalence of low back pain in New Zealanders is high (1 in 3 as quoted in the document), and the prevalence of potential causes of low back pain are higher in the Māori populations (National Health Committee, n.d.-a).

I acknowledge that an argument can be made that these technical documents do not need to consider diversity, as they simply weigh efficacy against cost. However, these discussions of funding often focus on cut-off points for care that are mostly to do with age⁴⁵ or quality of life⁴⁶ (as well as the ability to benefit). Factors such as life expectancy and cultural awareness amongst others, then become highly relevant. Authors of these documents and those making related service provision decisions should acknowledge this relevance in discussions of funding, given the “the legal and moral obligation to reduce health inequalities” as explained in the Chronic Condition document (National Health Committee, n.d.-b).

There are also problems with using health data sets or national surveys where service utilisation (due to lower service use) or response rates may not be representative for subgroups of the population (Bramley & Latimer, 2007; Swan et

⁴³ This is NZ's no-fault accident insurance provide to all based on taxation and levies. For more information, see: <http://www.acc.co.nz/>

⁴⁴ HTAs are likely also undertaken by individual DHBs on an ad hoc basis and there are some academic HTAs, but these three agencies were the main users of HTA up until recently.

⁴⁵ If life expectancy is lower for a group, or morbidity begins earlier, care caps for these groups could be lower than for the general population if we were addressing equity. This is of course, contentious and will be discussed further in Chapter 6.

⁴⁶ Research exists that outlines this problem (Chamberlain, 1985), but no reference to this is made, in any of the documents at any time.

al., 2006).⁴⁷ Another document created by the NHC regarding chronic conditions and their management is comprehensive. It makes explicit statements about the lack of evidence in certain areas related to culturally appropriate care and the need for government to fill this gap, but also makes clear statements about the importance of culturally sensitive care, considerations of inequalities in designing care, patient-centric management and so on (National Health Committee, n.d.-b). A statement that best typifies this document is: *“Any effort to limit the impact of chronic conditions should ensure that outcomes for groups at greatest disadvantage improve earliest and most significantly”* (National Health Committee, n.d.-b). However, this document is much older than the other NHC documents available (2006, versus 2015). It is probable that the stark difference in tone reflects the change of government in New Zealand.⁴⁸

PHARMAC HTAs (eculizumab and Herceptin) and ACC HTAs that were available online similarly lacked reference to inequalities or specific groups such as Māori. However, PHARMAC has a section of their website that listed some Māori research references and a section of their website addresses Māori issues.⁴⁹ The ACC website, which has a publication section for their evidence-based reviews, procurement reports, guidelines, and research project outcomes, has one document that is specifically about Māori (ACC, 2016). The NHC Chronic Condition document (the described more favourably above) is the only one to mention Pasifika and no HTA documents mention people with learning disabilities anywhere.

This lack of reference to the three case groups in these kinds of documentation and tools is important because within the health system and policy settings, guidelines, prediction rules, cost-benefit analyses, and the like, are becoming fundamental to

⁴⁷ To be clear, data sets from census or mortality data is likely to be accurate, but this is only very specific information. Various prevalence and service use data, as well as data from surveys, may be less reliable.

⁴⁸ The National government, which would be described as centrist-right/right took over government from a three-term Labour government. It is generally acknowledged that during that Labour period great headway was made in terms of disparities in New Zealand, and this in part was due to various health policies that were underpinned by the tagline “Better Health For All”. The National governments initial health policies had taglines and titles such as “Better, Sooner, More Convenient”.

⁴⁹ PHARMAC have also recently launched new “factors for consideration” which are their decision-making criteria and these include specific reference to inequalities and Māori outcomes. These new factors are still in the process of implementation and the degree to which they are weighted is not clear. This question of weighting was specifically asked at an AABHL Conference in 2015 of a presenter from PHARMAC introducing these factors, who stated there currently were no weights assigned to individual factors and how they would be traded off against each was not yet clear.

healthcare and healthcare decision-making. These tools are essential in a system marked by economic-targets, standardisation, and managerialism (Adams & Leveson, 2012; Bill Doolin & Stewart Lawrence, 1997; Maddock & Morgan, 1998; McCloskey & Diers, 2005). Where these decisions and tools are created using research that lacks external validity to the setting and population, there is the risk of disadvantaging people further, by failing to address their needs and alienating them from the healthcare system.

The Ministry of Health developed a tool “Health Equity Assessment Tool” in 2008 (Signal, Martin, Cram, & Robson, 2008) to help those designing services, programmes, guidelines and policies to incorporate health equity considerations. The tool outlines a step-by-step process for understanding health inequities by identifying determinants and addressing them in your setting. Again this document predates the current government, and the degree to which it is being used is unclear. Interestingly, it does require that work using the tool is evidence-based, but calls for the inclusion of evidence from grey literature, qualitative work, as well as key informants (in addition to the general evidence definition). None of the documents sourced referenced this tool.

2.7. Research for the Case Populations

From the previous sections, we can see that there is relatively little clinical work or ‘evidence’ generation done specifically for the groups chosen to represent disadvantage. It is important, however, to confirm what work people are doing outside of these main settings.

2.7.1. Māori Research

Te Puna Kokiri is a government funded organisation that provides advice to government on all matters Māori.⁵⁰ They also conduct trials to test policy (not solely health related). One of their most significant portfolios is the Whānau Ora programme⁵¹, a programme championed by the Māori Party⁵² that uses an innovative model to improve Māori well-being across multiple domains (i.e. health,

⁵⁰ For more information on Te Puna Kokiri, please see: <https://www.tpk.govt.nz/en/>

⁵¹ It is important to note here that while the Whānau Ora services are a Māori-led model, and were originally only for Māori it can now be accessed by, any New Zealander, irrespective of ethnicity.

⁵² The Māori Party is a New Zealand political party that specifically advocates for and supports Māori aspirations within a kaupapa Māori framework (i.e. one that privileges Te Ao Māori: Māori world view).

education, housing). Te Puna Kokiri and the Ministry of Social Development fund it as a joint initiative.⁵³ While Te Puna Kokiri does not have a specific health research remit or stream, Whānau Ora has a Whānau Ora Research page embedded within the Community Research (Tangata Whenua, Community & Voluntary Sector Research Centre, a registered charity and incorporated society focusing on collecting, disseminating and promoting community research)⁵⁴ website. This webpage collects research on “Whānau Ora, communities, and whānau” and shares this openly while providing a space for discussion and networking.⁵⁵

In this repository, 38 projects are listed and provide information on a wide variety of topics. These topics include models of health; frameworks for undertaking health interventions, research, or evaluations of Whānau Ora; what is appropriate evidence; discussions of Tino Rangatiratanga (sovereignty) in relation to well-being; best practice guides; service tools; and implementation research. The majority of this research is about understanding how to conduct research or provide services or measures outcomes in a way that is responsive to Māori and does this through theoretical or empirical work.⁵⁶

Another source of research information for Māori is the Māori edition of the “Research Reviews”. A private company employs recognised experts in various fields to collate and comment on recent research in a given area to create each review, which are distributed via email to those who subscribe.⁵⁷ One of these expert areas is Māori Health. Currently, there are 61 reviews available online. These reviews include a mixture of epidemiological research, national and international research that includes Māori or is of relevance to Māori. Interventional work is mostly international (and therefore does not include Māori in the sampling). Reviews also contain local studies and qualitative work on occasion.

Each University has a Māori research unit of some form, i.e. Auckland and Otago have specific health research units, Victoria has a Treaty of Waitangi unit, Waikato

⁵³ For more information, see: <https://www.tpk.govt.nz/en/whakamahia/whanau-ora/>

⁵⁴ For more information, see: <http://www.communityresearch.org.nz/>

⁵⁵ For more information, see: <http://whanauoraresearch.co.nz/about-whanau-ora-research/>

⁵⁶ A full list is available here: <http://whanauoraresearch.co.nz/browse/all/>

⁵⁷ For more information see: <http://www.researchreview.co.nz/nz/About-Us.aspx>

has a unit with a psychology focus, AUT has a Māori Health Team, and so some dedicated resources and funding are being allocated to research for Māori.

There is, therefore, reason to believe that information exists that could provide a broader picture in decision-making if used. However, this information may not reach grading standards if evaluated based on evidence-based hierarchies. It is important to remember that such hierarchies only measure information against one dimension of validity (efficacy); ignoring information that might provide other useful material (this is discussed fully in Chapter 5).

Māori have representatives on most formal government committees from those that sit in the Ministry of Health to those sitting on ethics committees or grant funding panels, and other organisational committees. Working parties may not have specific representation, but they may ask for advice on policy and documents. While Māori representation is somewhat more formalised and protected through NZ's Treaty⁵⁸ with Māori, there is an indication in Chapter 4 that there are questions as to the quality of this representation.

2.7.2. Pasifika Research

Pasifika peoples have a Ministry of Pacific Peoples much like Te Puna Kokiri (but smaller) that provides policy advice to government and supports Pasifika peoples' flourishing in NZ through a variety of initiatives.⁵⁹ There is no equivalent Whānau Ora programme for well-being or health but after changes to Whānau Ora any person of any ethnicity could access the programme. There is no dedicated website to the dissemination of Pacific Health research. Some universities do have Pacific Health Research units; these exist at AUT and Auckland. Other Universities have a research stream within other health research units, such as at Massey or Otago.

The "Research Reviews" organisation also has an expert review in Pacific Health, although this has not been available as long (only 24 reviews are online) as the one

⁵⁸ The Treaty of Waitangi (Tiriti o Waitangi) is the constitutional document that establishes the relationship between the Tangata Whenua (People of the Land) and the Crown. The document is controversial, insofar as it is argued that the English and Māori translations did not marry up, and so Māori believed they were signing something else (it is also of note that not all iwi (tribes) representatives signed the Treaty). The Treaty is used in modern times, to underpin Māori self-determination and rights, and for Māori to make claims of compensation. For more information see: <http://www.teara.govt.nz/en/treaty-of-waitangi>

⁵⁹ For more information, see <http://www.mpp.govt.nz/what-we-do/>

described above for Māori.⁶⁰ Again, as with the Māori Health Research Reviews, much of the work included is epidemiological where it specifically applies to Pasifika Peoples, intervention studies in the reviews were mixed regarding their inclusion of Pasifika peoples, and some qualitative or theoretical work was present.

Representation in decision-making processes that directly affect Pasifika peoples is not enshrined in policy as it is for Māori. Therefore, representation for Pasifika relies on individual organisations' philosophy regarding representation and consultation.⁶¹

2.7.3. People with Learning Disabilities Research

The Office of Disability Issues is the government department tasked with providing advice for policy and services that affect the disabled, and this includes people with learning disabilities, but people with learning disabilities are not their sole focus. The Donald Beasley Institute (a not-for-profit organisation) is the only dedicated research organisation or unit for people with learning disabilities, although individual researchers at Auckland, AUT, Massey, Victoria and Otago do conduct research for and with people with learning disabilities. There is no Research Review for people with learning disabilities. There is no dedicated funding, as was mentioned for Māori and Pasifika in Section 3.3. of this chapter. There is no dedicated representation on general health service committees that make decisions that will impact their lives, although some committees and services specifically for this group will consult, and some (advocacy) organisations are committed to ensuring people with learning disabilities have a voice and are considered (like the Donald Beasley Institute, IHC or People First, to name but a few).⁶²

People with learning disabilities, while being a very small percentage of the population, fare the worst in health outcomes (life expectancy at birth of 59.7/59.5 years for males and females respectively, well below the global average of 71.4

⁶⁰For more information see: <http://www.pacifichealthreview.co.nz/ph/Pages/Recent-Reviews.aspx>

⁶¹ And the advocacy and activism of Pasifika health champions who argue for appropriate representation.

⁶² The Office of Disability Issues has recently undergone a major consultation process as it is updating the current disability strategy. The Office is very good at providing ways for all to participate in this kind of consultation allowing various forms of submission from recorded to written, open forums, support those making submissions and so forth. (Personal communication with Donald Beasley Institute).

years)(Linton et al., 2011; WHO, n.d.-d) with little research support to change that outcome.⁶³

2.8 Data for the Case Populations

Big Data is the use and combination of large datasets collected by various government organisations. Within this context, those organisations are government organisations providing health and social services, although Big Data is also possible in commercial settings.

Big Data is put forward as a solution to data scarcity for minority populations (Raghupathi & Raghupathi, 2014), insofar as those populations not taking part in research will have accessed services and so decision-makers can use information regarding their access use as a proxy. Māori and Pasifika health service data is dependent on ethnicity reporting, while learning disability data is much harder to collect.

The reporting of ethnicity data is variable (Swan et al., 2006; Bramley & Latimer, 2007). Efforts are being made to improve this.

While reviewing all 20 District Health Board Māori Health Plans for 2013/2014 for information regarding District Health Board decision-making, it was found that all included the priority of improving ethnicity data collection (specifically for Māori). The Ministry of Health also introduced a Primary Care Ethnicity Data Audit Toolkit⁶⁴ in 2013 to support DHBs in improving their ethnicity data collection.

Statistics New Zealand created a framework for Māori statistics (Statistics New Zealand, 2002) discussion document recognising the need for measures and data collection that was reflective and responsive to Te Ao Māori (the Māori world view). It is not clear how well things have improved or how well this framework has been adopted. Statistics New Zealand also recently created the Integrated Data Infrastructure⁶⁵ combining large sets of government data across ministries which researchers can access on approval (anonymised datasets), but there is no specific

⁶³ One could argue that due to their smaller proportion in society that funding and attention is currently adequate, but this claim will be investigated further in Chapter 6.

⁶⁴ Available from: <http://www.health.govt.nz/publication/primary-care-ethnicity-data-audit-toolkit>

⁶⁵ Available from: http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure.aspx

mention on their website as to how Māori (or any other group is being considered appropriately in this work).

For people with learning disabilities and those seeking to make their lives better, data availability is even direr. As noted in the Linton report above (Linton et al., 2011) there are issues of classification, under-diagnosis, and under- and misreporting, meaning that quantification or identification of the population is in and of itself an issue, before seeking data on service use.

In addition to Big Data, open data is a term for the sharing of raw research data between researchers. Open data, which also presents a means of reducing the research burden on minority populations and a way of making up for research data scarcity (by using and combining already existing datasets), rests on researchers inclusion and reporting of detailed demographic data. As presented earlier in this chapter, that reporting is variable and arguably insufficient.

2.9. Summary

In this chapter, I have provided a description of health disparities that exist for three case populations; Māori, Pasifika, and people with learning disabilities. These differences showed poorer outcomes for these groups, especially for chronic conditions, but also for injury-related illness (such as falls, motor accidents, and suicides).

While others have investigated the incorporation of Māori scholarship in public health documentation (Came, 2012, 2014) or the use of trial registries in NZ (Currie & Jull, 2012; Jull et al., 2005), this work is the first of its kind to try and establish representation of those who suffer health inequity in research activity and the processes that use research in decision-making. Based on the limited information available in funding, trial registry and ethics committee records, there is an indication that representation in research activity for these groups is weak. Documentation that signifies decision-making within the health system showed poor reference to all three of the case populations (although Māori were somewhat better represented).

Not only is the dearth of research used in decision-making troubling, but the lack of overall research for each group is problematic, as advocates who wish to draw attention to a specific population and problem, require evidence to move governments to take action. Governments determine what work they will prioritise based on proof of a problem. This proof includes research. There is, therefore, a circular barrier to addressing inequalities, when the only way to be prioritised is through research that shows evidence of disparities, but research itself is inequitable.

Ethics committees should review representation based on the definition of justice within ethics guidelines in NZ. In Chapter 3, I move to ethics committee review as means of understanding why representation is lacking and if committee review is the appropriate avenue for improving this lack of representation.

Chapter 3: Justice and Ethics committees

An important point of evaluation, when deciding whether the research we conduct is just, is ethics committee review. Ethics committees are responsible for ensuring researchers and their projects meet ethical standards. One of those ethical standards is the principle of justice within the Aotearoa New Zealand (NZ) (and most Western) frameworks (Beauchamp & Childress, 2001; NEAC, 2012a, 2012b; The National Health and Medical Research Council, 2015). Justice in ethical review is included to protect those who have vulnerability, in regards to not only their participation but also their exclusion (Bismark & Morris, 2014; Emanuel, Wendler, Killen, & Grady, 2004; Pieper & Thomson, 2013; Ryan, 1978). What is meant by justice, how committees review justice and what recommendations they make, is problematic, given that guidance explicitly states that researchers must incorporate justice into research design, yet we ask for no real accounting of it. Nor is it evident in practice based on the work outlined in Chapter 2. If we see the lack of representation both within individual trials, as well as the lack of representation across all possible trials as an injustice, then this prompts questions of who is responsible for ensuring representation as a form of justice. How are ethics committees tasked with addressing justice, if at all? How do ethics committees understand and enact this duty?

3.1. Background

In NZ, some but not all ethics committees are accredited. The Health Research Council (HRC) of New Zealand provides accreditation based on their mandate as set out in the Health Research Council Act of 1990. The HRC Ethics Committee only provides this accreditation to committees on the submission of evidence of a committee's ability to provide a fair and robust review. The guidelines created by the HRC ask for evidence of this ability to review (HRC-NZ, 2012). Ability to review is measured based on evidence of processes for the review of applications; annual training; an appropriate mix of gender, ethnicity, lay and expert perspectives; and a full and safe procedure for record-keeping and annual reporting (HRC-NZ, 2012). If a committee provides sufficient evidence, the HRC grants accreditation. Accreditation provides a committee with:

- 1) Reputational Confidence – i.e. people can trust that they have met government standards of practice as a committee.
- 2) Only research approved by an accredited committee can receive HRC funding.
- 3) Only research approved by an accredited committee has coverage under the Injury Prevention, Rehabilitation and Compensation Act 2001, meaning those injured in any way during a research process have access to Accident and Compensation Corporation services, rather than an individual institution's indemnity insurance.⁶⁶ (HRC-NZ, 2012)

Of note, the types of accredited committees fall into three categories:

- 1) Health and Disability Ethics Committee (run by the Ministry of Health)
- 2) Institutional Ethics Committees (run by Universities and Polytechnics)
- 3) Private Sector Committees (such as Zentech's committee, now defunct)

The Health and Disability Ethics Committees (HDECS)⁶⁷ are charged with reviewing any research that involves human participants in their capacity as consumers of health and disability support services (or their relatives/caregivers), human participants in their capacity as volunteers in clinical trials (including bioequivalence/bioavailability studies), any project involving human tissue (with some exceptions) and any project using health data (with some exceptions). They do not review low-risk medical device projects, low-risk observational studies, audits, or student projects (unless they are an intervention and at PhD level). Institutional Ethics Committees review work that does not meet the minimum threshold for HDEC review.

Approved ethics committees have some guideline documents they can and should take direction from in their operations:

- 1) Ethical Guidelines for Intervention Studies. National Ethics Advisory Committee (2012).
- 2) Ethical Guidelines for Observational Studies: Observational Research, Audits, and Related Activities. National Ethics Advisory Committee (2012).

⁶⁶ There are some caveats specific to commercial endeavours

⁶⁷ See: <http://ethics.health.govt.nz/applying-review>

- 3) Good Clinical Research Practice Guideline (Part 11 of the Guideline on the Regulation of Therapeutic Products in New Zealand). Medsafe, Ministry of Health (2011).
- 4) Guidelines for Researchers on Health Research Involving Māori. Health Research Council of New Zealand (2010 version 2)
- 5) HRC Guidance Notes on Research Ethics 6 Guidelines for the Use of Human Tissue for Future Unspecified Research Purposes. Ministry of Health (2007).
- 6) Guidelines for Using Cells from Established Human Embryonic Stem Cell Lines for Research. Ministry of Health (2006).
- 7) Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996. Health Information Privacy Code 1994. HRC Guidelines for Approval of Ethics Committees. Health Research Council of New Zealand (2012).
- 8) Non-Therapeutic use of Human Tissue NZS 8135:2009. Standards New Zealand (2009).
- 9) Pacific Health Research Guidelines. Health Research Council of New Zealand (2014)
- 10) Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members. Pūtaiora Writing Group (2010).

Documents 1) and 2) pertain to most health research, while 5) and 6) for example are only used in very specific fields. One would hope 4), 9), and 10) are read widely used, but there is no way of knowing this at present.⁶⁸ The first two documents are guidelines that those assessing and designing clinical research should be aware of and they have very specific justice requirements (see Figure 10). Given the findings in Chapter 2 of a lack of representation, it is important to understand who is considering representation as an element of justice in the process of generating evidence and how, so that we can address the failing. Ethics committees would seem an obvious starting point given the NEAC guidelines (Figure 10).

⁶⁸ Document 1 and 2 are also the only documents to set all aspects of ethical review, except for documents 9) and 10) which relate indigenous perspectives and Pasifika perspectives to research and ethics review.

| Justice | |
|----------------|---|
| 4.5 | Justice requires that, within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. Accordingly, investigators must: <ul style="list-style-type: none"> (a) avoid imposing on particular groups an unfair burden of participation in intervention studies (eg, vulnerable members of a community should not bear disproportionate burdens of studies from which other members of the community are intended to benefit) (b) design studies so that the inclusion and exclusion conditions for participants are fair. (See also the criteria in 'Inclusion and exclusion of participants', paragraphs 5.26–5.27.) |
| 4.6 | Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. |
| 4.7 | The Treaty of Waitangi is the founding document of New Zealand. The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable, should be incorporated into all health research proposals (HRC 2005b). The principles can be explained as follows: <ul style="list-style-type: none"> • partnership: working together with iwi, hapū, whānau and Māori communities to ensure Māori individual and collective rights are respected and protected in order to achieve health gain • participation: involving Māori in the design, governance, management, implementation and analysis of research, particularly research involving Māori • protection: actively protecting Māori individual and collective rights, and Māori data, cultural concepts, norms, practices and language in the research process. |
| 4.8 | There should be due recognition of Māori as the tāngata whenua and indigenous people of Aotearoa New Zealand. |
| 4.9 | Any potential cultural and ethical issues pertaining to Māori must be addressed through appropriate engagement with Māori, which may include discussions with appropriate representatives of specific whānau, hapū and iwi as determined by the scope and method of the study. |
| 4.10 | Comprehensive, high-quality Māori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whānau, hapū and iwi to be involved in meeting these priorities. |

Figure 10 - Section on Justice, NEAC Guidelines for Interventional Studies (NEAC, 2012a, 2012b)

These justice requirements cover both a micro and macro-level of justice and make clear our obligations to the Tangata Whenua.

How is this micro/macro distinction being used here? Justice directed towards individuals is micro-justice: is each participant within a research study treated justly? Macro-justice is external to the research study; it relates to population(s) in society or society as a whole, who are advantaged or disadvantaged by the research study. So 4.5 (Figure 10) includes both micro-justice (balance of burdens and benefits for the individual) and macro-justice (fair distribution) whereas 4.6 would address macro-justice, 4.7-4.10 are a mixture of both.

It is interesting that some prescriptions set out in this section of the guidelines include qualifiers, such as “where applicable” (4.7 – Figure 10), but the guidelines give no further explanation. What constitutes applicability? When does a study

meet the requirement for incorporating Treaty principles – what is the bar at which Treaty principles need to be incorporated and below which they do not? Direct impact is an obvious answer, but what of indirect impact and what level of impact, what of potential participation of Māori, without necessarily being the primary focus? To switch this around for further clarity, what are the characteristics of studies, where no consideration of Treaty principles is required? Laboratory studies? Phase 1 Pharmaceutical studies? These too can impact on Māori lives. Moreover, as we saw in the preceding chapter for Pasifika peoples, genetic variation can make a significant difference in drug safety (McCormack et al., 2012). Researcher recognition of applicability cannot be taken as a given.

Furthermore, these statements are all phrased imperatively – guiding action, even if differently detailed in that guidance, except 4.10 which simply makes a statement. How committees can assess an application against these prescriptions is less clear and especially so for those points that address macro-justice. I interpret 4.6 to mean that all studies should consider ways in which they can reduce inequalities through the choice of their study questions and processes in their given area of interest. What is not clear, however, is how a committee has evaluated this point or directed applicants to change protocols or processes based on this point (more to this later in the chapter).

Therefore in trying to understand fair representation in research, 4.5 and 4.6 are of particular interest (addressing inequity/inequality more globally), but also 4.7-4.10 are equally important given that these address Tangata Whenua, to whom NZ has distinct obligations based on the Treaty.

I felt it was important to understand:

- whether committee members agreed with these definitions and principles;
- whether they felt that they had the mandate/power to request changes to a project in relation to these statements;
- whether they did ask applicants to address these statements in their projects; and
- whether applicants contested any requested changes.

These items are necessary for the greater project because they inform an analysis of where justice could be considered fully in the research process. As was shown, in Chapter 2, representation is currently not just. Given the mandate of ethics committees (Figure 10), I felt it was vital to understand whether committees do not agree with the definition of justice, are unable to review it, or unable to enforce it. This information would help inform recommendations for future practice change. For example, if committees agree with the definitions of justice and agree that they are the point at which to evaluate it, but do not feel able to do so, then this requires a different approach, than the problem of committees not agreeing with the definition or not agreeing it should be their responsibility to review justice.

In addition to these fundamental questions regarding justice, I thought that questioning ethics committees regarding two potential avenues of increasing health equity in research, based on arguments in the literature was appropriate. These were:

- 1) Big & Open Data usage⁶⁹
- 2) Stakeholder Engagement & Collaborative Partnerships⁷⁰

Data is the “new frontier” in research with many promises made as to what it can deliver (Doll & Patel, 2015; Kisely, 2016; Mittelstadt & Floridi, 2015; Raghupathi & Raghupathi, 2014; Reardon, 2014; *The use of routine healthcare data in New Zealand*, Gurney, 2012). Equally, data use raises its own questions, with literature citing worries around its accuracy, safety, and privacy (Bramley & Latimer, 2007; Iorio, Carinci, & Oderkirk, 2014; Jepson, 2014; Mittelstadt & Floridi, 2015; Swan et al., 2006). As noted in Chapter 2, data usage could be useful for marginalised populations if decision-makers can use data already available in the various systems that exist where research data is lacking. However, if the data is also deficient (due to poor data practices and inappropriate classification categories) and is analysed using dominant perspectives with no consideration of marginalised views, then data holds no further promises for these groups. Ethics committees would seem like an

⁶⁹ See Appendix B-1

⁷⁰ See Appendix B-1

obvious place to promote and support good practice; I wanted to know if they agreed.

Engagement practices that include communities and participants in the decision-making of research are not new and people have been advocating for them for some time (Barkhordarian et al., 2015; Hunt, Gogognon, & Ridde, 2014; MacQueen et al., 2015; O'Mara-Eves et al., 2015; Sarrami-Foroushani, Travaglia, Debono, & Braithwaite, 2014; Shakespeare, 1996; van Bekkum, Fergie, & Hilton, 2016; Varvasovszky & Brugha, 2000). These practices which can vary in type, duration and frequency of input are dependent on researchers and their professional practice and commitment to relationship development. People engage in various ways whether a one-off meeting with the major stakeholders to determine an issue or get input on intervention design, or the commitment to co-design (participants/community as co-researchers). The evidence, however, would suggest that researchers can engage perfunctorily or with little understanding of what proper engagement is supposed to mean (Deverka et al., 2012; S. R. Oliver et al., 2008; Wright, Foster, Amir, Elliott, & Wilson, 2010). Again stakeholder practices and more involved collaborative partnerships raise ethical concerns related to managing relationships and power. Collaborative partnerships which involve co-ownership and shared responsibility can be particularly challenging given they do not neatly fit into our ideas of informed consent, research objectivity, and intellectual property for example (Beebeejaun, Durose, Rees, Richardson, & Richardson, 2015; Goodyear-Smith, Jackson, & Greenhalgh, 2015; Hunt et al., 2014; MacQueen et al., 2015). It, therefore, seemed prudent to ask ethics committees what they understand by these terms; how useful they might be in addressing equity; and how problematic (if at all) they might be for ethics committees to review.

3.2. Aim

Given the larger project examining research practices and health equity, within this sub-project, the aims were to:

- 1) Explore NZ Approved ethics committee member views of justice review in ethics:
 - a. do they agree with the definition,

- b. do they review aspects of justice within an application,
 - c. do they make recommendations,
 - d. do they want to make recommendations but feel they cannot, and
 - e. are recommendations addressed?
- 2) Explore NZ accredited ethics committee member views on the research practices proposed (data practices and engagement practices) and their usefulness for improving health equity and their implications for ethical review.

3.3. Methodology

3.3.1 Survey Development

I designed a cross-sectional, descriptive online survey, using both quantitative (yes/no; Likert scales) and open text box responses, to explore aims as described. In choosing this method and combining both aims into one survey (versus two) I considered various factors:

- 1) Choosing an online survey as the first point of contact seemed prudent given an awareness of ethics committee member workloads and the nature of committee commitment often being voluntary. A survey albeit a longer one in the norm of surveys (25-35mins) seemed like less of an imposition than a focus group or interviews.
- 2) Choosing to complete one longer survey versus two short surveys was considered more likely to provide a positive response rate. There was a risk in separating the surveys that the first may have a good response rate, but the rate may have dropped when asked to complete the second survey.
- 3) Contextually, it was also important to have both the discussion about justice and what practices may help improve elements of justice in the same “conversation”.

Using accepted survey methodologies, I created the survey and planned a pre-test (Hunt, Sparkman Jr, & Wilcox, 1982; Andrews, Nonnecke, & Preece, 2003; Kelley, Clark, Brown, & Sitzia, 2003; Groves et al., 2011). The survey included 31 questions (all optional). Part 1 covered the statements from the NEAC guidelines, asked

participants to rate their responses to different questions around the justice statements on 5-point Likert scales (plus “no comment” point; considered best practice) or provide open answers (see the full survey in Appendix B-1). Each question involving a Likert scale also provided an open text box for participants to make any further comments they may wish to make and in some cases had follow-up questions with comment boxes.

Questions built on each other, from:

1. Do you agree with the statements (statements provided from guidelines)?
2. How often do you receive applications that address these statements in their initial submission?
3. How often does your committee make recommendations to applicants around these statements?
4. How often have you felt your committee should make a recommendation around these statements, but has not?
 - a. If you felt there were instances where matters of justice were not addressed, why do you think this was the case?
5. How often has your committee made recommendations in relation to the following statements that were contested or opposed by the applicant?
 - a. Where they were met with opposition, explain what you think the reasons for that opposition were?
 - b. Where they were met with opposition, how was the situation resolved?
6. How often has your committee made recommendations in relation to the following statements that were well received by applicants?
7. Do you as a committee member ever omit recommendations in relation to justice that you would like to make? Why?

These questions asked participants to report based on their recollection; this is a limitation of the methodology, but one that recognises constraints of the setting.⁷¹ I hypothesised that applications where participants felt some form of injustice or

⁷¹ The ability to assess each committees' assessment of each application they reviewed was not possible within the limited resources of the project (i.e. some of these committees have open meetings, but to attend them all would mean travelling the country monthly).

discrepancy occurred were likely to stick out in their minds. A further triangulation of data was undertaken using committee minutes, and this is described in the limitations section 4.6.

Between this first and second section of the survey, participants were asked to describe in what order they reviewed an ethics application. In the second part of the survey, I then used a similar methodology to the first section to elicit ethics committees' views on the benefits and risks of, and their review role in: Big Data, Open Data, Stakeholder Engagement and Collaborative Partnerships. For each topic, participants were first asked to give an explanation of what they understand by a term, such as "Big Data". I then provided a definition of the term as is commonly accepted in the literature, before asking further questions rating statements around the use of the term in research. Questions addressed both the usefulness of a described term for health equity and how well an ethics committee can evaluate the practice related to the term (see Appendix B-1).

I revised the draft survey with supervisory input before also pre-testing it with three purposively sampled members of non-approved ethics committees.⁷² These pre-test answers and respondent feedback of their survey experience resulted in the revision of wording of some questions (adding clarity).

3.3.2 Māori Consultation and Ethical Approval

I undertook Māori Consultation with Ngai Tahu through the University of Otago process. Consultation led to the inclusion of a demographic question, which I originally omitted given the small target cohort. I added this demographic question and amended the information sheet to make clear that I would make every effort to analyse and report on data in such a way as to minimise the risk of participant identification. Ethics approval was gained from the Otago University Human Ethics Committee (14/195) (Appendix B).

3.3.3. Recruitment

⁷² Two members of the Otago Polytechnic Research Ethics Committee & two members of the New Zealand Ethics Committee were asked to voluntarily provide input. Three of the four volunteers asked agreed to provide feedback. Members of non-accredited committees were chosen to pilot the survey so as to not reduce the potential pool of participants.

The Health Research Council website provided a list of accredited committees. From this, I searched the listed committees' institutional/organisational websites for contact details. An initial email was then sent to the administrator/Chair of each committee requesting their dissemination of the invitation to take part in the survey to their members. It also asked each committee to confirm the number of members that sat on their committee for response rate calculation. I sent reminder emails at two weeks and one month after the initial dissemination, and gave a survey end date. These emails, however, went through a "gatekeeper" in that I depended on either a committee administrator or Chair distributing the emails. This likely contributed to the response rate but was unavoidable.

3.3.4. Analysis

I undertook a descriptive analysis of quantitative data and open textbox answers were used to contextualise this data. I added a very simple thematic analysis where sufficient participants provided full comments in textbox answers.⁷³

3.4. Results

3.4.1. Response Rate

I emailed an invitation and the survey to committee administrators and Chairs. Those that confirmed they had distributed it to their committees also provided the number of members who sat on their committees. 138 members of approved ethics committees received the email with 35 of these members taking part in the survey. This number of respondents provides a response rate of 25.36%. Of those responses, only 23 were complete (i.e. clicked through entire survey, did not necessarily complete all questions, given that none were compulsory). The completed survey response rate is therefore 16.67%. This rate is inadequate to make any claims of representation.⁷⁴

3.4.2. Responses

3.4.2.1. Demographics

⁷³ It is accepted (Groves et al., 2011) that these types of surveys with complementary text boxes very rarely elicit full answers from participants that can provide sufficient material for thematic analysis, although they may provide contextually important qualifiers or explanations.

⁷⁴ To achieve a 95% confidence with +/-5% margin of error 102 response were required; even when increasing the margin of error to +/-10%, 57 responses were required.

The survey was specifically sent to approved ethics committees, however, to reiterate that this was the primary audience, the first question asked participants to confirm that they were approved ethics committee members (Figure 11). One non-accredited committee member also appears to have opened the survey. They may have been a committee administrator or manager, and one participant skipped the question.

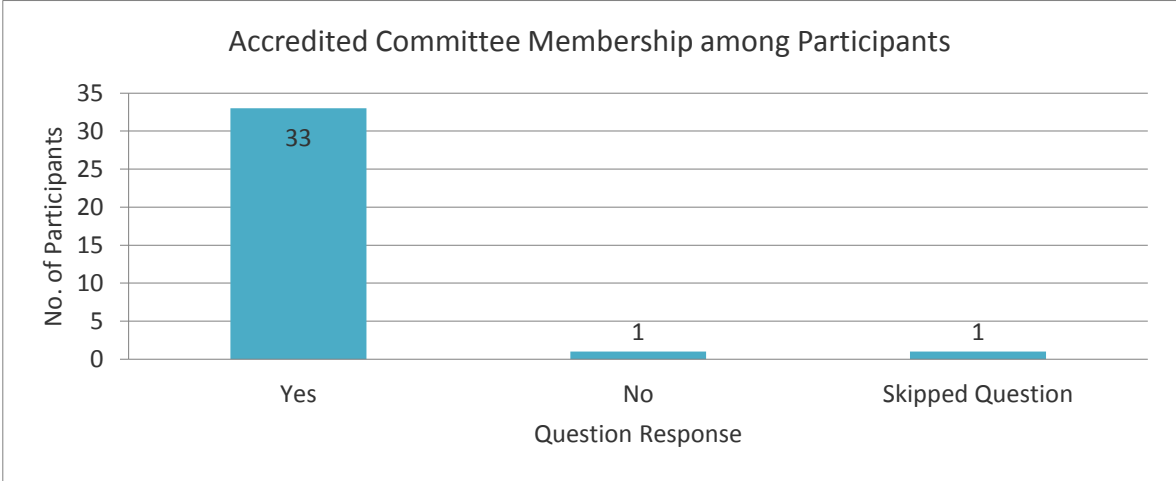


Figure 11 - Question 1: Are you a member of an HRC Approved ethics committee in Aotearoa New Zealand?

The second question of the survey asked people to report their ethnicity where they felt comfortable doing so. The option was given to tick more than one category. Ethnicity categories were those used by NZ Statistics Census Data options. Results are reported below in an aggregated fashion to maintain anonymity.

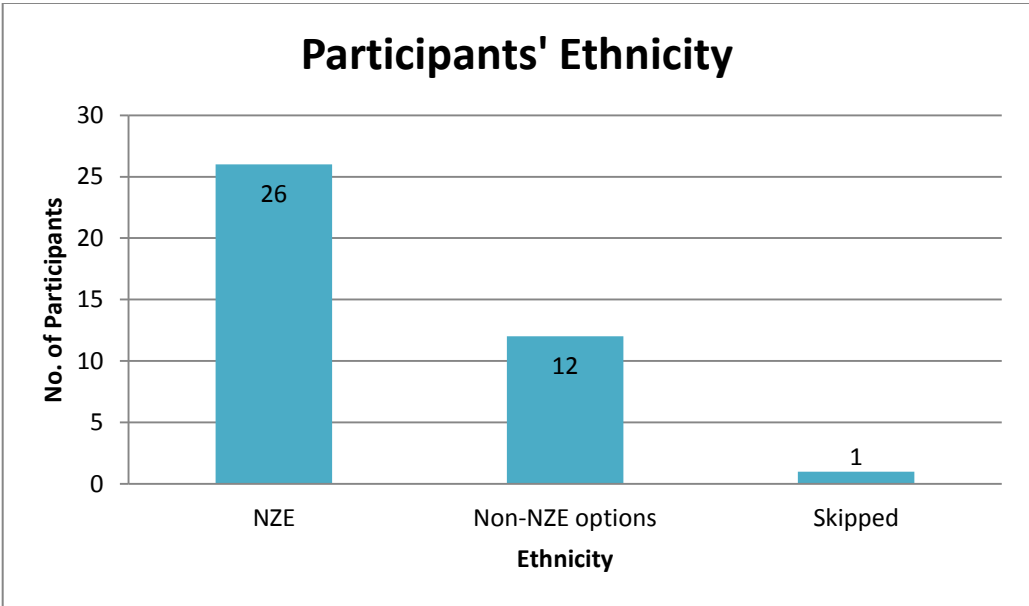


Figure 12 - Question 2: What ethnicity do you belong to? Tick all that apply⁷⁵

3.4.2.2. NEAC Guideline Statements

As provided earlier in this document, the NEAC statements form the foundation of Questions 3-12. Reported are number of responses as a count. Percentages were calculated but then abandoned due to the small numbers represented.

To begin the questionnaire, we asked committee members whether they agreed with the statements around justice as set out in the NEAC guidelines.

Table 7 - Question3: Do you agree with these statements?

⁷⁵ NZE – New Zealand European

| Do you agree with these statements: | | | | | | | |
|--|-------------------|----------|----------------------------|-------|----------------|------------|----------------|
| Answer Options | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 2 | 0 | 2 | 8 | 17 | 0 | 29 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 1 | 2 | 4 | 10 | 10 | 1 | 28 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 1 | 1 | 2 | 8 | 16 | 0 | 28 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 1 | 0 | 4 | 9 | 14 | 0 | 28 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | 1 | 1 | 0 | 7 | 19 | 0 | 28 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 1 | 1 | 1 | 7 | 18 | 0 | 28 |

Responses show that participants overwhelmingly agreed with statements and in most cases strongly agreed with statements. The weakest agreement and the one more evenly split between “Agree”/“Strongly Agree” (71.42%, even split 50:50 between “agree”/“strongly agree”), was the statement (4.6) about health inequalities and consideration of health inequity. Participants ranked most other as “strongly agree”. There was some disagreement with the statements, but this represented less than 10% of the participants for each statement (when disagree/strongly disagree were combined).

Comments included the need for qualifications. Participants stated they would have agreed more strongly to individual statements if the wording had included qualifiers. This comment included recommendations to add “where relevant” and other recommendations to be more prescriptive by using words such as “should” or “must”.

Another participant commented that justice and Treaty issues were not well considered within ethics committees, as committees were mainly used to assess risk, protecting “*institution, researcher, and participants; roughly in that order*”.⁷⁶ I interpreted this as frustration, i.e. that they would like ethics committees to be doing more, but that they felt within their setting that this was not the case. Equally,

⁷⁶ All quotes in italics are from respondents’ survey comments

I could have interpreted this to mean that the participant felt that this was the way things should be.

Participants were then asked to report how often they thought they received applications that addressed these statements when first submitted (i.e. before review recommendations).

Table 8 - Question 4: How often do you receive applications that address these statements in their initial submission?

| How often do you receive applications that address these statements in their initial submission: | | | | | | | |
|---|------------|-------|------------|--------|-------|------------|----------------|
| Answer Options | Very Often | Often | Some-times | Rarely | Never | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 1 | 8 | 9 | 6 | 1 | 0 | 25 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 2 | 5 | 15 | 2 | 1 | 0 | 25 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 5 | 7 | 9 | 4 | 0 | 0 | 25 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 4 | 7 | 9 | 5 | 0 | 0 | 25 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl.discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | 4 | 9 | 10 | 1 | 1 | 0 | 25 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 2 | 7 | 7 | 8 | 0 | 1 | 25 |

Responses to this question showed that initial applications were mostly thought to address the statements “sometimes” or “often” (58% -80%). While I did not complete significance testing due to the response rate, it is worth noting:

- 1) Statements 4.7-4.9 regarding the Treaty principles, due recognition of the Tangata Whenua and consultation were those that represented the highest percentage within the “very often” category.
- 2) In the ‘Rarely’ category 4.10 (research informing Māori health priorities) and 4.5 (fair distribution of burdens/benefits) received the highest percentages (32% and 24% respectively, where other statements ranged from 4-20%).

Where participants were asked to comment further on this section, many did. Comments showed that many committees had application forms, which asked people to be explicit around statements 4.7-4.10, but in the selection of statements from participants that follows, there was recognition of:

- a) **Tokenism** *"(...) 'cut and paste' type answers that don't directly answer or engage in the question and show lack of thought or genuine insight" and "Most address the PPPs⁷⁷ with a sense of reluctant compliance"*
- b) **Avoidance** *"Often researchers will avoid involving Māori participants if they can because anything Māori is perceived to be "hard work" (...)."*
- c) **Lack of knowledge** *"Applicants struggle with identifying how to apply the TOW⁷⁸ principles in their work (if they recognize their relevance for their own study)" and "(...) many researchers accept the basic principles here, but have difficulty - unless they have connections into some Māori communities - in realising how these could be implemented (...)"⁷⁹*

Other participants explained that their forms did not make it clear how applicants could express thinking in this area and that clear pathways for consultation did not exist in their setting.

Only one participant commented on 4.5/4.6 relating to justice as fair distribution/representation, insofar as they felt justice was implicit. In this response it would seem justice, when applied to society, is implicit and only explicit when applied to Māori, based on the specific sections of committee forms requiring responses.

I then asked participants how often their committees made recommendations to applicants in response to these statements, to qualify the previous questions regarding the frequency with which applications addressed them.

Table 9 – Question 5: How often does your committee make recommendations to applicants in relation to these statements?

⁷⁷ PPPs are the principles of the Treaty of Waitangi; these are partnership, protection, participation.

⁷⁸ TOW – used by participant as short form of Treaty of Waitangi principles.

⁷⁹ All quotes in italics are from survey comment boxes (i.e. from respondents)

| How often does your committee make recommendations to applicants in relation to these statements: | | | | | | | |
|--|------------|-------|------------|--------|-------|------------|----------------|
| Answer Options | Very Often | Often | Some-times | Rarely | Never | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 3 | 3 | 11 | 4 | 1 | 0 | 22 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 1 | 2 | 10 | 7 | 2 | 0 | 22 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 2 | 6 | 11 | 3 | 0 | 0 | 22 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 2 | 5 | 4 | 8 | 3 | 0 | 22 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | 6 | 3 | 12 | 1 | 0 | 0 | 22 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 1 | 3 | 4 | 10 | 3 | 1 | 22 |

Participants mostly reported that they felt their committees responded to these statements “sometimes” – the spread of responses was relatively wide across the scale. What was of particular interest was that in Question 4, 32% of participants said that initial applications rarely addressed 4.10 (research informing Māori health priorities), yet this category also had the highest number of participants stating that they “rarely” made recommendations about this statement (45.45%).

If the applicants are not addressing this element of justice (4.10) and the committee equally does not respond to it, then either its wording or content is failing to engage either party.

Many comments to these questions referred again specifically to 4.7-4.10 stating that the application form specifically requests responses to justice and Māori communities. Therefore, recommendations were not necessary, or participants presumed that applicants would have had to resolve any issues in Māori consultation which they complete before submitting ethics. Evidence of this is in this selection of responses from survey participants:

“There is also presumption and expectation that the Māori consultation component of the application and the actual consultation itself will have raised these issues and no recommendations will be made (unless Māori consultation has not been carried out or intended)”

“(..)there is a section on the form pertaining to consultation so there is an expectation consultation has occurred with Māori, when there are Māori participants (...)”

Only one comment related to 4.5 and 4.6 (fair distribution/representation and equity), stating that it would be useful to have more explicit statements or questions in the application form that addressed these. Some general comments indicated that much was implicit and committees always made recommendations where they found shortcomings. Participants also expressed the view that these statements were not always relevant.

Following this question of how often committees made recommendations, it then made sense to ask whether there were times where participants felt the committee should have made recommendations but had not. I, therefore, asked participants to answer how often they felt this was the case.

Table 10 - Question 6: How often have you felt that your committee should make a recommendation in relation to the following statements, but it hasn't?

| How often have you felt that your committee should make a recommendation in relation to the following statements, but it hasn't? | | | | | | | |
|---|-------------------|--------------|-------------------|---------------|--------------|-------------------|-----------------------|
| Answer Options | Very Often | Often | Some-times | Rarely | Never | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 1 | 0 | 5 | 3 | 14 | 0 | 23 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 1 | 1 | 3 | 5 | 13 | 0 | 23 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 1 | 1 | 3 | 4 | 14 | 0 | 23 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 1 | 1 | 2 | 3 | 15 | 1 | 23 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl.discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | 2 | 0 | 3 | 4 | 14 | 0 | 23 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 1 | 3 | 1 | 3 | 14 | 1 | 23 |

Most participants felt that their committees never failed to make recommendations they should make, with all statements ranked “Never” 60% of the time. The only statement below the 60% average was 4.6 (health equity), but this was only minimally so. It may be of note, that within the “often” category, 4.10 (research for Māori health priorities) was again the highest.

I then asked participants to qualify their responses again with comments. Those that did respond reiterated that much was left to the Māori representative or presumed covered in Māori consultation rather than directly deliberated by the committee. It was re-emphasised by one participant that these matters of justice were not relevant to all research.

One participant stated that their committee always passed all recommendations they made to researchers. While another participant expressed the view that projects they reviewed were of little import to justice and society and were largely

for the benefit of academic careers. Once again, I interpreted this participant’s views as an expression of frustration.

I asked participants to explain why they thought committees omitted recommendations if they had been. Responses largely seemed to indicate that a lack of recommendations around justice was either due to:

- injustice not being apparent, or
- justice was not a priority for review (e.g. risk was), or
- the form itself did not link the review to “*broader, overarching themes such as justice*”.

One participant felt that there was prioritisation of some interests over others, as they put it: “*Fear of losing international investment in research (...)*”.

From this question, I then asked participants whether recommendations were contested or opposed by applicants.

Table 11 - Question 8: How often has your committee made a recommendation in relation to the following statements that were contested or opposed by an applicant?

| How often has your committee made recommendations in relation to the following statements that were contested or opposed by an applicant: | | | | | | | |
|---|------------|-------|------------|--------|-------|------------|----------------|
| Answer Options | Very Often | Often | Some-times | Rarely | Never | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 0 | 0 | 2 | 4 | 15 | 1 | 22 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 1 | 0 | 1 | 3 | 16 | 1 | 22 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 1 | 0 | 2 | 1 | 17 | 1 | 22 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 1 | 0 | 1 | 1 | 18 | 1 | 22 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the | 1 | 0 | 2 | 3 | 15 | 1 | 22 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 0 | 0 | 0 | 1 | 18 | 3 | 22 |

Participants overwhelmingly stated that this “Never” occurred (68.18%-81.82% across statements). Within the “Rarely” category, statements with the highest

agreement were 4.5 (fair distribution), 4.6 (health inequalities/inequities) and 4.9 (consultation) with all other statements having a singular agreement.

Comments to further explain these responses showed that some participants did not encounter opposition to recommendations. Participants explained this lack of opposition to recommendations in multiple ways. Either participants thought no opposition had arisen because they believed researchers had taken comments on board; or they were aware that opposition if it did exist, was managed by the Chair without further discussion at committee; or, as one participant described it, researchers choose: *"(...) the path of least resistance and so instead of directly opposing, they provide, for example, token, tick box evidence of Māori consultation."*

One participant also reported:

"Contesting by applicants around these issues is rare but mostly occurs around the reluctance to modify protocols which are derived from reputable collaborative research groups for whom issues around justice of vulnerable people and indigenous people do not receive the same focus as here in NZ."

I asked participants about the reasons for opposition. Again for some, reasoning behind opposition was not transparent, because this information did not come back to the committee or it was not clear that opposition had occurred at all to their review. Others felt that opposition was often a matter of recommendations requiring more resourcing or time than was available, rather than a fundamental disagreement as to the principles underlying the recommendations.

Those that had experienced more negative opposition felt that it showed an *"Annoyance at being challenged about their study. Frustration, with different opinions (within and between committees) about what is required or appropriate"* and that there was a *"lack of thought"* and meaningful engagement with Māori.

I also asked them where they had experienced applicant opposition, how was it resolved. For those participants who had encountered opposition, comments described clarification and mediation processes, using discussion and identifying appropriate members on the committee to interact with different applicants. One participant expressed frustration:

“(...), but as we see the same researchers putting forward applications with the issues repeated again, it obviously is not resolved in terms of changing thinking”

From here, I then asked how often applicants receive ethics committee recommendations well.

Table 12 - Question 11: How often has your committee made recommendations in relation to the following statements that were well received by applicants?

| How often has your committee made recommendations in relation to the following statements that were well received by applicants: | | | | | | | |
|--|------------|-------|-----------|--------|-------|------------|----------------|
| Answer Options | Very Often | Often | Sometimes | Rarely | Never | No comment | Response Count |
| 4.5 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | 2 | 2 | 8 | 2 | 0 | 8 | 22 |
| 4.6 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | 2 | 2 | 7 | 2 | 0 | 9 | 22 |
| 4.7 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | 2 | 2 | 5 | 3 | 0 | 10 | 22 |
| 4.8 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | 3 | 1 | 3 | 5 | 0 | 10 | 22 |
| 4.9 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | 3 | 1 | 5 | 2 | 0 | 10 | 21 |
| 4.10 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | 2 | 1 | 1 | 3 | 2 | 13 | 22 |

Distribution of responses across the scale fell predominantly for all statements in the “Sometimes” and “No Comment” categories.

It is evident from the comments that this question was not necessarily applicable to all participants in that the Chair did not necessarily communicate this kind of information to the committee, or as a participant had earlier commented, their committee did not make recommendations, or the question itself was thought to be unclear. Others responded that only bad feedback was reported back to the committee, while others stated that recommendations were often well received, but recommendations themselves were not often necessary.

One participant made a comprehensive comment relating that sometimes recommendations were made to researchers to better answer questions regarding the impact for Māori and their involvement and that this was normally done “without protest”. Issues of justice and inequality were rarely raised by the committee, but were: “sometimes part of applicants’ presentation of their research projects, particularly in health-related research”.

One participant made clear that within their committee’s recommendations to applicants, the committee provided helpful information:

“I think it’s a matter of knowing who to go to for consultation and support about Māori issues in research, and just not sending them off to deal with yet another faceless bureaucracy.”

To understand whether in-committee dynamics might play a role, I then asked participants whether they had ever omitted questions they wanted to make about justice while sitting on their committee.

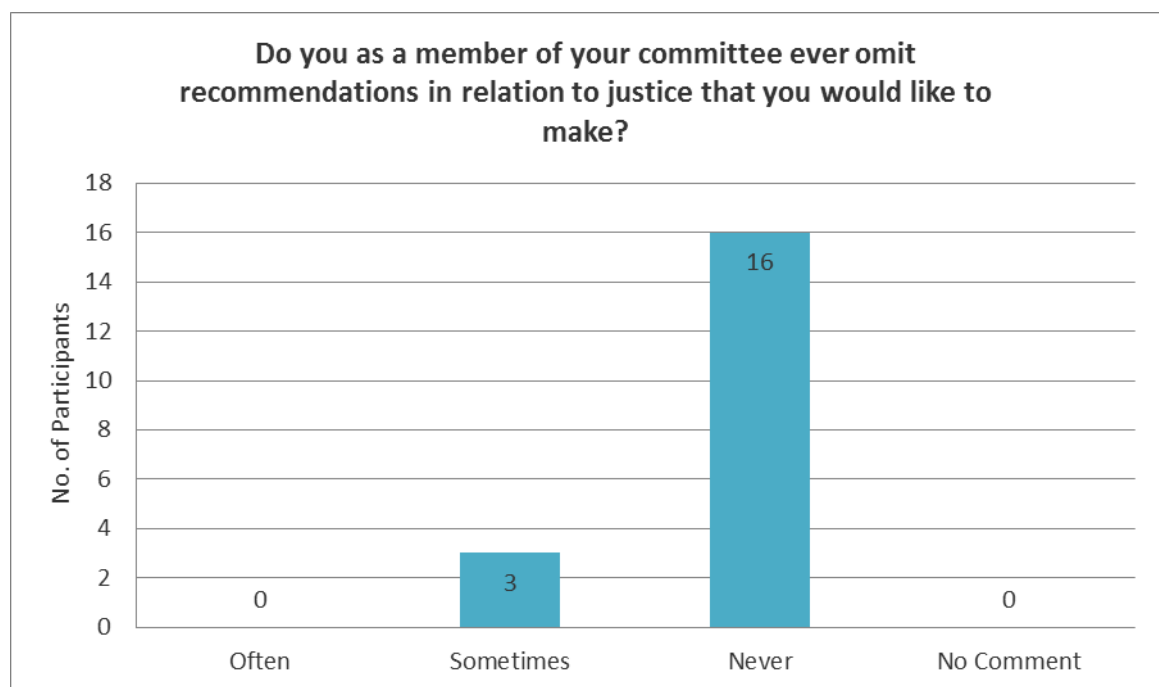


Figure 13 - Question 12: Do you as a member of your committee ever omit recommendations in relation to justice that you would like to make? Why?

Participants overwhelmingly said that they “Never” omitted recommendations they wanted to make (84%). When asked to comment on their answers here to provide more information, participants explained that their committees allowed for robust discussion and openness, with high levels of knowledge and expertise, allowing all to have a say and voice concerns. They noted the importance of raising issues and working collaboratively as a committee.

For others, they did not see recommendations around justice as part of their role:

“I believe the issue of justice is more of an institutional responsibility. The primary work of ethics committees should be to mitigate participants from harm resulting from participating in the research.”

It was also reported that sometimes other considerations override individual recommendations, such as:

- a) Primacy of other ethical issues that are perceived to have a greater import, *“Sometimes larger ethical issues take up the ‘air time’ for a particular review (...)”*
- b) Importance of review consistency within committees, therefore, recommendations omitted that may have contradicted previous decisions, *“(...) consistency is desired.”*
- c) Primacy of priorities – when research is part of an international study *“(...) the benefits of knowledge outweigh smaller regional concerns.”*

One participant also mentioned that their committee discussed the bigger question of why researchers were not doing more research for health inequalities but that this was beyond the review of an individual application.

3.4.2.3. Review Order

This last question concluded the section on the NEAC statements. Before moving to Section 2 of the questionnaire, participants were asked to describe the process by which they reviewed an ethics application. This question was designed to provide information as to what sections/elements of an application provide the information ethics committee members want to understand, to assess an applications ethical practice. Twenty participants described their process.

Participants fell into two groups, those that read the form in the order presented and those who went about it in an alternative manner (9 in order; 7 out of order; 4 not explicitly stated). Those reviewing in a different order favoured reading the Patient Information Sheet and Consent Forms first, or methodology before going back through the document to then further understand the project.

Participants reported picking and choosing what information to scrutinise most based on their expertise and the expectation that others with different roles and skills would do the same (i.e. and therefore pick up their particular gaps).

Risk/safety came through as the element most investigated in undertaking a review where this involved both direct risk and risk to privacy/confidentiality and safety of data/samples. Multiple participants commented on the need to consider the project from multiple viewpoints including the “(...) *participant, researcher, University, General Public.*” and “*Focus on 'safety' in its broadest sense - for and between populations, communities, organisations, family groups and individuals*”.

Participants described very involved and thorough processes for review including the notation of questions to ask the applicant when they presented at the committee meeting. Others also reported that time constraints could affect their level of review, prioritising some elements over others to get work done.

It was clear that participants wanted to see a demonstration of the applicant's processes and understanding of ethical practice and cultural sensitivity about their work and the use of appropriate codes of conduct, guideline documents, or advice.

Justice was only mentioned by participants insofar as they reported that forms did not include it and therefore it was not prioritised; participants reported that pressures of reviewing the volume of applications that the committees dealt with precluded the promotion of justice; or that when issues of justice did arise they came up after other considerations.

This section ended with participants being prompted to provide any further comments they might have to this first section.

One participant pointed out that the survey itself was dependent on the recollection of those responding. I was aware of this as explained and justified in the "Methodology" section above.

Another participant raised some very valid questions regarding the differentiation of health research and social science review; the compliance cost of ethical review across disciplines; why ethics committee members with no special status or training have the role of "*judge or censor*" over others and the implications for academic freedom. These were all valid and highly interesting questions to the researcher, but beyond the remit of the current project.

3.4.2.4. Data

The survey then switched to a discussion around potential research practices/ methodologies that may be beneficial in reducing health inequities. This section began by asking participants what they thought the term "Big Data" meant. Twenty participants provided answers to this question.

Nine participants stated that they were not familiar with the term or that their committee did not use the term. The remaining eleven participants demonstrated good knowledge of the term. The low response rate to the survey and then the more limited response to this question precludes the drawing of any conclusions, but the fact that almost 50% of those responding to this question were not familiar with the term would suggest that further work in the data space is necessary.

I then provided a definition of Big Data⁸⁰ before asking participants questions related to it, to ensure that all participants had a clear understanding of what was meant by "Big Data" within the context of the survey. Participants then completed questions about how much they agreed/disagreed with the following statements, the wording of which varied in strength:

⁸⁰ See Appendix B-1

The expanded use of health/government data for research purposes is critical to addressing health issues in the 21st century.

The expanded use of health/government data for research purposes can aid in addressing issues of health inequity.

The expanded use of health/government data for research purposes carries a high risk.

Oversight of the use of health/government data can safeguard against risk and ensure proper use.

Ethics Committees are best placed to provide oversight for use of health/government data.

Figure 14 - Statements used in Question 16

Participants answered as follows:

Table 13 - Question 16: How much do you agree with the following statements about "Big Data" initiatives?

| How much do you agree with the following statements about "Big Data" initiatives: | | | | | | | |
|---|-------------------|----------|----------------------------|-------|----------------|------------|----------------|
| Answer Options | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment | Response Count |
| The expanded use of health/government data for research purposes is critical to addressing health issues in the 21st century. | 0 | 0 | 7 | 6 | 3 | 2 | 19 |
| The expanded use of health/government data for research purposes can aide in addressing issues of health inequity. | 0 | 0 | 3 | 11 | 3 | 2 | 19 |
| The expanded use of health/government data for research purposes carries a high risk. | 0 | 0 | 9 | 5 | 1 | 2 | 19 |
| Oversight of the use of health/government data can safeguard against risk and ensure proper use. | 0 | 0 | 5 | 8 | 3 | 2 | 19 |
| Ethics Committees are best placed to provide oversight for use of health/government data. | 2 | 2 | 6 | 3 | 1 | 2 | 19 |

Participants did not strongly disagree/disagree with these statements, except for two who felt that ethics committees were not the appropriate providers of oversight for Big Data. Over 70% “agreed” or “strongly agreed” that the expanded use of Big Data could aid issues of health inequity and nearly 60% “agreed” or “strongly agreed” that appropriate oversight could be used to safeguard against any risks involved in using Big Data. There was much ambivalence within this response with nearly a third of participants ranking most statements as “Neither Disagree, Nor Agree”, which in all likelihood represents those participants who were not familiar with the term.

As with other questions, participants had the opportunity to provide further comment, 14 of which did so.

Some expressed a need for more clarity in the question and its relationship to ethics committees. Half the participants (7) who made comments expressed concern that committees did not have the specific expertise available to provide careful oversight of data management appropriate to “Big Data” sets. Being mindful of the limitations of the response rate, this concern is interesting given that only four participants disagreed that the committees were the proper body for monitoring – implying that some believe it is the appropriate body, but that they require more resourcing/expertise to do so.⁸¹ Others suggested that other governance bodies would be better placed to provide oversight or that a case-by-case approach was warranted.

Participants raised the concern that while people can manage datasets, this does not necessarily mean that “(...) *privacy and confidentiality*.” could be guaranteed given that “(...) *unforeseen risks may be the major issue (...)*” for data, meaning that the assessment of risk may not be adequate. One participant thought a collaborative approach between the ethics committee and another body might be the answer due to the ethics committee’s limitations:

“Ethics committees can be part of the process, however (...) (and the standard application process) aren't currently configured for good consideration of the issues specific to secondary data use, data matching etc. informational risk, dignitary harm etc. are writ large for big data.”

Participants were then asked to describe what they thought the term “Open Data” meant. Of the 19 participants that responded to this question, five were not familiar with the term, and the remaining 14 rightly described it as research data sets that are de-identified and shared freely. The accepted definition was provided to participants before they were then asked to rank their agreement with the following statements:

The compulsory sharing of research data is critical to addressing health issues in the 21st century.

The compulsory sharing of research data can aid in addressing issues of health inequity.

⁸¹ Naturally, all statements of this kind pointing to interesting findings, take into account the lack of response rate, and therefore the inability to make any kind of definitive statement.

The compulsory sharing of research data carries a high risk.

Oversight of the sharing of research data can safeguard against risk and ensure proper use.

Ethics Committees are best placed to provide oversight for the sharing of research data.

Figure 15 - Statements used in Question 17

Given these statements included the word ‘compulsory’ Participants were slightly less equivocal about these statements:

Table 14 - Question 18: How much do you agree with the following statements about Open Data initiatives?

| How much do you agree with the following statements about "Open Data" initiatives: | | | | | | | |
|--|-------------------|----------|----------------------------|-------|----------------|------------|----------------|
| Answer Options | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment | Response Count |
| The compulsory sharing of research data is critical to addressing health issues in the 21st century. | 3 | 2 | 8 | 4 | 2 | 2 | 21 |
| The compulsory sharing of research data can aide in addressing issues of health inequity. | 0 | 4 | 7 | 6 | 2 | 2 | 21 |
| The compulsory sharing of research data carries a high risk. | 0 | 3 | 4 | 6 | 6 | 2 | 21 |
| Oversight of the sharing of research data can safeguard against risk and ensure proper use. | 0 | 4 | 4 | 9 | 2 | 2 | 21 |
| Ethics Committees are best placed to provide oversight for the sharing of research data. | 3 | 4 | 7 | 3 | 2 | 2 | 21 |

Agreement was higher for the statements that sharing carried high risk and that oversight could ensure proper use and a reduction in risk. Disagreement was highest (although still low) for the statement that ethics committees were best placed to provide oversight.

When asked to provide further comment, opinions reiterated the lack of expertise within ethics committees to consider the technological aspects of Big and Open Data. Participants made comments that sharing data made sense regarding the reduction inequalities/inequities, but other participants contradicted these comments because they felt that this should not be “open slather” but rather access for particular groups or felt: “I do not believe anyone should be compelled to share their research data”.

Others considered the question(s) was too broad to answer – different situations/cases called for various responses. The risk of loss of de-identification/anonymisation was reiterated through multiple statements (with examples being provided) and the risk of misuse or misinformation was also raised,

with one participant articulating it, as: *“(...) Once the genie is out of the bottle, not sure over-sight can protect against mis-use?”*

Another participant felt that oversight of the datasets would contradict the principle of open-access.

No participant availed themselves of the opportunity to comment on the section as a whole.

3.4.2.5. Collaborative Partnerships and Stakeholder Engagement

From here Participants were then asked:

“Please describe what you think is meant by the term ‘stakeholder engagement’ in research, including who stakeholders might be and what engagement might entail?”

Fifteen Participants answered this question and described it as talking/discussing/consulting with *“(...) people who will be affected by the research”,* where “people” was defined as:

“Communities, professional associations and individuals, advocacy groups, iwi and half, organisations - govt and not for profit” and “(...) e.g. Māori groups, advocacy or support groups relating to a particular condition being studied etc.” and “It very much depends on the type of research. It might range from very engaged research generated out of a community of interest itself, through to research like clinical trials that engage with clinician stakeholders but perhaps not patient stakeholders.”

Participants stated that the description of stakeholder was project-dependent, but could be defined broadly as: *“Stakeholders are anyone who could benefit from the research, could participate in the research, could inform the research processes and conduct.”*

Responses described stakeholder engagement as a process that improved the chances of the project leading to more positive outcomes. While some participants described stakeholder engagement as consultation and talking to inform a project, others felt that it was something much more involved than this that should begin very early on: *“Active engagement should begin in early stages of project design and*

continue throughout. Engagement is more than 'consultation' or informing" and "Stakeholder engagement is the idea that people who are part of the research, have an interest in the outcomes of the research should be involved in the design of the research and the analysis or interpretation of the data."

Others commented on the need for researchers to be open and honest when engaging in stakeholder relationships ensuring things like the purpose of the project, project funders, conflicts of interest, and the like were known.

From this question, they were then asked to do a similar task, describing their understanding of collaborative partnerships:

"Please describe what you think is meant by the term 'collaborative partnerships' in research, including who are the 'partners' in these relationships are and what activities such partnerships might entail."

Again 15 Participants answered this question.

Participants recognised that collaborative partnerships included greater activity by partners in the research process. However, whereas the literature conceives of collaborative partnerships in the community context, participants defined these collaborative partnerships more broadly in line with their definition of stakeholders (i.e. collaborative partnerships could include industry or other academic institutions, as well). One participant described it fully:

"This implies an active role where researchers and their partners undertake the whole research journey - what questions matter and need to be answered, how they should be answered, how the research should be undertaken and analysed and then how this should be presented back. Partners I would consider communities of interest e.g. ethnic groups, disease advocacy groups, patients."

Other participants found the term nonsense or the referred to concept unhelpful:

"Collaborative partnership is a tautology. A non-collaborative partnership is not a partnership. Partners are those who agree to work together."

and

“Too theoretical a concept. Partners will vary depending upon the research. In many cases there will be no partners”.

From here, I then asked participants whether these recommended relationships, present challenges for researchers and participants.

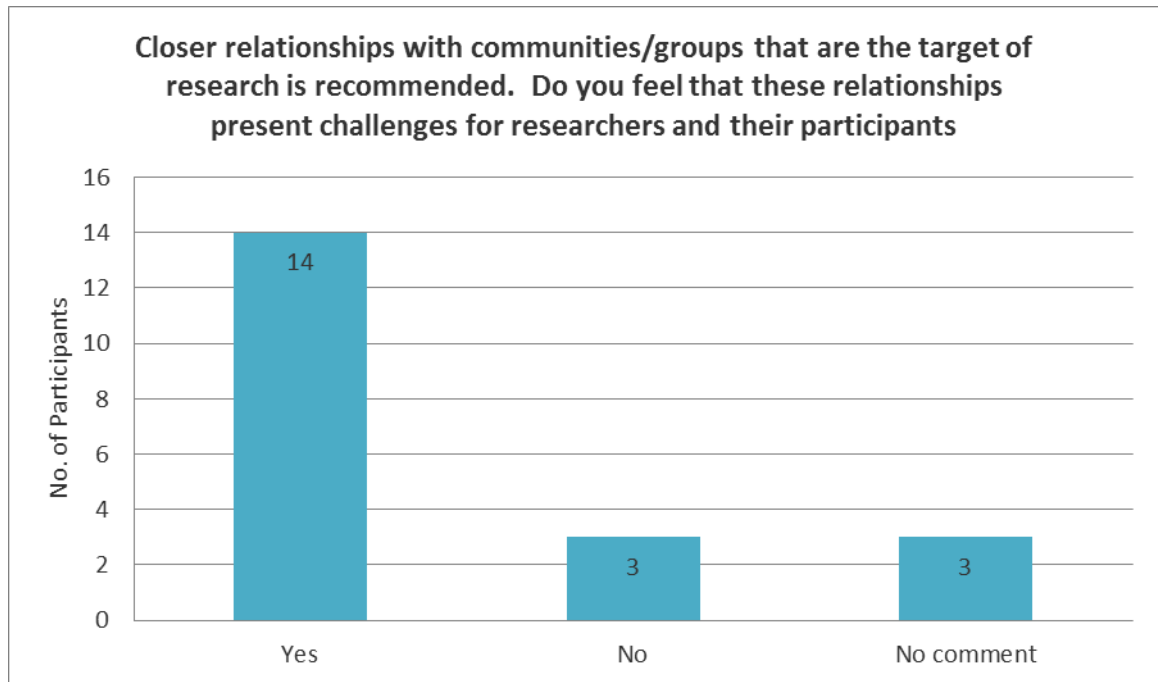


Figure 16 - Question 22: Closer relationships with communities/groups that are the target of research is recommended. Do you feel that these relationships present challenges for the researcher and their participants?

Twenty participants responded to this question, with the majority (70%) feeling that these relationships did present challenges. Comments to this question were then separated based on people’s response. Those that answered “yes” were asked to explain what problems they felt arise.

Responses to this question fell into a number categories:

Time – challenges of time both for participants (burden) and researchers (restrictive timeframes set out from organisations that do not work with community engagement). Consultation and finding the right people to consult with takes time.

Skill – engagement requires skill, understanding, a certain level of infrastructure within the community, these skills are not necessarily present naturally.

Conflict of Interests/Priorities – this was described not only between researcher and participants, but within communities that may be heterogeneous, or the difference between the representation of a community and the community itself (i.e. research participant wants to take part, community “group” does not want people to take part). Agreement between parties is not a given and requires negotiation.

Research Outcome – some saw this as bettering the research outcome (even with increased time needs) other felt that it could create “*issues with impartiality of research results*”.

Knowledge Barriers – this was presented in two forms; one in that community groups were not necessarily aware of ethical practices/principles and the related requirements, but secondly researchers privileging their knowledge over that of the consulting partners.

For those that responded that they did not see issues, their comments showed that they thought relationships were “*crucial*” and that researchers have to manage these relationships. I interpreted these comments as meaning that problems arise but just need to be managed rather than that no issues arise per se.

The survey was designed to probe this further. The next question, therefore, asked whether participants thought researchers could manage issues that result from relationships in research.

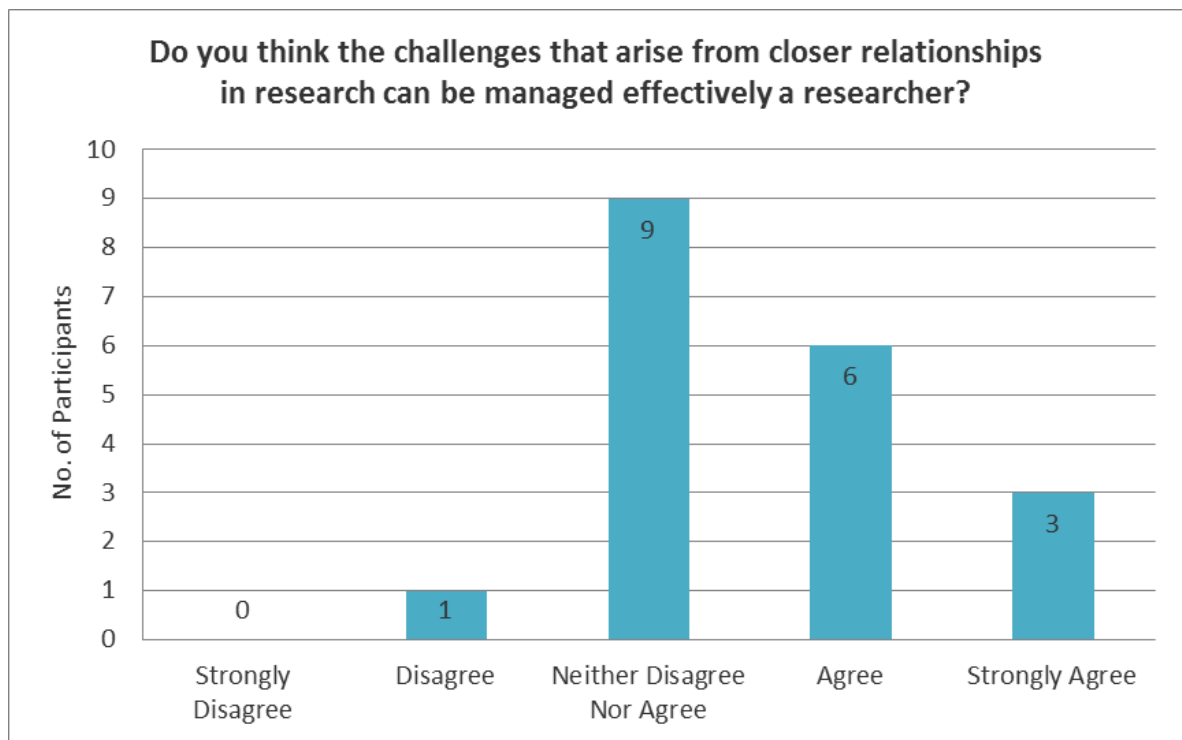


Figure 17 - Question 25: Do you think the challenges that arise from closer relationships in research can be managed effectively by researchers?

Participants' responses were either agreement that researchers could ("Strongly Agree" and "Agree" category combined) or neutral ("Neither Disagree, Nor Agree"). Of the 19 participants, eight made further comment when offered the opportunity.

Half of these stated that *"it depends"*, explaining that whether a researcher could manage it or not depended on the individual researchers, their expertise, institutional support, whom they were developing relationships with, and whether external factors played a role for example.

While one participant pointed out that they were not clear that this question was meaningful:

"Not sure what challenges you are referring to? All relationships with people involved can be challenging but generally they are not, rather they are empowering which is the purpose of stakeholder and collaborative relationships"

Another thought that researchers were mostly well-intentioned and *"often want to 'do the right thing' but want guidance on how or what that might look like"*.

One participant pointed out that: *“It takes a skilled researcher - with networks - and working in a way that some researchers would see as foreign”*.

The final question in this section then asked whether participants had wanted to make recommendations regarding engagement, but had not.

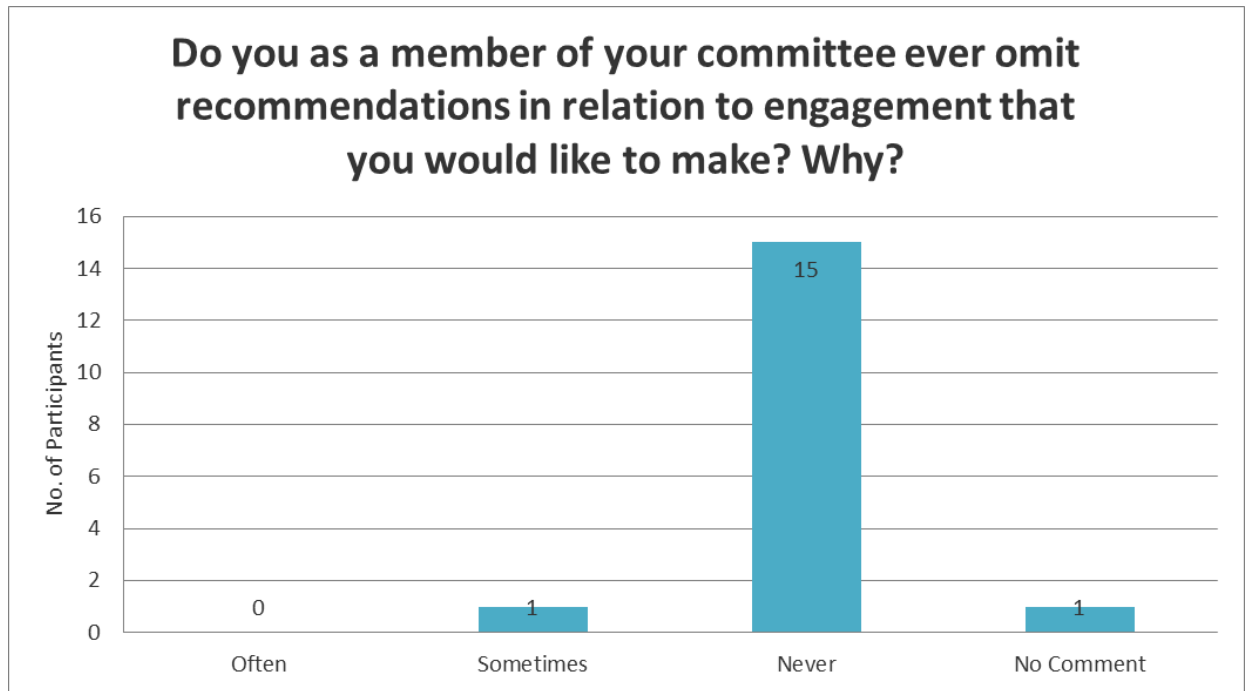


Figure 18 - Question 26: Do you as a member of your committee ever omit recommendations in relation to engagement that you would like to make? Why?

Participants overwhelmingly said “Never” to this question (88.24%) with one participant choosing “Sometimes” and one choosing “No Comment”. Four qualified their response in this section, one of these however misunderstood the question, referring to those applying to ethics rather than themselves (i.e. if ethics applicants omit engagement).

Another felt that engagement was not part of the “*ethical remit*”. The remaining two participants were supportive of engagement, one stating that it was the “*most important thing a researcher can do*” and the other explaining that while it was important, it is:

“Often seen as the role of the Māori or Pacific members of the committee but sometimes feel that the tendency to rely on perfunctory consultation or localities authorisation as the practical way to do so, feels lacking sometimes in genuine engagement.”

There were then two further options for commenting on this section of the survey and commenting on the survey as a whole. The majority of responses commented on the length of the survey and the fact that some participants felt that the questions asked would have been better answered in a focus group or interview setting rather than as a survey. Participants also made a few positive comments, which were received gratefully.

3.5. Discussion

It is the task of ethics committees to review research protocols, and this review draws on the four principles in Western settings: beneficence, non-maleficence, justice and autonomy (these have been added to, but are the core of most guidelines)(Beauchamp & Childress, 2001). This study specifically set out to examine how approved ethics committees (i.e. those more likely to be reviewing health projects) considered the consideration of justice within their work, whether they felt they could make recommendations based on justice, and what they thought of measures that may promote justice. Weijer (Weijer, 1999) and Rogers (Rogers, 2004a; Rogers & Ballantyne, 2009) consider that justice at the very least must cover fair representation, while Emanuel et al (2004) also include fair distribution of benefit and risk. Fair representation is thought to provide justice by ensuring that the generalisability of a trial is broad rather than directed at a particular group of people (those that are similar to the trial participants). Our guidelines here in NZ specify what is considered 'just' practice in health research in relation to distribution, representation and specific requirements concerning the Tangata Whenua.

The results of this survey cannot be considered representative of approved ethics committee members' views due to the low response rate. However, those that have responded have provided points for discussion. These points are summarised below and then addressed more fully in Chapter 7.

3.5.1. What belongs in ethical review?

There was a feeling from some participants that matters of justice were not always relevant to the review of projects, that they were less important than risk, or that the prevalence of injustices in research design was so small, as to hardly ever warrant consideration. This perception is of interest given that justice is one of the

cornerstones of ethical review in the literature and the guidelines, and that work on this project that examined fair representation in research activity showed it to be lacking (Chapter 2). It raises the question of whether justice and injustice are easily understood, recognisable and open to addressing through the ethical review process; is justice capable of being operationalised at the ethics committee level or should issues of justice be considered elsewhere – if elsewhere, where and how?

3.5.2. What does justice mean in ethical review?

What naturally follows from this study is a discussion of what is meant by ‘justice’ when reviewing a project. We can often quickly delineate risk when reviewing projects, more so for physical than psychological/emotional or professional/peer-harm, but for risk, this identification is much simpler than the question of justice. Familiar examples of injustice discussed in ethics classes and the literature are researchers completing drug trials in low-income countries for drugs that will never be available/affordable within those countries (Emanuel et al., 2004), or vulnerable populations (such as prisoners or people with learning disabilities) needing protection from exploitation (Ryan, 1978). What is lacking are relevant and more nuanced examples in the local setting. Examples that show the apparent injustice of under-representation as clearly as that of distribution. It would seem that ethics committees implicitly make a distinction between micro-justice and macro-justice regarding their remit.

Participants agreed with statements of the NEAC guidelines around the issues of health inequity the least, and one can only assume this is due to the perception of relevance, i.e. health inequity is not relevant to all research.⁸² It is clear that ethics committees are not in a position to ensure that there is a balance of representation across all research activity. What they could be empowered to do, however, is ensure that individual studies address macro-justice through their design, processes, and engagement with appropriate populations. In fact, there is some literature that argues that lack of representation in studies is not only based on minority populations distrusting researchers because of past research abuses. This literature puts forward the idea, that lack of representation rests on the absence of effort by researchers to recruit a diversity of people using activities such as

⁸² This is discussed further in Chapter 6 – is this assumption a fair one/accurate one?

outreach (Maghera et al., 2014; Symonds, Lord, Mitchell, & Raghavan, 2012; UyBico, Pavel, & Gross, 2007). Broader discussion and agreement is necessary to ensure macro-justice given such complex matters: distinctions between the obligations of commercial versus public research, the binding nature of ethics committee recommendations/ requirements that incur further costs, minimum standards versus desirable standards, and many others.

At present ethics committee application forms do not provide information to assess these matters appropriately. A detailed description of the demographics of those affected by the condition/situation of interest and who fares worst within that population, would be an example of information required. At present inclusion and exclusion criteria are the only information sought, although many applicants would describe some demographics of their populations in the background sections of their application. Currently, committees rely on the expertise and experience of their members to assess whether recruitment methods are fair and research designs implicitly exclude certain subgroups of any given population (as they do with other elements of the application). This reliance on individuals appears ad hoc in upholding justice within ethically sound research. Adjusting a form only works as a proxy for measuring true practice and understanding. Some would argue (Smith, 1999; Tolich & Smith, 2015), and it has been noted in responses to this survey, that current form requirements about Māori consultation, much like other cultural requirements and engagement, can be filled in, in a tokenistic fashion, rather than genuinely.

What is more, Statement 4.10 (Figure 10) which reminds us that high-quality research can inform policy and empower Māori, fails to direct action as it places no requirement on researchers to ensure that this is indeed occurring. Equally, one could argue that this statement should apply to more groups who are suffering disadvantage or marginalisation. It is unclear what the purpose of this statement is within the guidelines. Researchers are said to find ethical guidelines unhelpful (Stark, 2012; Tolich & Tumilty, 2013), and anecdotally researchers describe guideline-use as something at the point of applying for ethics, not at the point of research design itself, where such guidance would be informative.

Some participants repeatedly stated that matters of justice do not only apply to health research but also to other forms of research. I agree with this view, but given the scope of this work, I was only able to consider health research in this instance. What would be helpful in emphasising the need to consider justice across the scope of research would be guidelines from NEAC that addressed more than interventional/observational research projects, given that health research can often also utilise sociological rather than biomedical methodologies and that these also require ethical review.

3.5.3. Demanding workloads

Participants in some cases made mention of the workloads they dealt with on their committees and that this could affect their review of applications. There was also reference made to the demanding workload of researchers and the consequent restrictions on their ability to connect with populations affected by their work. This connection to populations is often key in not only designing just research, but research with impact (Dunston, Lee, Boud, Brodie, & Chiarella, 2009; Faulkner & Thomas, 2002; Gillard, Simons, Turner, Lucock, & Edwards, 2012; Hewison, Gale, & Shapiro, 2012). Workload issues are an ongoing problem for both committees and academics.

3.5.4. Tokenism

There were comments made throughout of researchers “talking the talk” but not necessarily “walking the walk” and just doing what was necessary to get approval. Participants saw evidence of this for relationships and ethics requirements in general, but also more specifically for researchers and their commitment to Te Ao Māori and its tikanga and whenua (insofar as in some cases they saw no commitment). Comments showed that this was due to a lack of understanding or knowledge and again, issues of time and resourcing.

3.5.5. Big Data/Open Data

It was of interest that most participants felt that data practices could affect health inequity and oversight was appropriate for data practices to minimise risk, but that this oversight might not be best provided by an ethics committee (or at least not in their current form). It may be that committees could add a “data-tech” expert much like the previous inclusion of biostatisticians into HDECs. It could also be the case

that a separate system is more desirable that deals with all data management nationally. Issues around data persist, for example:

- management of informed consent where researchers use data in multiple projects over extended periods of time;
- the possibility of identification where multiple sets of data are combined; and
- misuse of data for purposes that may be counter to participants' values.

An alternative model exists for Māori in some cases with Kaitiaki⁸³ groups managing access to data (described further in Chapter 7) and some discussions have been had around cultural issues and biobanks or collective consent⁸⁴ (Hudson, 2009; Beaton et al., 2016). Collective consent is controversial and often misunderstood. The collective consent model proposed by Maui Hudson (2009) asks researchers to consult with iwi (tribe) and get consent from iwi prior to individual consent from participants within the tribe. This prior iwi consent addresses questions of benefits and risks to the community, rather than individual. Others have interpreted this to mean that collective consent trumps individual consent, but this is not the case. This kind of consultation is important especially for biobank data given the importance of whakapapa (bloodlines and heritage) in Māori culture and the fact that bodily products are tapu (sacred/taboo).

Aside from these discussions regarding Māori however, little has been discussed regarding broader issues of inequity and other groups' disadvantages in the consideration of data.

Data practices require ongoing consideration and stakeholder discussion before we establish (national) systems and standards. I discuss big and open data further in Chapter 7, including its advantages and disadvantages in affecting health inequity.

3.5.6. Engagement

It is fair to say that most participants agreed engagement was worthwhile and necessary, but that it was also a very challenging and time-consuming process to get

⁸³ "Kaitiaki" is translated as guardians and these groups manage who accesses data and for what purposes, with appropriate consideration for Māori benefits and risks.

right that required skill and expertise. Again, some comments reported tokenism in engagement practices described to committees, but there was also the provision of guidance from committees to researchers to help get it right. Engagement with Māori specifically was described as being a process that researchers struggle with, knowing whom to go to and with whom to establish relationships, and so some try to get 'sign off' on very superficial versions of engagement.

It would seem from these comments that participants felt that they did make recommendations relating to justice where they identified them and that they felt there was an indirect enhancement of justice through the emphasis on Māori consultation and appropriate relationships. However, given the results of Chapter 2 showing a lack of representation, specifically in NZ, it would be fair to say that researchers are not meeting justice requirements.

What this work could point to is that ethics committees are not necessarily the best point at which to incorporate justice requirements into work where they are lacking. Ethics committees can only be the final stop gap for integrating justice. Justice would have to be explicitly incorporated somewhere much earlier in the process, and ethics committees would serve only as a final safety net to ensure nothing passed that did not meet our agreed and specified requirements of justice. Again matters of engagement are discussed more in-depth in Chapter 7.

3.6. Limitations

Aside from the low response rate, there was an awareness from the beginning that an online survey using Likert scales and text boxes does not provide as rich data as focus groups and interviews. Also, in this case, the survey itself was too long. The likely availability of research ethics committee members was a factor in choosing a survey, as mentioned earlier in this chapter. An online survey was thought to be the least burdensome method to committee members of eliciting information while working within the resource constraints of the project (i.e. committees are spread geographically across all of NZ, and so interviews/focus groups would have required extensive travel).

Feedback received from committee members both in email and in the survey shows that participant lacked engagement with material to some degree, insofar as the

questions evoked no strong responses, and in many cases were not fully completed.⁸⁵ Lack of participation could have been avoided by socialisation to the material before its release or with an email which provided a richer explanation of the reasoning for the survey at the time of invitation.⁸⁶ It was evident in some responses that participants felt by some that the survey was meant to show that ethics committees were not performing adequately in some way and this was not the intention at all. The purpose of the survey was not to show that they performed their role inadequately, but rather to gain an understanding of committee members' views on their mandate and review of justice. Along with getting their opinion, on the challenges of reviewing applications in future that include very complex issues involving data practices or complex relationships between participants and researchers.

To partially address limitations of self-reporting as noted in Section 4.3., I reviewed all committee minutes for 2014 (44 sets of minutes available on HDEC website).⁸⁷ Of these minutes, 21 made some form of recommendation regarding either:

- specification of cultural issues on participant information sheets (inclusion of information regarding culturally appropriate tissue disposal, the inclusion of information regarding cultural advocacy contacts, for example);
- recommendations to include information related to the consideration of ethnicity or inequalities in future applications (i.e. recommendations for explaining work when applying in the future, while approving the application under consideration), and
- two made specifications regarding the provision of translators (these related to the provisions for translation already made, rather than a recommendation to add translation).⁸⁸

⁸⁵ Some very thoughtful answers were provided by participants, but many participants chose to answer very few questions, and more than 1/3 did not fully complete the survey.

⁸⁶ The author, in this case, made assumptions based on her own experience of sitting on ethics committees, and her own views as to the need for research about ethics committees in NZ.

⁸⁷ Minutes are available from: <http://ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes>

⁸⁸ The list of minutes that made relevant recommendations are: NTA (May-14); NTB (Sept14); NTB (May14); CEN (full list 2014); STH (Feb, Mar, Apr, May, Sept, Oct, Nov, 14).

This review of minutes is also incomplete insofar, as access to applications is not available, and therefore the ability to judge whether committees always made recommendations when they should have is not possible. It would seem that the Central Ethics Committee whose documentation included reference to adding appropriate cultural information in the participant information sheet in every set of their minutes often for multiple applications (with further recommendations also present in some minutes) would seem to have a rule for checking for this specifically. Other committees may not be this disciplined about adding cultural information to information sheets. Laura Stark has argued that Ethics Committee set their own “local precedents” meaning that each committee while working with the guidelines and standards, applies those edicts differently, based on their committee composition and various members’ strengths and personalities (Stark, 2012). This example from the Central Ethics Committee would seem to be a possible indication of a local precedent.

These minutes and the survey provided a limited picture of the review of justice in approved ethics committees in NZ.

3.7. Summary

A survey of approved ethics committee members was undertaken to try to gain an understanding of their views of justice within review, their ability to request changes to projects for justice, and their thoughts on specific research practices that may increase health equity. This information does not currently exist in the literature and is needed to understand where justice in research is considered.

The survey itself did not reach a high enough response rate to provide representational work. A review of approved ethics committee minutes in 2014 was also undertaken to support responses and provided a limited view of committees’ review of justice in applications. Minutes showed recommendations mostly dealt with appropriate information in Participant Information Sheets, relevant information for future applications, and some recommendations regarding accessibility of studies for participants (i.e. translators). The limited survey responses combined with the findings from the minutes’ review would suggest that further work in understanding justice in ethics committee review in NZ is necessary.

What role ethics committees play in reviewing justice, what this review could or should look like, and where other responsibilities may lie in ensuring research practice is just is something I take up further in Chapter 7, after having further input on ethics review in the next chapter from researchers working with marginalised populations.

Chapter 4: Institutional Ethnography of Researchers working with Marginalised populations

It is not our role to speak to the people about our view of the world, nor to attempt to impose that view on them, but rather to dialogue with the people about their view and ours. – Paulo Friere

In Chapter 1, I explained definitions and causes of health inequity and posed the question of whether one cause of inequity may be related to marginalised population representation in health research used for evidence-based medicine and policy. To answer this question, I went about seeking evidence of marginalised groups' health inequity and their representation in evidence and knowledge-generating activities. Empirical data showed that their health inequity mirrors an inequity in research visibility, as well as potential under- or misrepresentation in government data (Chapter 2). In New Zealand accredited ethics committees have a responsibility to review justice (as defined in the NEAC guidelines) when considering health research ethics applications that potentially lead to evidence and knowledge generation and I, therefore, surveyed ethics committee member views on this responsibility and their ability to meet it (Chapter 3). The results of this survey were not substantive.

This chapter diverges from the previous ones, shifting from a methodologically descriptive position to a political one. In this chapter I use an institutional ethnographic method; the aim of which is to reveal the 'ruling relations' (explained in 5.1) coordinating a group's actions or practice (Smith, 1999, 2005). In this context, the ruling relations are those that create a health research space, more specifically a research space for researchers working with marginalised populations.

The purpose of this shift is to understand how research for marginalised populations occurs and how the health research environment influences that activity. By doing this, I provide insight not previously available in NZ about research for, and researchers working with, marginalised populations.

An ethnography can be a large undertaking that is the sole purpose of a thesis. An institutional ethnography is somewhat different in that it can be both a grand undertaking, Ethnography with a capital “E”, but also an analytic method that purposefully sets out to explore conditions, from a particular perspective within a specified analytic frame. More time, informants and analysis of government policies, documentation and more field work⁸⁹, along with greater discussions of the political and sociological theory underpinning the concepts used, would provide an ethnographic undertaking of the larger scale. Such an endeavour would undoubtedly shed a more nuanced light on the ‘ruling relations’ as they exist for researchers working with marginalised populations. However, it is this latter version that I have used here based on the reasoning that the method and analytical frame were the most appropriate for answering the question at hand. Namely, “how do researchers working with marginalised populations do their work and what determines how they do that work?”. But also, because this is one piece of the puzzle rather than the sole question I am investigating.

One discovers ruling relations through the analysis of informant experiences, which serve as entry points into the ‘problematic’ (Smith, 1999, 2005), investigated alongside the institutional texts and processes that help maintain the power of the ruling relations across time and place.

This thematic shift explores not only the ruling relations. It makes possible an exploration of the researcher perspective when conducting research, which will contribute to the discussion of epistemology in Chapter 5. The aim of this chapter is first to explain what an institutional ethnographic method is and why I chose it for this stage of the research programme, which is then followed by the ethnographic work itself. A full description of the methodology, sampling, analysis and limitations of the study are available in Appendix C-1.

In this chapter through informant testimony, I discover the problematic as an environment that is full of contradiction. Researchers struggle with relationships that provide them both with the ability to do their work, but also make demands that can be challenging. These relationships are between the researchers, the

⁸⁹ For example, being able to gather information in funding round assessment panels or ethics committee reviews, and interviews with junior researchers.

institutions they work for, and the communities they work with. I have categorised these experiences of the everyday as issues of, or related to: legitimacy, precarity, population/communities as *raison d'être*, practices and priorities, burnout, peer community as self-care and co-conspirator, silencing; and for Māori and Pasifika informants, the added factors of the “Brown Tick”, tokenism and extra burdens.⁹⁰ These everyday experiences are created by and maintain the ruling relations, that I argue, are characterised by neoliberal policies (in health and education) and the dominance of the biomedical perspective that ignores and constrains the work of these informants within the broader research environment.

4.1. What is institutional ethnography?

Institutional ethnography is a feminist, sociological methodology, developed by Dorothy Smith. Many have adopted the methodology (Campbell, 2002; Campbell et al., 2006; Hansen, Holmes, & Lindemann, 2013; Lund, 2012), but the theory was originally largely theorised by Smith (Smith, 1987, 1999, 2005). Institutional ethnographies begin with the experiences of people in their everyday/everynight setting⁹¹, to uncover the way generalised institutional discourses organise these experiences and actions through the medium of text (Campbell et al., 2006; Smith, 1999, 2005). The institutional ethnographic method is used to focus on the discovery of ‘ruling relations’ that, through institutional documentation and processes, affect and control trans-local activities of actors in their everyday/everynight experiential context (Campbell et al., 2006; Smith, 1999, 2005).

What does this mean?

Smith, writing within a Marxist and feminist tradition, makes the distinction between the ‘local’, which is the everyday of people’s lives, and the ‘extralocal’, which is the abstract position outside of the everyday experience. Extralocal is analogous with a ‘bird’s eye view’ perspective; a detached and objective position not taken by anyone in particular. To discover the ‘ruling relations,’ Smith’s

⁹⁰ Each of these issues is defined and described in sections below.

⁹¹ IE’s have been used in a multitude of settings from mothering, to academia, social-work, nursing, etc. where the setting of work can be at all times hence the everyday/everynight specification (Campbell et al., 2006; Smith, 1987).

methodology compels us to return to, or focus on, the local. In other words, the intention is to consider the standpoint⁹² of everyday experience (Campbell et al., 2006; Smith, 1987, 1999). The 'ruling relations' are processes that objectify us, and through which we become part of a system that, not only directs our actions but is maintained by our very actions. The extralocal is the position of the 'ruling relations' – an abstraction. She states:

The ruling apparatus is that familiar complex of management, government administration, professions and intelligentsia, as well as the textually mediated discourses that coordinate and interpenetrate it. Its special capacity is the organisation of particular actual places, persons and events into generalised and abstracted modes vested in categorical systems, rules, laws and conceptual practices (D. E. Smith, 1987, p. 108).

By attending to the local, we ground ourselves in the everyday of people's lives and obtain a view that we cannot access otherwise. Starting from this locus, we gain direct access to the social organisation of our experienced world (Smith, 2005).

While other sociological methodologies attempt to explain behaviours, understand feelings, or experiences; institutional ethnographies begin with people as they are in the world in order to explain "*the social relations of society of which we are part, explaining an organisation that is not fully present in any one individual's everyday experience*" (Smith, 1987, p. 89). The purpose is beyond the experience. Smith believed that methodologies within sociological practice and universities, in general, are part of the overall hegemonic discourse of capitalism, "*promoting concepts, methodologies and relevances*" (Smith, 2005, p. 29) that are detached from the everyday, and embedded in their ongoing promotion. A consequence of capitalism's⁹³ social relations is the creation of circumstances within which individuals "*become externalised as differentiated systems of relations*" (Campbell et al., 2006, p. 17).

⁹² While her work can be described as a standpoint theory, it moves beyond Harding (Harding, 1987) and Hartsock (Hartsock, 1983), insofar as the standpoint is not "politically, economically or socially defined", but rather utilises the subjective/objective dichotomy privileging the first (Smith, 2005)

⁹³ Smith writes about capitalism because that is the world she lives in. It is also the type of society, I live in and those who took part in this study live in. This discussion and methodology is not meant to involve a greater discussion of the worth of capitalism over any other political ideology, but one can criticise something without talking about the merits or failings of comparable others.

To understand the conditions outlined above, one has to take a different perspective. Using a sociological method that begins with people's experience is crucial, but it does not end there. Smith writes:

Locating the sociological problematic in the everyday world, does not mean confining the problematic to the everyday world. Indeed, as we shall see, it is essential that the everyday be seen as organised by social relations not observable from within it. (D. E. Smith, 1987)

By locating our inquiry in the everyday, an understanding of others' experience lets us see the way in which these very experiences are coordinated and organised. The experiences are the starting point of analysis, rather than the sole purpose. The experiences are used to identify the ruling relations; the social organisation of individual lives, where the latter's participation in those very relations sustains this social organisation. Individuals both experience the relations and sustain them. Smith states that "*a mode of ruling has been created that transcends local particularities but at the same time only exists in them*" (Smith, 1987, 2005). What one gains through an institutional ethnographic method is the description of peoples' experience from those people directly, and subsequent analysis of those experiences using texts and discourses to understand how they are controlled. This approach provides the ability to see a thread of the ruling relations; the organisation and coordination of activities trans-locally within the dominant framework. It is a "thread" because the overall discourses of ruling relations across all activities within a society are large and complex and this chapter focuses only on particular activities within a particular setting (DeVault, 2006).

Institutional ethnography is not a comparative methodology; it does not compare experiences. This chapter makes no claims regarding the experience of researchers who work with general health research populations. Nor does an institutional ethnography explain the intentions of ruling relations, other than when their texts explicitly described them. That is, the ethnographic analysis does not surmise from the collation of various texts and experiences, detailed motives where these are not

plain other than the overall organisation of activity within a capitalist, and in this case specifically, neoliberal⁹⁴ society.

4.2. Why Institutional Ethnography

The purpose of an institutional ethnographic method is to try and understand how ruling relations organise the experiences of people, which they are to some extent unaware of, where this organising occurs through institutional texts and discourse. In this work, the purpose is to understand how the health research system (as it exists across universities, government and health systems) acts on and directs researchers working with marginalised groups. What views of marginalised population research emerge? Of interest here, is the “what”, the “where”, and the “how”. Gaining this understanding is important as it makes it possible to grasp the production of knowledge for marginalised populations in NZ within a larger overall system. Understanding what work does and does not happen (and why), provides information to assess whether there is an injustice or problem of some kind. The work starts from the standpoint of those working with marginalised populations looking out to the system.

I chose this methodology because of the preferencing of perspective in viewing the system. It will also become clear in this chapter that the emphasis of perspective resonates with that of the researchers working with marginalised populations. The informants in this study also on occasion choose to look out at society and the structures that affect the well-being of the populations they work with, rather than always looking from the outside-in; a view from society *of* the marginalised population itself.

This complementarity between the philosophies of those whose environment and actions I wish to understand and the philosophical foundations of institutional ethnography makes this choice of methodology particularly germane for this part of the thesis.

⁹⁴Neoliberalism is defined as a political theory (with accompanying practices and processes) that prefers a limited state whose sole role is to promote the free market and free trade where the ideal of the self-interested individual is promoted and can thrive with private property and limited governance. The market itself does not require state intervention, it regulates itself and the successful individual is one who is competitive and enterprising in this environment. (Olsen & Peters, 2005; Roberts, 2007)

In this chapter I aim to provide a description of the experiences of a variety of senior researchers working with marginalised populations (the informants), followed by an analysis of the ruling relations that organise their research practice (everyday). This analysis described thematically uses as points of entry both informant experience and the texts that informants engage with in their everyday. These themes are then related to the ruling relations, theorised as systems formed in the biomedical tradition combined with neoliberal policy, that focus on performance (measured narrowly) and impact (largely measured economically and reputationally) (Ashcroft, 2006; Burrows, 2012; Docherty, 2014; Sayer, 2014). What is drawn out and then discussed in the next chapter (Chapter 5) is the epistemic injustice (Fricker, 1998, 2007a) that arises from these systems.

4.3 The Problematic

The ruling relations are organisations that co-produce the health research system in New Zealand for the informants in this study, who are senior researchers working with marginalised populations. These organisations are governmental (both in health and education), but may also include non-governmental organisations (NGOs) and private companies. Organisations direct the informants' actions through processes, documentation, and discourses, thereby creating the circumstances in which research is funded, approved, conducted, reported and utilised. To understand the ruling relations within this problematic, I describe the experiences of the informants which are used alongside literature and institutional texts to uncover the ruling relations and the influence the ruling relations exert on action.

4.3.1. The Everyday for Researchers working with Marginalised Groups

I provide a full account of the informants in Appendix C-1, including the inclusion criteria. Nevertheless, it is important to highlight several key factors: the majority of informants were female (10 of the 11); the group was ethnically varied (Pakeha 6, Māori 4, Pasifika 1); all the informants were senior researchers, and their research settings were mixed (university or NGOs; various employment conditions – permanent, contract, or a mix). The communities they worked with, and for, were Māori, Pasifika peoples, people with learning disabilities, youth, mental health and addiction service users. I have used the term communities for the populations these

researchers work with, but readers should consider this in a broad sense of the word. Not all of our informants were “community researchers” in the typical sense that people might imagine. The group included a wide variety of practices, methodologies and philosophies. However, all our informants identified themselves as serving a “community”. For some, this was a very clear and particular community that they spent much time in; for others, it was a community conceived of as a group of people tied together through shared experiences, characteristics, and in these cases disadvantages. These latter researchers could work in multiple sub-communities (geographically determined) of that larger community. It is also by no means suggested here, that these populations represent the full breadth of disadvantaged populations in New Zealand. Nor, do I suggest, that researchers working within other communities with groups that may not be considered disadvantaged do not have some of the same experiences in their practice where it includes certain types of questioning and methods prevalent for those working with disadvantaged populations.

The informant “everyday” might be a mixture of teaching, research, and service, in the university setting. In the non-university setting, the “everyday” might be but was not limited to, research and community liaison activities. All informants experienced visits to government ministries, NGOs, and interactions with their populations and communities. Relationships were important for all informants, not only within the institutions they belonged to and had to navigate, but more importantly, within the communities they served.

4.3.1.1. Legitimacy

Informants required different forms of legitimacy between the communities they work with and represent and the academy/government agencies they work for. Being part of academia is beneficial for the informants; it provides access to an intellectual community, time, and resources. Academia provides a level of legitimacy to them as a researcher going out into the (public) world when engaging with government departments and organisations that directly affect their

communities.⁹⁵ This legitimacy, within the academy, is performative⁹⁶, but this performance can undermine the informants' status or ability to engage in the communities with which they work. Marginalised individuals and communities can distrust figures of authority from government agencies and organisations, especially when the latter have historically treated their community poorly. There is, therefore, an ongoing need to switch from one type of researcher mode to another where this shifts between the academic and community settings.

I observed an illustrative example of this dynamic in a seminar given by a Māori woman⁹⁷, whose role within the University was health researcher and more specifically epidemiologist. Her presentation outlined her involvement in a development project in her community, a suburb classed as lower socio-economic. The project itself involved community members as leaders in improving health and well-being for their area. Since the researcher's department was related to the Medical School, fellow academics from the school attended her presentation. Importantly, members of the community leadership project also attended. Her tikanga⁹⁸ was to bring food, which she justified to the audience, who should have acknowledged this but did not. Proper tikanga would have also been to introduce her and the community members in line with Māori protocols: no-one did this. In introducing her topic, she qualified her professionalism (spelling out her quantitative practice and experience) before describing the wearing of a "different kind of hat" for the community project. There was a sense she felt caught between the community members present and the academics in performing her identity and building legitimacy. One felt she wanted to make clear to the academics in the room that her professional training and practice was rooted in quantitative methods in health, that her "normal" research practice was something more "robust"; because her description of the community work undertaken was pragmatic, openly emotional, and non-linear. There was a risk that this way of presenting would

⁹⁵ Those informants who were independent or based in other organisations had gained their legitimacy through qualifications earned in universities and had ties to universities, and had completed joint projects with universities early in their careers, to build a slightly different type of legitimacy.

⁹⁶ Performativity is defined as communication that not only communicates meaning but crafts identity in certain spaces (Butler, 2010)

⁹⁷ Not an informant (taken from Field notes)

⁹⁸ Māori custom and cultural practices.

change her identity within her academic community. Questions from the audience supported this interpretation, insofar as attendees asked her about funding, evaluation measures, and the like. The speaker provided evidence of small immediate benefits to the community, but the group had not undertaken any long term evaluation. Although the audience did not dismiss the so-called “soft outcomes” as such, many of the attendees were concerned with understanding how this process could be “operationalised”. In other words, how might these outcomes be validated or verified and then implemented? One audience member recognised and commented on the emotional labour the presenter had provided in the project and thanked her for her open manner in discussing work during the presentation.⁹⁹

The act of balancing legitimacy was also apparent in informants’ experiences of what their communities valued versus what the academy required of them to prove their ongoing validity and performance.

Yes. Because I'm known in the community, those invitations to be involved around things come. Yeah, I think that we try to be collaborative. Again, or we are collaborative probably to our detriment. (...) That's a double-edged sword for us though because the people who assess my work are not going, "Hey, she's great. She's out there, and she's been for 20 years doing this stuff." They go, "She has not enough publications." (...) It's a double-edged sword. There would be barriers created, challenges created from working outside, but also working inside as well because I do believe that we wouldn't have the relationship we have with the community if I had been located in the university. (Informant 1)

Performance measures specifically within the university (created by government) but also for funders focus on international recognition as a measure of research excellence. This emphasis is evident in the goals of universities who reflect back in their strategy documents what governments measure them on. For example, Otago University in its strategy document states that its Vision is to be “A research-led University with an international reputation for excellence”.¹⁰⁰ The University of Auckland does not have a Vision statement, but its Mission statement, reads: “A research-led, international university, recognised for excellence in teaching, learning,

⁹⁹ The project had been positive and negative. The community had suffered some losses during the time of the funding, which had been hard on the leaders of the project and the community itself.

¹⁰⁰ Available from: <http://www.otago.ac.nz/about/official-documents/index.html>

research, creative work, and administration, for the significance of its contributions to the advancement of knowledge and its commitment to serve its local, national and international communities".¹⁰¹ At first glance, this seems somewhat more comprehensive and fairly focused, but on reviewing the strategy document, one finds that the measures for "High-quality research that benefits society" are around publication in peer-reviewed journals with international collaborations and successful funding applications.¹⁰²

While research excellence measures have multiple metrics that are easily quantified, the measure for connections to the community is singular – "Number of engaged alumni".¹⁰³ The actions listed under this measure include engagement with "key partners", broadly defined across local government and community. This metric for community engagement would indicate that it is not measured meaningfully. Wright et al (2015) have found that this emphasis on internationally recognised impact can be detrimental to researchers working on the local level or with indigenous populations, as their work fails to garner the attention from overseas, that is required to meet performance targets within the institution (Wright, Curtis, Lucas, & Robertson, 2015). This type of performance measuring as a means of undermining and constricting informants' work is repeated throughout various sections and is discussed further in section 4.4.

Interestingly, informants were able to describe the gulf between the two locations of their work as both physical and philosophical. Many used the words "inside" and "outside" to delineate the difference in spaces for their work; "inside" the academy, "outside" in the community.

Straight away, at that very onset, you're caught between two different worlds. One doesn't work for Māori and works for non-Māori, but you are having to go down that path because, at the moment, there is no alternative. It's not even about having an alternative; it's about complete lack of understanding. (Informant 4)

¹⁰¹ Available from: <https://www.auckland.ac.nz/en/about/the-university/mission-and-values.html>

¹⁰² Available from: <https://www.auckland.ac.nz/en/about/the-university/official-publications/strategic-plan.html>

¹⁰³ Ibid 89.

To get funding, we have to talk about disparity and problems and deficits, yet as a [PROFESSION]¹⁰⁴, as a [MARGINALISED GROUP] health person, as someone who works from a healthy [MARGINALISED GROUP] development philosophy, we're about building assets and creating a safer environment rather than taking a really individualist approach to healthcare. (Informant 7)

This dislocation appears to stem from the role of academic as separate and separated from society and communities. Informants felt this separation in how they are asked to perform and measure their academic role leaving no space for their relationships and community-embedded work, but it is also apparent in the lack of community relationships academia has as a whole. Marginalised populations especially sit beyond the academy. Gendron has described the former as the “construction of the academic performer,” where academic identity is intimately bound up with the ongoing (high impact) publication (Gendron, 2008) or what Burrows calls the “Quantified Academic” (Burrows, 2012). This performance and the continuous evidencing of it serves to constrain the academic within universities, but also constrains researchers external to universities, who must compete with university-based academics for funding and so must show the same ‘credentials’. The latter, the distrust of academia by marginalised communities, has been described by Linda Tuhiwai Smith (Smith, 1999) and others (Anderson & Solomon, 2013; Guillemin et al., 2016; Robinson & Trochim, 2007) and is based on the after effects of colonising practices and discourses. Research practices of “researching on” communities rather than with or for them. Communities see researchers in government or commercial organisations as not having their (the community/population) best interests at heart.

4.3.1.2. Precarity

The precariat is a relatively new term, generally understood as the social underclass that suffers from high-level job insecurity and unpredictability, and lacks psychological and social welfare within the neoliberal state (Standing, 2011). The “Academic Precariat” is an ever increasing group of workers who work on non-permanent research and teaching contracts (Brown, 2011; Reay, 2000). Their

¹⁰⁴ Throughout the quotes from informants words in square brackets are replacements for identifying material.

insecurity exists because of the neoliberal policies in many countries in the Global North that create a scarcity of resources within academia, leading to greater competition, and market rather than public accountability (Brown, 2011; Butterwick & Dawson, 2005; Ivancheva, 2015).

All but four participants had permanent, full-time academic positions. Despite this, there remained an underlying sense of precarity even though some participants held what are considered to be “senior” roles. Across our sample, depending on the particular informant, this feeling of precarity was traceable to a constant restructuring of “non-profitable” academic departments, pressure to generate “revenue”, fixed-term employment in institutions with no guarantee of renewal, uncertain research funding environments and independent/private contracting. The current system measures outcomes based on commercialisation, cost-effectiveness, and value-for-money given the current neoliberal zeitgeist within the academy/ government institutions adding to this employment insecurity. This background employment context contributed to the overall unease these researchers felt given the work they do is always seen methodologically and politically, as less valid because the focus is on smaller populations. While their work can potentially have a great impact for the target population and society as a whole, those assessing projects always ranked it as less of a priority when compared to projects or activities that bear a clear commercial impact, or larger population impact (Health Research Council: health significance¹⁰⁵/impact rating, university: revenue, and commercialisation, governments: cost-effectiveness).

This precarity is described in the literature and is especially pertinent for female academics, NZ-trained scholars, or those working on NZ issues (Wright et al., 2015) and contract staff (who interestingly are also often female) (Reay, 2000, 2004) working both within and outside academia.

I don't actually have a contractual relationship with the university, because I cannot get funding, but I have little bits and pieces of the jobs they do for various

¹⁰⁵ HRC rates its grants based on rationale of research, scientific method, track record and health significance, where health significance means that the application addresses a significant problem in NZ. An extra point is also given if the work can be classed as translational.

organisations, and I just have to accept that I'm not going to be a paid academic.
(Informant 5)

Informants who held permanent positions face other issues of precarity. Specifically, the pressure to continually publish in high impact journals when their philosophy was one of disseminating to their populations and stakeholders first, and the work they did publish was in lower impact journals because of its particularity.

The practice that we would have is prioritising what I see as our responsibility or obligation back to the community. That's to our detriment at times because by the time you've done all of that reporting and plain language formats, (...) By that stage, we're having to look at other work and pick up other funding, so the academic writing, which should always occur, we're always falling behind on that. As I said, to our detriment, because that's what you're assessed on for the next grant, not how many people in the community that you're working in, have got to hear about this and might have learned something or changed their ways or the general practitioner might have got to hear about something that might be a different way of doing things. (Informant 1)

Informant commitment to work that did not fit neatly into the overall systems of measurement meant that they sacrificed their own time and status (seen in the comments by Informant 10 and 8 below). Arguably, this also hinders their practice, insofar as others within the academy may also be going over and above in their work, but it is recognised more readily in the measures of impact used. A somewhat circular problem occurs in that the lack of recognition of their work fails to support their activity, which in turn means they must take actions that further undermine their position to complete the activity, leading to a further lack of recognition.

The community sector itself is really low resource. At least a third of the work I do is voluntary, you don't do community research in the sector I'm in without accepting that you would end up doing a lot more work to get a project done than might be paid on the contract. (Informant 10)

To be quite honest, one of the reasons I don't apply for a promotion, I've reached the top of the bar¹⁰⁶ for [RESEARCH-BASED ACADEMIC POSITION]. There is no point. It is hard enough getting funding on my current salary. It just pushes your research grant further. I'm not in it for the promotion, it doesn't drive me any other way. What's the point in putting all the time and energy into a promotion, it's just going to make getting a research grant even harder. (Informant 8)

An underlying insecurity of position is in and of itself stressful and arguably adds to the “burnout” phenomena discussed below (4.3.1.5).

4.3.1.3. Population/Community as *raison d'être*

All of the informants, in one way or another, either self-identified as an active member of a particular population or community (e.g. Māori or Pasifika), had family members who were part of a specific population or community, or had developed a deep connection with a population or community over time. Their marginalised populations were these informants *raison d'être* in their research. Understandably, this meant the driving force for the informants in conducting their work, were direct outcomes for these groups. Informants' research practice was defined by what worked best regarding achieving positive change rather than necessarily blue skies, commercially-, or reputationally-valuable work. This focus, of these researchers working with marginalised populations, was a positive aspect to their motivations, but they could also experience this aspect as great responsibility or burden. Consider the following from the researcher identified as Informant 8:

You have a responsibility to the group, but I think it's also partly that the types of people who work with marginalised groups are there because they are really passionate about that group. That passion drives whatever you want to do. It's not just about responsibility. It's really, these are a group, I'm really concerned about. I'll do whatever it takes to make sure they get a voice. I think that's ... there's very few people who are working that I know of who are working with marginalised groups who are not really passionate about working with those groups. (Informant 8)

¹⁰⁶ In many New Zealand tertiary institutions, academic roles have salaries situated within a band (i.e. minimum amount to maximum), where the top tier of this band is above a “bar”. When employed staff are placed on the level in the band that is commensurate with their skills/experience, and the progress automatically through the band during their employment until they hit the “bar” at which stage they have to apply for a salary increase justifying why it is deserved.

Informants described how they often went over and above. Where institutions were unsupportive of activities that they thought were important for their communities, they would do the extra work in addition to the work they needed to do for organisational approval. This “over and above” could include extra time, out of pocket expenses, and sharing expertise for other purposes than research, amongst others things. Informant 7 said that:

You do, do a lot more than you get paid for. (...) I don't know if other people have that same responsibility, but also expectation from their communities to do all that extra stuff. Because it is our community, because it's something that we're passionate about, we do give more because we feel there is this ethical and moral responsibility to do a good job and go above and beyond because it's your people. (Informant 7)

The informants made it clear that the processes, at present, did not facilitate any opportunity to “give back” to the communities. And yet, sharing resources, giving back, and supporting their communities were things they felt very strongly about:

Another key principle that I always use is as much as possible of the money that we have for that research should be spent in that community. As much as possible, can we employ people there either as translators or caterers, etc. being aware that managing confidentiality and all of those issues is not insurmountable and just needs extra care. (...) Everybody in the research machinery is earning money out of this, but the community whose information this comes from are expected to turn up for nothing when they are the poorest? (Informant 9)

This awareness of the discrepancy between the money in the system and the money in the community is, I would argue, unique to this group. Trying to support communities with research resources is challenging when ethics committees frown up practices that could be interpreted as coercive (payments) or create conflicts of interests (employing people in the community). Informants felt that coercion and conflicts of interest are manageable and that giving back was the greater ethical priority.

Not only their time but often their intellectual work was something informants gave away for free, recognising that these actions put them at a disadvantage. In a competitive setting where institutions measure researchers on the academic identity, they craft and perform, sharing ideas and work is counterintuitive. The

feeling expressed by informants was that giving away ideas was necessary to make sure someone, even if not them, got the work done if it had the potential for positive change when they could not access funding or resources to do the job themselves.

I think what happens is that as a researcher someone that's seen as having knowledge around this area that we give a lot away for nothing. We give a lot of ideas away. I sit at the moment in the [GOVERNMENT] working party, tell them a whole lot of stuff, give a whole lot of things that other researchers possibly wouldn't. For me, I'm sitting with a group of the community that I work in. And again, ethically there's a moral and ethical obligation to contribute in a way. (Informant 1)

These informants described their communities as both the beginning and the end of their work; the place where it must start and where it needed to finish by reporting back and creating positive change. This starting could be the co-production of ideas, or the buy-in/endorsement of ideas they as researchers had recognised were an issue. Communities were powerful motivators, but also could weigh heavily on participants.

4.3.1.4. Practices and Priorities

Informants working with vulnerable, marginalised and hard to reach populations or groups (both socially and geographically) not often considered by mainstream health research, prioritised and practised research differently. Their starting point of inquiry was different and informants seemed to welcome practice innovation and were flexible and pragmatic in thinking about how to get the information required. However, this flexibility again puts them at a disadvantage within performance measurement exercises, as standardised practice is easily rated and recognised, innovative practice is controversial and harder to measure (Löhkivi, Velbaum, & Eigi, 2013; Olsen & Peters, 2005; Roberts, 2007). For these senior researchers (informants), they did not view their pragmatism as a lower standard of theory or method; it was not an indication of a drop in standards, but rather included a broader range of methods and tools, and variations in their application. Informants also recognised that their connection to people meant sometimes they could not perform their researcher role or had to shift priorities in different moments of the work. For these informants their values, relationships and community connections

are paramount and therefore doing what needs to be done to achieve outcomes for the community is crucial.

I guess that is one of the reasons for why we haven't had as much success around attracting health research funding in this area. Our philosophy is...and my personal philosophy is conducting research that keeps people at the centre of it, it keeps [MARGINALISED GROUP] at the centre of the research. That is contextualised around their lives and their situations and that will have some practical utility for either people themselves or the groups that work around them in terms of it could be families, it could be support workers, it could be health professionals. In order to change the situation. Transformational, really. (Informant 1)

Well, it's an ethical thing. It's a really key ethical issue. If you were ... I don't know if other people have said this, (...) historically, when [MARGINALISED GROUP] have sort of been researched on, and people fly in and take their expertise, fly out and nothing happens, nothing changes or improves for them, that there is a term for that which is tarmac professor or researchers have even been called parasite people. There's traditional hostility to people doing research on [MARGINALISED GROUP]. I think if people are going to give you their time and expertise, therefore it is a partnership, therefore the dissemination that suits them has to be prioritised. Of course, it's a conflict in the university. (Informant 5)

Informants thought quantitative and qualitative dichotomising and dogmatic attitudes were largely unhelpful. Through experience, they prioritised and utilised the methodology that best addressed the questions arising from community need. What was emphasised, however, was being explicit about the perspective from which they were undertaking any particular piece of research, rather than methodology, per se. In exploring this idea of perspective over methodology with informants, this was not explained as relativism, but rather, explained as, a recognition that all science and research practice contain values. Most of the group of informants made this point in reference to “other” researchers, those meant to be “objective”. In every discussion where it arose, the informants indicated that they are open about their values, their perspective, their “bias”, but wanted other researchers to be more honest about the values and perspectives they bring to their work. Making these values explicit is important in understanding the research results.

(...), it's just a tool, and you can indigenize and create quantitative methods, or deliver quantitative methods in a way that align quite closely with Kaupapa Māori approaches, which some people struggle with, but it's probably well more framed. (Informant 3)

It's not whether you use quantitative or qualitative methods or perhaps if you believe in a constructivist or positivist perspective, but for me it's about "How do we put on the table what our values and our underpinning beliefs are?" because that is what is determining the questions that are asked and the analysis that we bring to it. (...) So this is where you're getting into values, and the whole idea of the objective researcher going into a population and being able to come out with some science is not something that I agree with at all. (Informant 9)

That's the idea that we can't be these objective, neutral scientists who go into the community and somehow objectively measure something and then state this expert opinion about what works or this is what needs to happen. The idea we all have our own cultural age, gender, cultural, sort of lenses we bring to our work, we need to be aware of those. That impacts all parts of our practice, really. (...) Added to that, a [MARGINALISED GROUP] (...) aren't passive recipients of research or services that we might be evaluating. They're actually active participants. They have agency and they have the right to participate in decisions that affect them, but also to participate in the development of services for them. For me, that makes the voices of [MARGINALISED GROUP] central to actually both evaluating and developing services. (Informant 10)

Arguably, informants' work is much more transparent than that of traditional "objective" researchers because of their awareness of how their values influence their practice and their openness about this. Additionally, informants' recognition that communities and participants also have agency and values, goes some way in explaining their commitment to being responsive to those they work with. This recognition is in contrast to researchers who may only see participants as "subjects" to be studied.

There was a discourse that formulaic/standard research practices as described by guidelines or preferred by other researchers did not work in their settings where the participant pool itself was small and people lived in vulnerable and challenging situations. Conducting randomised controlled trials with vulnerable youth, or the learning disabled, for example, was not often able to be done in a way that would

ensure the results were meaningful, depending on the intervention that was necessary. Evident again was a pragmatism and consideration of their participants in getting the research done.

I have to say that..., once you're actually out there, I mean I've done between 60 and 70 focus groups and hundreds of interviews in multiple projects. And often with vulnerable [MARGINALISED GROUP] without families, including going into [MARGINALISED GROUP] prisons, schools, community groups. We were talking about this the other day, no research plan..., you have your plan written out and what you submit to the ethics committee and, of course, you're going to follow the ethics and that, but I have to tell you, that once you get out there and you're in the community, in order to make that project work, you really have to be iterative with it. You really have to be flexible and adaptable. (Informant 10)

But maybe it's about the way that we approach people. Why can't we go to people's homes? Why can't we take bloods at their homes if they want? Why can't we do things that are slightly different and creative way that is actually about us making life easier for them rather than us making their lives really complicated? That comes from that whole medical model of, "We know best. You come here. We'll do this for you and you'll be grateful," kind of thing. (Informant 7)

Responses indicated consideration for what would work best for participants rather than what would be easiest for them. Prioritising participant needs partly comes with an experience of what those needs might be. For these informants who are senior researchers, they have developed knowledge of their community and its needs over time. Through this experience, informants have relationships which mean they can consult and discuss the best way to do things within a project before they begin.

Informants described their research practice as collaborative. They shared with their peers and communities more than just the outcomes. Benefits were also shared where possible, as well as information. There was recognition that well-designed research could also be beneficial for participants individually and in some cases transformative.

In little ways, I sort of could share a bit of research funding so they could go to conferences. Just little, you know it was a little bit in that respect, a respectful relationship, so that's sort of something I've developed. (Informant 5)

I think yes. Speaking from the clinical trials where there is all the evidence that Māori that take part in a trial, the better it is for your overall health. For the Māori participating in the research in the [HEALTH CONDITION] trial or the [HEALTH CONDITION] trial, they really enjoyed the process. I think that is partly been because it has been Māori led. So it is about the relationships. It is about making sure people are getting good quality care. (Informant 2)

Many informants spoke about their research participants valuing feeling heard in qualitative projects. Informants reported that for some participants taking part in research had been the first time they had been able to have conversations about certain aspects of their lives, and they saw this a positive experience. To make their populations/communities priorities for others, informants recognised the necessity of relationships with those who prioritised and funded research and services. These relationships were created through persistence and patience - waiting for the right opportunity. In addition to establishing relationships with peers by attending conferences, workshops, and meetings, the informants used these meetings as an opportunity to establish relationships with “decision-makers” in research and service structures.

Practices and priorities as has been outlined here are a point of difference for our informants. There was a feeling amongst informants that the broader health research community sees certain methods as better than others, but for this group choosing the method that best suited the terrain was paramount. Evidence-generating gold standard methodologies were not always useful or practically possible. These kinds of methodologies were often impossible to operationalise based on their small populations, spread geographically, or some groups' capacities to comply and understand with trial protocols precisely. Also, these methodologies test efficacy, and this was not always the issue in our informants' settings. While there is greater recognition in the literature of complexity in community settings that requires consideration when informing evidence-based practice (Fraser & Taylor, 2016; Trochim, Kane, Graham, & Pincus, 2011; Urban & Trochim, 2009),

informants did not necessarily feel this recognition in dealing with practice or research-based funders. The need for appropriate methodological selection, according to context, was often articulated by informants. These researchers placed additional emphasis on questioning the implicit, value-laden perspective of the researcher in relation to the community. This explicit seeking of perspective and power relations ties to their understandings of marginalisation and disadvantage as socially determined.

4.3.1.5. Burnout

Precarity, competing demands, the required performativity between spaces, the burden of the communities' disadvantage, the extra time and work to do activities that their environment did not support could all lead to informants' having a sense of resignation or total burnout. Burnout is the result of physical or mental exhaustion when workers (in any setting) are exposed to emotionally challenging situations (varying in intensity and frequency) (Lackritz, 2004). Burnout is often also related to moral distress which as a concept originated in the field of nursing but researchers have explored this in other settings (Epstein & Hamric, 2009; Ganske, 2010; Hamric, 2012). Moral distress relates to feelings that arise in institutional environments that either actively or passively stop a person from doing the thing they feel is the morally right thing to do (Epstein & Hamric, 2009; Ganske, 2010). It is evident in this work so far that there is a clash between institutional environment and researchers working with marginalised populations in what is considered the right thing to do. For informants in this study, burnout led either to a complete time-out or a stepping back, to be able to engage in their work sustainably. Stepping back or out of the work could, however, be seen as an abandonment. Absence could be felt both by the person and by the community as a form of betrayal or a let-down.

The other side of it, though if you're really passionate about something, you're engaging at a very emotional level, too, you are working a lot, you are doing a lot above and beyond. There are people who have to leave, simply for their own health and just to keep their own sanity. It's not necessarily everybody that comes into the field, stays in the field. It's not necessarily everyone that leaves the field is not passionate about the field. Part of it is about survival. (Informant 8)

The emotional component of working relationally and feeling that your research is necessary to creating social change for a marginalised or disadvantaged group was important to these researchers, but also contributed to their stress and burnout. Those participants who identified as Māori or Pasifika or had family members who were part of the community that their research was for especially felt this pressure. They had no way of “escaping” their perceived commitment in the same sense that researchers might who did not have family ties. They could reduce workloads, but they could not remove themselves from the evidence of disadvantage their community faced. This recognition of particular pressure for some is not to say that other researchers working with marginalised populations did not experience strong emotions about their communities and pressures, but that it was qualitatively different.

One informant who worked with a community who suffers a range of disadvantages, also discussed her need for professional support in her work to debrief, recognising that the conversations she was having with participants were impacting her emotionally. She did not want to pull back from the work itself feeling committed to its goals, but saw that she also had to look after her well-being to practice sustainably.

Burnout as a phenomenon makes sense for researchers (emotionally) committed to communities and therefore providing extra time and effort, while in a system that fails to support their activity and in some cases actively obstructs it. Their only obvious recourse is either withdrawal (voluntarily/involuntarily) or practices of self-care.

4.3.1.6. Peer Community as Self-Care & Co-Conspirator

Communities of practice were a location of support. These communities of practice were not necessarily located within the informant's university department, however, and might be spread across institutions and organisations (particularly when participants sat in larger departments). Those informants, who were in specialised units concerning their population's health, valued the protected space both physically and philosophically. This space was felt as somewhere where one was “safe” but still challenged intellectually through peer critique and support.

People could have useful discussions without having to justify basic starting points. For those informants working outside of the university, their organisations were “specialised” to the population they served and so similar to specialised units in universities with sympathetic peers.

Peers could also be members of the marginalised group community either as service providers, advocates or marginalised members themselves. People, who understood the informants’ position between “worlds” and could empathise with them, were necessary for debriefs, planning and problem-solving to overcome roadblocks and feel well in their work.

*There's just the relationships, the working with the people themselves, as supportive.
(Informant 6)*

*I think fabulous colleagues. People who you can sit with, who can encourage you, who can challenge you. (...) Having inspirational mentors, colleagues, people who you can say this stuff out loud with and debate and not feel stupid. You can explore.
(Informant 8)*

Descriptions from informants regarding their everyday showed their marginalisation within the research system, through the dismissal of their views, relationships, connections, methodologies and knowledges. These marginalising actions meant that they sat apart from others within their organisations where the organisation’s focus was not disadvantaged populations.

Being able to link with other researchers with particular expertise and build multi-disciplinary teams is a supportive thing and stops us being marginalised, too. I think to make a real difference that [MARGINALISED GROUP] has to become part of wider, broader projects. But it's often being dropped out. That says a lot about just how people are valued. You're a kind of non-person. (Informant 1)

Large-scale meetings and conferences around the population of interest were felt to be helpful and invigorating for informants. Some occurred annually, while others could be less frequent, and costs of attending could be prohibitive (some of these meetings provided funding for some attendees or were free). In these kinds of meetings, there was not a feeling of having to fight for the basic respect of their position, as could be the case in other settings.

Yeah, Hui Whakapiripiri was great, it's so good on so many levels. It showcases the great variety of Māori researchers that we have and non-Māori researchers who are doing Māori research, to be honest. It's also an excellent opportunity for networking, collaborating, talking to the issues (...). What it does is it provides a safe space for us to do that in so that you're not actually fighting and arguing your case. Everyone is on the same waka so to speak. That has been good. (Informant 4)

However, those peer relationships can, much like the community, also act as a source of pressure.

So the relationships that we had with each other in the field worked two ways. So one, we're all so passionate, we're all so hard working that we all kind of supported each other to be passionate and hard working. Which has its benefits, but it also has its disadvantages. If you work like that, you decide to step back, then what does it mean for those other people and that has implications. At the same time, with me being really clear to people that I'm just needing to have a work-life balance for a wee while, people are really supportive. (Informant 8)

Informants were builders of networks. They valued and maintained complex, challenging but also nourishing relationships within their population and intellectual communities (and these could be overlapping). They worked hard on connecting to decision-makers at various levels to maintain dialogue and encourage understanding of their communities needs and the practices and support required to affect improvement.

4.3.1.7. Māori and Pasifika – Brown Tick, Tokenism, & Extra Burdens¹⁰⁷

Issues for Māori or Pasifika researchers were slightly different from those of other informants and distinct from each other. Institutions have formalised processes to reflect the inclusion of Māori based on the Treaty, but also sometimes Pasifika based on their disadvantage in society. Institutions often have processes in place to support this inclusion in a variety of activities, but as an example, informants found that they were often added last minute to grant applications (“brown tick”) rather

¹⁰⁷ Informants have been given different informant codes in this section to stop cross-reference with previous sections and potential identification. This is less of a worry for the Māori informants given there are a number of them and they openly speak about Māori issues, but is a concern for the Pasifika informant as there is only one. All informants approved their quotes; this is an extra precaution.

than consulted about project design or implementation when inclusion was prescribed or implicitly encouraged. All informants who identified as Māori or Pasifika perceived tokenism in processes and described examples. Some informants explained that inclusion processes also had unintended consequences: their university service demands based on the terms of reference of committees¹⁰⁸ regarding representation, were much higher given their smaller numbers within the workforce.

What meaningful partnership have you had when you put a brown face on your application? What power does the brown face have on that application? When we're often asked to provide brown ticks for people, and then when you have a voice, the power thing comes out. (Informant A)

I guess one of the barriers we constantly get ourselves in, most departments at our university, we've got what we call a 40/40/20 split. 40% of our time is supposed to be allocated to teaching. 40% of our time is supposed to be allocated to research and 20% of our time is supposed to be for service, but because we're the Māori department, we're always called on for things like Matariki¹⁰⁹ or powhiri¹¹⁰ or whakatau¹¹¹ or anything like that. Actually our service demands exceed that of our non-Māori departments. (Informant B)

Informants recognised the importance of their representation and were encouraged by their inclusion, but it came at the cost of their other work – research and teaching.¹¹² They also worried that some representation was not genuine. Committees could choose people for their compliance with those in power. Also, the opposite problem, those that were representative were not listened to if they did try and advocate for their community's views.

¹⁰⁸ Based on Treaty of Waitangi obligations Māori representation is required for many types of committee both within government and tertiary education institutions. This is also applies to working party type activities and consultation work.

¹⁰⁹ Matariki – Māori New Year (Matariki denotes a constellation that signals the beginning of a new year within Te Ao Māori).

¹¹⁰ Powhiri – is a formal welcome protocol that can involve speeches and singing and is generally conducted on a Marae but is also used to welcome new cohorts or visiting groups to an institution or open a new institution.

¹¹¹ Whakatau – is a shortened version of Mihi Whakatau, which is a formal welcome speech, not conducted on the Marae, largely at universities or government buildings to welcome new staff or open new buildings, for example.

¹¹² And in practice, it was explained that this is more often at the cost of research, as teaching has fixed times and deadlines, where classes need to be provided, or assignments marked, whereas writing grants and publications were more easily delayed, and pushed aside under pressure.

But one of the things I worry about, about setting up those kinds of specific roles is they're often done as tokenism, the quality is not demanded of them and there's not enough accountability, because it's easier for the organisation to roll on and keep doing what it's doing, and we've got this docile Pasifika group that we're just sitting in the corner. (Informant C)

Te Ao Māori (Māori World View) and Kaupapa Māori were distinctive philosophies for Māori researchers. Kaupapa Māori is actively promoted as the ideal for Māori research (Bishop, 1999; Smith, 2012; Smith, 2000). It is in different places described as a philosophy and in others as a methodology; anecdotally it is often referred to by non-Māori as akin to participatory action research. This comparison, however, is a mistake and a conflation of method and philosophy. Participatory action research emphasises collaboration and transformative change in communities helping participants help themselves (Selener, 1997). The emphasis is on a research method that enables this collaboration and change. Kaupapa Māori research, however, does not specify method in any way, but rather perspective. A Kaupapa Māori approach could use any method; the key is in centring the Māori world view when using the method. Are the questions asked arising from a Māori perspective? Are methods used to address the questions appropriate in the Māori setting, what things need to be added/changed to make it so? Is data analysed within a Māori world view, and so on. When people equate participatory action research with Kaupapa Māori, they are imagining participatory action research in a Māori community thought of as a collaborative and engaged practice. However, this is not the same thing, it is missing an underlying philosophy and commitment and is why some informants and other researchers feel non-Māori researchers have misunderstood Kaupapa Māori. Some informants felt that the incorporation of Kaupapa Māori in funding and ethical processes had meant that Kaupapa Māori as a source of resistance¹¹³ was being institutionalised and subverted and that these processes were redefining its meaning as a method, rather than a perspective and practice.

¹¹³ At its very core, Kaupapa Māori research demands a centring of the Māori world view, this means not that a specific method is used, but rather that the world is seen from the view of where Māori principles, practices, colonised history are taken as the norm, rather than the “minority”.

I use kaupapa Māori because it makes sense. I work with Māori, and when you look at Māori health inequities, you see that, by far, the biggest drivers for inequalities in health, stem back to privilege, racism, colonisation. You can add surface causes, but if you dig deep enough, you're getting back to those. I guess a way of reframing that and reclaiming that space, is to work within a Māori worldview, so you're centralising Māori or things Te Ao Māori¹¹⁴ as the worldview are now normalised. What this does is it enables you to actually turn the gaze on others (...) it's akin to feminism in a way with women actually taking the reins and saying "we've been excluded or marginalised or invisible and "othered" in research, so we're actually going to turn the tables now." Kaupapa Māori's got a resistant movement, a little like that, but more than that, it's also making sure that your research makes sense to your informants and yourself, within your own local and cultural context (...). (Informant B)

I think that's where people have got a bit confused around what kaupapa Māori is, and I think that some of the confusion comes from the HRC, itself, and the way it asks researchers to when applying for funding, to explain these things. (Informant A)

Within the current setting for research funding informants articulated that the ability to investigate perceived societal causes of disadvantage was challenging. A point that came up repeatedly was informants feeling a need to fight constantly for the appropriate viewpoint to analyse data.¹¹⁵

You're looking at a cell, or a disease function process, or drug therapy, that's our answer to health, whereas, again your framing, whereas I'm looking at power, privilege, you know, disadvantage, racism, those are my interests, those are my drugs I want to explore, and that's not an RCT. (Informant A)

I'm really grateful to have colleagues who are very politically supportive and encouraging of, for instance, we have a data access policy (...) and it's really making sure that any data, any questions, any research that we do is under this philosophy of looking through an equity lens, always of privileging Māori views, and trying to reframe things in a positive assets way. (Informant D)

¹¹⁴ Te Ao Māori – means “Māori world” which generally encompasses three main things: Te Reo Māori (the language), tikanga (protocols and practices) and the Treaty of Waitangi. However, more broadly it includes whānau, hapū, iwi (familial and tribal connections) and the Marae (the community focal point), whakapapa (genealogy) and Waahi Tapu (sites of importance)

¹¹⁵ This viewpoint is important – for example, if looking at a big dataset regarding prevalence and from there trying to understand causal factors, your perceptions of the environment and culture will determine the factors you find relevant.

Asmar, Mercier & Page (2009) who interviewed Māori academics in New Zealand describe academic life for Māori academics as mixture of experiences (Asmar, Mercier & Page, 2009; Mercier, Asmar & Page, 2011). There is a coming together with other Māori (both staff and students), as well as educating and advocating for indigeneity within and external to the institution, and also an effort of educating others and fighting for space (Mercier, et al.,2011). This fighting for space and understanding or responsiveness to things Māori also came out in these interviews with informants (both Māori and Pasifika-identifying).

When funding was earmarked by funders for Māori or Pasifika health specifically, this was seen as largely positive, but could also have undesirable effects. Earmarked funding meant that other researchers might perceive that “the problem” was fixed or addressed and that they, therefore, did not have to consider Māori or Pasifika peoples. It also meant that work to integrate desired thinking more globally was not occurring (i.e. all researchers considering their obligations under the Treaty meaningfully for instance).

There's also some weaknesses associated with that, because what then happens is the resource is never enough, the rest of the organisation then defaults to say, "Well, the Pasifika stuff sits over there and we're not going to bother with it." Managing that interface is an important thing, but I would argue, that having that space is really a critically important thing to happen so that you find good capability that's able to front that and be credible, that you allocate some resources to it and that within the organisation there is an absolute commitment at the highest level to supporting and growing that. (Informant C)

I agree, it's great having the Rangahau stream, I don't want to be arguing against that, it's fantastic, I think, for Māori there needs to be a space for Māori in resourcing, but then, in saying that, the trouble with that, is that everyone's thinks Māori have that space, that is theirs, they operate within in it and we can get on with business as usual. You need a 2-pronged approach where Māori have that set space to be safe, to have the resources to develop as is their right under the Treaty, but also that needs to be integrated into mainstream society. At every level, health and education, in politics. I think it's only when we've got that latter integration that we're going to be achieving anywhere near social equity. (Informant B)

Reports from informants showed that they had mixed feelings about funding applications that included a section requiring applicants to justify how their research would benefit Māori. While informants agreed that it did make clear that research must be beneficial to all, in their experience these sections of grants could include “boilerplate” answers or the most tenuous of links to Māori health. Participants that had sat on evaluation panels for ethics review and funding reported a high variability in the quality of the explanations and their content.

Value-laden, judgments of value, around a [BIOMEDICAL] experiments, which might lead to some amazing hormone, which might lead to the development of a new cancer drug, which might lead, therefore cancer is high in Māori, therefore it's got to be positive for Māori. To be fair, we're not getting access to the current therapy, so why on earth some new therapy that might come about 50 years away? How on earth are Māori going to benefit from that? (Informant A)

Professor Tony Blakely, who is a prominent New Zealand researcher of the social determinants of health has said: “Reducing health inequalities requires interventions that work as well, if not better, among disadvantaged populations” (Blakely et al., 2011). This sentiment was also echoed in the National Health Committee document on Chronic Conditions examined in Chapter 2 (National Health Committee, n.d.-b). Informants articulated this very same idea that getting services and interventions right for the most vulnerable works for the least vulnerable.

I think if you are doing intervention studies, where you are actually working with them to design an intervention and applying it across populations. Because we've always argued if you get it right for Māori, you'll get it right for everybody. (Informant E)

As a whole if it's good for Māori, it's good for everyone philosophy, yeah. (Informant B)

When you were talking about clinical trials, there is increasing evidence that the biology and genes of different ethnic peoples mean that we might respond differently to drugs, that we might respond differently to treatments or programs, and because of that, Māori may not be getting the best evidence for them, rather than the best evidence for the general population which generally tends to be non-minority groups. (Informant D)

For Pasifika, it was arguably harder to carve out their area of attention and funding, because as an immigrant population, they do not have redress to the Treaty. While many problems for Māori and Pasifika people are similar, there are also important differences in cultural practices, norms, and beliefs that influence health and well-being. “Pasifika”, “Pacific Islander”, “Pacifica” are some of the words used as a naming term for what is a very diverse group. There are a variety of languages, cultural practices and genetic factors that make up this group “Pasifika” that is rarely paid attention to when grouping them together based on a geographic region. Moreover, while this cultural conflation in itself is wrong, their health issues are often further conflated with those of Māori.

Then next is Māori, which is absolutely correct, New Zealand is bi-cultural country in its origins and there are massive inequalities and these have had to be addressed. But the inequalities agenda is largely about Māori health. You see these titles all the time. Ethnic disparities and then the analysis is only by Māori, and you go, "Hmm."

(Informant C)

Informants reported being encouraged by the progress made in the appropriate inclusion of Māori (and to a lesser degree Pasifika) priorities, interests, and representation in education and health settings. Having said that, they feared that in some cases, formalised processes had replaced meaningful engagement and representation. These informants repeatedly mentioned issues of tokenism and inauthentic engagement, and this reflects discourse in the literature (Prussing & Newbury, 2016; Smith, 1999). Barry Smith¹¹⁶, in discussing ethics has said: “that what passes for acceptable engagement with Māori is largely ritualistic and of the tick-box variety” (Tolich & Smith, 2015). In the book, Smith describes observing ethics committees and finding little evidence of real thought and consideration for Māori, despite application forms explicitly promoting researchers to respond to this (Tolich & Smith, 2015). Another specific example is the recent National Science Challenges¹¹⁷ in New Zealand. The government made clear statements regarding its commitment to Māori knowledge, but then failed to create a Māori-specific

¹¹⁶ This book is divided into two sections, Barry Smith leads the latter section on issues of Māori consultation and engagement.

¹¹⁷ Science Challenges are a new investment strategy targeted by the government to key areas (after a process for discussing key areas) <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges>

challenge and did not appear (at least initially) to embed Te Ao Māori within the created challenges, which was felt by Māori as a form of silencing (Prussing & Newbury, 2016). Prussing and Newbury (2016) described this as “*as a tactic by neoliberalizing states to simultaneously recognize culturally diverse agendas while also undercutting their practical impacts*”.

For these informants, their lives are intimately bound with their research area which added other aspects to their experience. Their research work impacts their whānau, their hapu, their iwi or their Pasifika communities and this meant that, unlike for other researchers who could separate their professional and personal lives, this was not necessarily the case for informants.¹¹⁸

4.3.1.8. Silencing

Silencing is a term that originates in discourse analysis. It describes the imposition of one form of discourse upon another, making the latter conform, disappear or appear aberrant and undesired through positions of power in society (Thiesmeyer, 2003). Scholars have explored silencing in many areas of marginalisation (race/ethnicity, gender, disability, their intersections) and specific social contexts, but also in academia (to name a few: Gill, 2009; London, Downey, Romero-Canyas, Rattan, & Tyson, 2012; Moran, 1998). As mentioned throughout, for many informants, there was a feeling of being silenced by the various organisations involved in the research endeavour. Silencing could occur through the constant clash with processes that did not recognise their practice. Examples included ethics committees interpreting ethical principles in ways that seemed incongruous with their settings; funders dismissing their potential impact and methodologies; governments burying work that did not conform to their ‘message’; and universities using processes and structures that actively obstructed or ignored their practice. These processes served to communicate to the informants that they did not fit the norm; that what they wanted to do was not how things are done. Informants’ views on silencing were not only based on their experiences of undertaking research, but many of the informants due to their seniority had been members of ethics

¹¹⁸ Other informants had family connections to their work or emotional or professional connections only.

committees, funding panel committees, and other forms of review groups and also drew on these experiences.

Overwhelmingly, informants felt that both funding and publishing agencies were biomedically and quantitatively biased. Both failed to understand that other methodologies could be valid or necessary given the questions and size of the populations that were in focus.

An example of that would be Health Research Council, [PANELS] half of whom are lay but it would also apply to the biomedical people there. They never question research projects that go forward that might have mitochondria or genetics or microscope or pathophysiology. They'll never question those types of projects, and yet they'll always question the Māori funded projects, particularly in words that they would see as quite loaded political terms such as sovereignty or Tino Rangatiratanga¹¹⁹ or Whānau Ora¹²⁰. They would always dismiss that as being not science or not as valid as these other projects. Actually just because it has mitochondria in it doesn't mean it's good science either. You don't actually know enough to be able to say it is good science and this is not. (Informant 2)

So there's a major biomedical bias. A huge biomedical bias. (...) Then, sorry, I think it's both things, there's that, and then resources are not being distributed fairly because of that fundamental epistemological approach that they take, and the values that they bring. The values of the system and the values of the government are filtered down through the research processes. That's that positivist bias, there has to be an RCT, there's value in that, and that tells us something good, but it also tells us something bad when we don't have representation... so it can also do a lot of damage...and it's only one method, so why would we be restricting ourselves to one method? (Informant 3)

Not only is funding biased in the sense that it preferences certain epistemological approaches, but funders failed to understand the processes and costs involved with other approaches such as community-based research when they did look on them favourably. The perception of informants was that funders assumed that grants

¹¹⁹ Used to mean “absolute sovereignty”; also the name of a flag.

¹²⁰ Is a government funded work programme. The Whanau Ora approach is unique – it is a family-centred wrap-around approach that considers multiple elements in promoting well-being (including education, health, housing, etc.). For more information, please see: <https://www.tpk.govt.nz/en/whakamahia/whanau-ora/>

related to a laboratory were justifiably expensive, but that they do not necessarily appreciate that engaging with a community can also be costly.

It takes a lot more time. (...) I think our proposal would struggle even more if we put the real cost on it. That's what you actually end up doing, is you end up putting in for the amount that you consider is likely to get funded. If you put the real cost of that funding in, I think most people would run a mile. (Informant 6)

This informant's experience was similar to others in this study. The short-changing of grant budgets to have a chance of receiving some funding, even if insufficient, contributes to the situation in which researchers for marginalised populations have to do extra unfunded work. Informants justified this by stating their belief that if they did not undercost their work, then no research would occur, as they would receive no funding at all. It is a form of self-silencing in an environment where perceived silencing occurs and illustrates the ways in which ruling relations are both restrictive of but maintained by, those who live within the problematic.

The use of informants' work by government and service organisations was found to be frustrating because decision-makers dismissed it for not being "evidence" or because often its conclusions were uncomfortable for those making decisions. When researchers conduct research from a perspective that examines the causes of social disadvantage, the conclusions will necessarily be critical of society and governments. The subsequent recommendations to ameliorate the situation frequently require additional service provision or change to disadvantaging structures, which are complex and costly. For neoliberal inspired policy making, policy-makers will necessarily view conclusions that require more government intervention and are expensive (which the complex often also is)¹²¹ unfavourably.

The issues for [MARGINALISED GROUP] are all about, not only do we not have capacity, we struggle with resources, but we don't have the leverage to not only get onto the research agenda but what happens when research is actually done? Is it valued? I had a lot of examples of our research where it's mainly commissioned by agencies. It shows them in a bad light because what do you think? We have gross

¹²¹ If not costly, complex interventions are often long-term. Long-term intervention requires ongoing commitment and ongoing committed funding, which can again be seen as unfavourable by policy-makers on short-term policy cycles.

inequalities because of these things. They get to not release the results. So I would argue really strongly that what we need to enable good research in this area is good public policy that says, "Taxpayer-funded research must be released publicly".

(Informant 9)

For informants, impact meant a positive change in the community or for the population. Informants' perceptions of other researchers' priorities for impact were economic or academic (reputation based on publications). As is explained later in this chapter, evidence of these impact priorities exists throughout the strategies and documentation created by organisations. Impact measurement was not unimportant to our informants, but how they measured impact was the crux of the issue.

It becomes a bit of a pointless academic exercise if you're only doing the research in the field of [MARGINALISED GROUP] for other researchers in the field of [MARGINALISED GROUP]. (Informant 6)

One of the things that I was very interested in was there is this whole mantra about evidence-based policy in practice, but when the processes which enable the generation of that evidence don't support that happening. You have a chicken and the egg process where there's no evidence for that policy, but our policy doesn't support the generation of that evidence so then we'll continue to have no policy. That is a marginalising process in itself, which I think is what your thesis is and what your research is getting to. (Informant 9)

Problems of justifying impact were felt directly by the author, who during the time of this PhD aided in the submission of two grants. The university process is such that one gains advice during the application process from a research advisor (this is the case in most universities). These advisors are aware through experience and interactions with funders, what exactly it is that funders like to hear and what is more likely to get funding. For both grants, the advice given was to emphasise how the work meant cost savings for governments in the long run given it was obvious they would not produce revenue. Even if the link was somewhat esoteric: the advice was that pointing out an economic value to the work was more likely to yield success, than if the applicants placed emphasis on ethical implications. Regardless

of the fact that the work aimed at bettering certain stressful situations for either clinicians or the public; this alone would not be sufficient.¹²²

Some informants felt that this mismatch in impact evaluation was partly due to a lack of representation in decision-making, i.e. informants felt they had no voice or champion.¹²³ Fair representation by community members or researchers on various panels was felt to be lacking, meaning that their communities did not have input in decision-making exercises. While Treaty obligations meant that government had embedded Māori representation on panels to some degree, the extent to which this representation had influence was not clear. For most other groups representation was entirely lacking or involved stakeholder consultation. For representation to be effective in informing decisions but also in ensuring that decisions are found acceptable by communities, representation must be accurate, comprehensive and authentic (Hunter et al., 2016). In speaking to informants and reviewing documentation, this did not seem to be the case.

I went to a presentation on disabilities recently, and a very simple principle is "Nothing About Us, Without Us." That's a really simple measure that I think ... I really argue strongly for that idea of governance that includes credible [MARGINALISED GROUP] representation... Not that they pick who they want and who is friendly. We need to have some processes where we say, "Here are the people who have done some work in this area who understand the complexity and can engage with researchers in a similar way." I used to see this on clinical guidelines groups and things all the time. Here's all these professors of medicine and sociology and anthropology, and here's a [MARGINALISED GROUP] community person. Tell me how we're meant to have a sensible discussion here...(Informant 9)

According to informants, ethics committees sometimes failed to recognise, their different types of practices, the different ways they practised, or the value of their research artefacts (products of research such as recordings, transcripts, narratives, photography, or art). Informants felt that biased preferences towards certain kinds of research were once again present. The exclusion of some research

¹²² Field notes

¹²³ A champion is someone who advocates for a particular group based on knowledge and expertise.

methodologies¹²⁴ from certain forms of ethical review (discussed further in 4.3.2.) highlights the dismissal of the work conducted by some of our informants when compared to that of clinical research.

The other thing about ethics is when I did my [RESEARCH], I wanted all the tapes to be archived, because this is our history. This is our taonga¹²⁵. That was difficult for the ethics committee, but I had agreement, I think only one person who worked for the [GOVERNMENT] said no, she doesn't want to have hers archived. (Informant 5)

Even at an ethical level, being on an Ethics Committee, all the lay members are always questioning the qualitative research. "What's the point of this research it's not going to make a difference". Being able to have both experience in quant and qual, it is really good being able to say "we don't know that statistical research is going to make a difference either. We don't have power to have randomised controlled trials", having enough knowledge to be able to argue at that level, having somebody there to be able to advocate those critiques. (Informant 2)

But I have had to spend a lot of time and energy working with ethics committees to convince them that it isn't unethical to do this research. (Informant 8)

Informants described endeavours to build relationships with committees, to facilitate a more healthy understanding of their projects and ways of working. For these informants the fact that Health and Disability Ethics Committees and some University Ethics committees allowed applicants to attend the review of their application, which enabled them to answer any questions personally was very valuable. Being able to explain to committees, their practice, relationships, and the ways they navigate ethics in challenging situations, face-to-face ameliorated some of the issues created by forms that did not ask for nor allow space for these kinds of explanations.

¹²⁴ While it is not worded this way, the perception in the research community is that Health and Disability Ethics Committees no longer review qualitative health research since the 2012 reforms. The guidelines state that any research that collects personal information from patients or carers in their capacity as such, should go through HDEC review. Anecdotally, people have described being told to go to another committee with this kind of work. Issues arise here for those organisations that are not tertiary education providers with access to their own ethics committees.

¹²⁵ The contemporary meaning of taonga is 'treasure' and a treasure can be anything from words to an artefact.

Informants felt that data practices presented another possibility for silencing, both of themselves and their populations. Processes of generalisation within large datasets were likely to ignore lines of questioning that draw out issues for those that suffered marginalisation or disadvantage. Informants noticed a lack of discussion around what was happening in this “Big Data” space specifically about representation.

For Māori, we've had data used on us in really damaging... and disempowering ways. I worry that people will take our data and do really disrespectful stuff with it. We have no control over what happens to it once it becomes open access. On the other hand, I think people keep data and not having access to data can be also a form of quieting and not letting our voices be heard. (Informant 7)

My heart always starts racing a lot faster about open datasets and big datasets, however, when I said my heart starts racing, it's because they are so open to abuse and mismanagement, and that really concerns me. We know that people use data incorrectly. We know that data can be used to spin...whatever purpose you want it to spin. So that worries me, about big data, bringing that back to the participant worries me because I have collected that data and I have made a promise to them that this is how it will work, so that's about my integrity and my relationship with that participant. That deeply concerns me. (Informant 8)

Some researchers had direct experience with or were aware of Kaitiaki groups (described in Chapter 3, and discussed further in Chapter 7). Informants perceived these groups managing data on behalf of populations as positive but also stated that this would not be possible were it not for the institutional backing of those groups providing them with authority. Informants were not data-sharing adverse, insofar as they perceived the benefits of sharing collected data in reducing the burden of research participation on their communities. Their emphasis, however, was on appropriate management, where they saw this as having their marginalised communities' best interests at heart first and foremost. Given their experience of various actors' lack of consideration for their populations in the research environment, their anxieties regarding data practices were understandable.

Informants also spoke about the dismissive or inconsistent attitudes adopted by various funding committees toward their research topics. The same was true of

decisions regarding the setting of priorities. The reported inconsistent atmosphere appeared to be attributable to the lack of expertise on the committees, meaning that a single member, by virtue of possessing a strong voice, may disproportionately influence the overall decision-making—an issue that often arises with constant membership changes.¹²⁶ Dismissiveness was related to the ways in which inclusion was talked about and described in strategies, but then no-one ensured inclusive practices at the ground level.

(...) Unless you've got someone there. It showed me a lot about how much time, and attention is paid if that's not your field and how easily [EXAMPLE OF REVERSAL OF SCORE BASED ON CHAMPION ON THE COMMITTEE] For me, that was one of my moments when I went, there's no point really. (Informant 1)

Just thinking when you're saying the barriers...at the political level, I was just thinking about the National Science Challenges, we were interested, or concerned, is probably a better word. As Māori researchers, when they determined what the [RESEARCH AREAS] were going to be, there was no Māori side, [RESEARCH AREA]. We would be incorporated into one of these other ones. I feel like it was another way that we were cut out of the decision-making. Our knowledge wasn't validated. (Informant 2)

The informants' experiences reveal how senior researchers working with marginalised populations are themselves marginalised and silenced in a system they feel undervalues their work and the population they do that work for. Nevertheless, over time they have successfully learned to navigate this system, such that, despite the obstacles, they can secure (limited) funding and publish their research as experts in their respective fields. How ruling relations explain this experience is the next part of this chapter.

4.4. The Ruling Relations for Researchers working with Marginalised Groups

The informant experiences resonate with those of other researchers examining the academic environment who have stated that these institutional systems and processes, “make us feel silenced, confused and sometimes angry” (Butterwick & Dawson, 2005). Butterwick and Dawson (2005) are only describing work the

¹²⁶ Field notes- departmental meetings on funding and HRC funding and panel review processes. Those who sat on panels at these meetings and those of our informants who sat on panels have described this aspect of panel review. This is of course not discussed at HRC roadshow meetings.

neoliberal university structure. I have presented here a specific view of the health research structure including researchers who sit outside of the university; the practices of research within the university influences those outside of it. Researchers outside academia must compete for limited funding on criteria established by those within academia and government. Using these experiences of informants, along with institutional texts and discourses, I now aim to “understand the exercise of power and the maintenance of hierarchies of privilege and subordination” within the research system (Butterwick & Dawson, 2005).

This chapter has repeatedly alluded to the way in which researchers as actors in the system generate knowledge and evidence. As explained in Chapter 1, the use of the term evidence signals the designation given to this word by Sackett et al., (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) as information of a certain kind, based on narrowly defined robustness. Knowledge has been used to denote information generated by research practices seen as less robust and beginning with a specified viewpoint or perspective.¹²⁷ It is argued that neoliberal policies that have pushed for a knowledge economy (Department of Labour, n.d.) and fostered managerialism within the health and university system, alongside a traditionally biomedically focused health research system and this has created a specific environment. A knowledge economy is one that shifts its focus from production to information. It is an economy that relies on the value of information and ideas and their trade, rather than manufacturing and products. Managerialism is an ideology that propounds that anything managers can manage any system (no matter how specific or complex) according to good management principles rather than any specific specialist knowledge of an area. Managerialism removes the power from workers, society, specialists, and so on and places all power in a management class, who run all organisations on principles related to efficiency and standardisation. Marketisation is when something previously provided as a public good becomes open to market principles, such as supply and demand. These three factors combined, the knowledge economy, managerialism and marketisation, create an environment in which measurement, standardisation, efficiency and economic value

¹²⁷ Evidence is now used in more than the evidence-based medicine domain and so is broader than Sackett’s original definition, but arguably still denotes a certain kind of information. Evidence generating research rarely discusses perspective or viewpoint and this will be discussed further in Chapter 5.

are paramount. This is an environment that preferences certain information generating activities, excluding and diminishing those that do not fit the marketisation of education, health, and research itself. This environment and its effects on information gathering are the ruling relations of health research in NZ. These ruling relations create the situation of precarity, silencing, and burnout discussed above, and our informants try to manage this environment through relationships (with peers, decision-makers, and their communities/populations) and practice flexibility.

4.4.1. Knowledge Economy, Marketisation, and Managerialism in Health and Education

The New Zealand Education Act of 1989 which sets out the role and definition of universities, is typically Humboldtian in its description (Ministry of Education, 1989). Part of the Humboldtian ideal of the university, described by Humboldt in the late 19th century, was that of autonomy from the state despite receiving state funding (Habermas & Blazek, 1987).¹²⁸ The legislation sets forth the following characteristics as those a University should have:

- (i) they are primarily concerned with more advanced learning, the principal aim being to develop intellectual independence*
- (ii) their research and teaching are closely interdependent and most of their teaching is done by people who are active in advancing knowledge:*
- (iii) they meet international standards of research and teaching:*
- (iv) they are a repository of knowledge and expertise:*
- (v) they accept a role as critic and conscience of society; and*
- (b) that—*
 - (iii) a university is characterised by a wide diversity of teaching and research, especially at a higher level, that maintains, advances, disseminates, and assists the application of, knowledge, develops intellectual independence, and promotes community learning (Ministry of Education, 1989)¹²⁹*

On the website for New Zealand Universities created in 2012, the following is appended to this section of the Education Act:

¹²⁸ His model also included a holistic conception of education across disciplines and a unity between research and teaching within the institution.

¹²⁹ Points (b-i, b-ii and b-iv referred to other educational institutions)

*“Universities are a vital part of modern society and are important not just for teaching but also for research and the development of society as a whole. As centres of research excellence they play an important role in **economic transformation and development**”¹³⁰.* (Universities New Zealand - Te Pōkai Tara, n.d.)

This shift to include “economic transformation and development” is arguably attributable to reforms in New Zealand which began in the late 1990s/early 2000s and persisted for the remainder of the decade. At the end of the 1990s, politicians argued that to transform the economy, New Zealand required a better-qualified populace (Shore, 2010a, 2010b). Reforms were put in place (by a then Labour party government) to facilitate increased access to university education to a larger proportion of the population (Shore, 2010a, 2010b) to achieve this better-educated society. This opening of access began New Zealand’s ‘knowledge society’. A knowledge society is one where knowledge is shared/dispersed throughout the society, the system flattens the previous hierarchy of knowers. A knowledge society is necessary for a knowledge economy, as workers are no longer the creators of things, but of ideas (David & Foray, 2002). During this period the university maintained relative autonomy, but on the pretext that the allotment of extra funding would ensure more New Zealanders gained access to undergraduate education (Shore, 2010a, 2010b). Outside the university, society witnessed an erosion of New Zealand’s Keynesian welfare state¹³¹ in the early 1980s in response to the emergence of free market economics. Education largely managed to remain unscathed (in the 80s, early 90s) but eventually also came under the purview of neoliberal policies which had become mainstream and normalised (Shore, 2010a, 2010b). The knowledge society moved to a “knowledge economy” along with international trends, and in 2008 a new National government came into power (Department of Labour, n.d.; Shore, 2010a, 2010b). The knowledge economy focused on highly skilled production and occupations (rather than low skilled

¹³⁰ My emphasis.

¹³¹ New Zealand is often referred to as the birthplace of the welfare state. The country chose to follow a Keynesian model (mixed model of private/government intervention with more of the later in times of recession) and implemented a socially democratic model that include state housing, welfare, public education and the like. This continued up until mid-80s when a Labour government began to advance the neoliberal agenda (Kelsey, 2015).

manufacturing or agriculture) and relied on universities to produce both skilled staff and innovation (Department of Labour, n.d.; Olsen & Peters, 2005). Within this environment, the emphasis was on courses with clear employment outcomes, efforts focused on the commercialisation of research, and an auditing culture repeatedly reviewing performance and value-for-money was introduced (Department of Labour, n.d.; Olsen & Peters, 2005; Shore, 2010a, 2010b). Thus, the marketization of the University.

Examples of this marketization within universities are their innovation centres (all universities in our list Appendix C-1 had these centres). These centres represent concentrated infrastructure, staffing, and resources, aimed at creating economic benefit from university-led research and innovation. Consider the University of Otago's "Innovation Centre." It is self-described as a resource for "commercialisation of intellectual property"¹³². Auckland University's "Uniservices" describes itself as a "matchmaker" between researchers and companies.¹³³ The innovation pages at Massey University are a lone exception in that they make comprehensive reference to outputs other than (international) commercialisation (although these are most prominent), listing projects that include the well-being of refugees and children living in higher socioeconomic deprivation.¹³⁴ The University Commercialisation Offices of New Zealand (UCONZ) further support these innovation centres by bringing the centres together with industry partners both nationally and internationally to build relationships.¹³⁵

NZ university websites, reference support services, funding, and metrics, for innovations that lead to economic benefits. None have centres or clear support structures for engaging with the community or addressing inequalities.

The relationship between the university and the local community is visible only insofar as some universities have student-led volunteer groups, publicly accessible seminars, or outreach activities that take place in a community for future student recruitment or placement. The term disadvantage appears concerning the recruiting

¹³² See: <http://www.otago.ac.nz/centre-for-innovation/index.html>

¹³³ See: <http://www.uniservices.co.nz/>

¹³⁴ See: http://www.massey.ac.nz/massey/initiatives/innovation/areas-of-interest/areas-of-interest_home.cfm (Health and Well-being and Society are those of interest).

¹³⁵ <http://www.universitiesnz.ac.nz/why-universities-matter/commercialisation>

of, and supporting of, students from disadvantaged communities (identified as Māori or Pasifika). However, the latter is also to some degree an economic strategy given that higher Māori and Pasifika enrollment and success rates result in higher levels of funding from the Tertiary Education Commission.¹³⁶ Some individual departments within institutions may develop community connections and outreach activities, but these relationships are established based on staff champions, rather than through university mandate. While university strategies and mission statements may make reference to communities, dedicated resources are not allotted to the same extent (if at all) in the way that they are for “innovation” or not so that it is easily identifiable.

Governmental emphasis on a knowledge economy has led to a change in the universities’ funding mix. This funding mix between government (40%) and external sources (remaining 60% a mixture of student fees, research income, and trading)¹³⁷ means that the university has less secure financial foundations and ones that are arguably open to easier privatisation. This funding dynamic also means that knowledge production within academia is now more dependent on economic drivers that determine student enrollment (i.e. student uptake falls for courses that do not lead to work within the knowledge economy) and government priorities for research and innovation. There is an erosion of this ideal of independent institutions positioned outside of the state and the market for the benefit of society put forward by Humboldt and articulated in Haldane principle.¹³⁸ There is still some evidence of university staff fulfilling their role as “critic and conscience” of society when they speak out on alcohol and smoking regulation, climate change, the Trans-Pacific Partnership Agreement or other government policies. However, there are arguments in the literature and on university campuses that a certain risk adverseness to playing the role of government critic is growing within tertiary education as governments reduce funding (Bridgman, 2007; Harland, Tidswell, Everett, Hale, & Pickering, 2010).

¹³⁶ See: <http://www.tec.govt.nz/Funding/Fund-finder/Equity-Funding/Funding-Requirements-and-Rates/> Limited funding is also available for students with disabilities but this is far less than that provided for Māori or Pasifika students.

¹³⁷ See: <http://www.universitiesnz.ac.nz/nz-university-system>

¹³⁸ Separation of government interests from University autonomy in research decisions – academic freedom

One way that neoliberal policies enact this power over universities is performance measurement and a focus on instrumentalism (Ashcroft, 2006; Bridgman, 2007; Cupples & Pawson, 2012; Harland et al., 2010; S. Wright et al., 2015).

4.4.1.1. Metrics & Excellence

Marketisation refers to the application of market principles to typically, non-market-based institutions (Reiners, 2014). The marketisation of the university arises through the creation of competition in an environment of scarce resources (Brown, 2011; Reiners, 2014). Managerialism reinforces this marketisation in the University, much like in the marketised NZ health system. It manifests in the introduction of private sector practices into the public sector (Teelken, 2012), practices that are target-driven and business-orientated. There are more and repeated bureaucratic and administrative tasks. These tasks ensure the quantification and measurement of performance and output (Brown, 2011; Reiners, 2014; Teelken, 2012).

Performance measures are, at best, simplistic. Such measures zero in on easily measurable outputs. At worst, they focus on the international and commercial (Wright et al., 2015). All of these metrics place our informants at a disadvantage, especially those whose work focuses on the local, the complex (regarding measurement) and the transformative for minorities within society. A continuing thread traceable in government documentation related to research, both within the health sector and university sector, is its status as ‘world class’. In New Zealand, the Performance-Based Research Fund (PBRF) aims to assess research quality and impact based on the submission of individual researcher portfolios within departments at universities and polytechnics on a six-year cycle.¹³⁹ The measure “world-class” is evident in New Zealand’s research performance exercise (PBRF), but also in health research strategy documentation (Ministry of Health, 2016), in the HRC documentation¹⁴⁰, and individual university strategy documents which naturally align with those of external funders and auditors. An obvious example of

¹³⁹ The Performance Based Research Fund is much like exercises in Australia (ERA) and the UK (REF), it is an auditing exercise to allocate funding based on performance measures around research.

¹⁴⁰ The HRC’s Research to Action report from 2015 is particularly interesting (<http://www.hrc.govt.nz/sites/default/files/Research%20to%20Action%20-%20HRC%20IIR%202015.pdf>) but other documents including their Annual Reports and current documentation around the “Strategic Refresh” they are undergoing are of interest.

what the government emphasises is in the HRC Annual Report of 2015. The outcome measures, on which the HRC had to report to government for the year were:

- Outcome 1: New knowledge, solutions, and innovations are created for health
- Outcome 2: The health system is improved through research evidence and innovation
- Outcome 3: The best clinicians and researchers are attracted, supported, and retained within New Zealand
- Outcome 4: The impact, responsiveness, and uptake of health research is increased (Health Research Council, 2015).

A quick search of the document finds 12 references to commercial benefits/outputs, 22 references to economic growth, revenue, or savings and just one reference to inequities (no mention of vulnerable populations, inequalities or disadvantage). The document discusses Māori and Pasifika populations and workforces throughout, and as previously mentioned there are specific funding streams and career awards for these populations from the HRC, but Māori and Pasifika communities are not the only ones suffering health inequities in NZ. The reduction of inequities is not a prevalent discussion within the documentation of the main funder of health research in NZ with the task of funding research that benefits NZ society (Health Research Council, n.d.). Of the four specific priorities the report outlines for the HRC dictated by the Minister of Health, two are mostly focused on innovation and economic gain (Health Research Council, 2015).¹⁴¹

A marketised university requires efficiency in production to be successful within the market. Researchers working with disadvantaged populations undertake projects that affect small groups, take a long-term view, and produce little revenue. Researchers working with minority populations may link with international researchers, publish in international journals, speak at international conferences, and the like, but those journals have lower impact factors and the communities they link with internationally are much like their local ones, small and marginalised

¹⁴¹ The other two focus on translation of research into practice and research workforce development.

within their local system. Research evaluation exercises and the environment of competition support more biomedical and laboratory-based sciences (Lõhkivi et al., 2013; S. Wright et al., 2015). Evaluation favours biomedical/lab-based work because research that is formulaic (has clear rules and standards) is more easily measurable, and scrutinised (Lõhkivi et al., 2013).

Research that is iterative, that uses community-based practice methods, participatory action research frameworks, or health research that utilises sociological methods with non-traditional paradigms for quantitative methods are not as easily evaluated. The continual audit/performance processes in an environment of competition can distort the research endeavour; academics within the institution assimilate their practice to the “path of least resistance” that will more easily get published, funded, cited (Karmaeva, 2016; Lund, 2012). To state this more directly, the perception (and reality) of what is likely to get funded and published, changes what research is put forward for publication and funding. The informants spoke of a level of pragmatism in “playing the game” to be able to sustain activity. Interestingly, they also indicated that they often perform acts of subversion. This subversion was doing what was necessary to be funded or approved, then using the resources in the way that would satisfy the needs within their community work. During the question period of a recent conference presentation¹⁴² about empowerment for health promotion, a discussion ensued regarding the contradiction of utilising deficit discourse to gain access to funding. How can this be reconciled to empowerment approaches that were the purpose of seeking funding? A researcher confidently opined that in her country (from the Global North), funders are aware that what researchers write in a grant application and what work the research team *actually* undertakes in a severely disadvantaged community, were two different things. The implication was that everyone was happy as long they could tick their boxes – i.e. the researcher could achieve outcomes that she and the community felt were meaningful, and the funder could tick off that they had funded research in line with the measures against which they reviewed applications.

¹⁴² “A proactive model for empowering women for health promotion: Utilising Anne Donchin’s pluralistic approach to women’s empowerment.” Carol Quinn, *Feminist Approaches to Bioethics 2016*, Edinburgh

It was also clear from informants that relationships and stakeholder engagement were key to their work and meaningful outcomes. These kinds of activities, however, are difficult to quantify and so are not recognised in performance measures. The lack of support for relationships and community building means that a researcher that values this kind of interaction for their work (and in fact, sees it as crucial), must rely on the benevolence of their department to allow time for this, or must do it outside of their employment time. Furthermore, any researchers who subscribe to a philosophy of collaborative partnership or co-production¹⁴³ in their research practice, find this almost impossible to do within a university setting. Co-production is the shared ownership of a project and its outcomes, and yet no process within the health research system allows for, or supports this, not funding, ethics review, or publishing. For reasons of research governance, each project must have a primary investigator. For purposes of publication and funding, each project must designate a primary author or primary investigator. The language used in most processes does not allow for a team philosophy or co-ownership.¹⁴⁴

In summary, the marketization of the university has created an environment in which funding is scarce; managerialism is rampant, and continuing performance measurement exercises are the norm. The impact of research is not measured robustly beyond funding and international recognition (based on publication and citation metrics). For this group of researchers, this meant that they were in a competitive environment, in which many of the measures of success were stacked against them. Impact especially was incongruent with their setting. For our informants, the impact was at the community level or the policy level. The Performance-Based Research Fund (PBRF) does not recognise this kind of impact in a way that equates with the impact other researchers may have. Efforts in NZ have been made in the continual editing of the PBRF criteria to acknowledge broader forms of impact, but they remain second rate measures. The lack of broader impact

¹⁴³ These kind of research practices see partners in the community as co-investigator or team members; for co-production especially, systems and processes are difficult as this model wants to remove the hierarchy of team members, i.e. everyone contributes, no-one is a leader.

¹⁴⁴ Researchers can have a team philosophy regardless, but much work then needs to be done with the co-producer to explain that processes require something, that is at odds with the philosophy being used.

measures is partly because these types of impact are harder to measure, so they normally do not count as highly within assessments, nor do they contribute to performance measurement in general.

4.4.2. Biomedical Bias

Evidence-based medicine (EBM) has begun to influence all manner of domains: evidence-based practice, evidence-based decision-making, evidence-based nursing, evidence-based implementation, to name a few. This expansion from what was originally a clinical, epidemiological method that aimed to improve clinical decision-making (Chalmers, Dickersin, & Chalmers, 1992; Cochrane, 1989) to the foundation of decision-making across health, social services, education and policy is problematic.¹⁴⁵ This spread of EBM occurs in parallel with the rise of neoliberal policies that favour measurement and standardisation described above. As such, EBM is the perfect tool for the job. EBM within the health system allows a clear focus on efficiency and standardisation. The majority of work done by our informants was not ranked highly within an EBM hierarchy of evidence.

EBM and a biomedical focus are not the same thing but they are closely related. Both privilege reductivist views of causality and health (Dowd, 2011; Solomon, 2006, 2015; Vandenbroucke, Broadbent, & Pearce, 2016) The biopsychosocial model, Te Whare Tapa Whā¹⁴⁶, patient-centered care, and other such resources have been introduced over time to allow a greater depth of understanding of health. However, while they are taught in medical curricula and referenced in government documentation, there are those that question to what degree they are understood and practised, again a kind of tokenism is seen (Bechtel & Ness, 2010; Bensing, 2000; Berwick, 2009; Kreindler, 2015).

¹⁴⁵ In New Zealand, the Ministry of Social Development now uses randomised controlled trial methodologies for social welfare interventions in order to generate best evidence prior to making decisions. In some cases the trial design has been questioned (application of EBM principles without, methodological know-how) Their “Early Start” project or “Project K” available from their website are examples: <https://msd.govt.nz/>

¹⁴⁶ One of the Māori models of health that <http://www.health.govt.nz/our-work/populations/Māori-health/Māori-health-models/Māori-health-models-te-whare-tapa-wha>

A biomedical and EBM bias in the health and health research system can be seen most strikingly in its documentation that both explicitly and implicitly directs readers or applicants to what the systems consider more valid. An example of this is the Health and Disability Ethics Committees discussed earlier in this chapter. These ethics committees refer applicants to two sets of guidelines, one specifically for “intervention studies,” and one for “observational studies, which includes audits and other related activities” (NEAC, 2012a, 2012b). The guidelines only mention qualitative methods once:

While these Guidelines may be useful for investigators conducting other forms of non-intervention study, such as qualitative and social science research, note that those studies use distinct methods that may raise separate ethical issues.”

“They may raise separate ethical issues”, but the document does not state where researchers can find guidance on what these issues might be or how committees and researchers should handle them. Nor is any mention made of non-biomedical research methods within the health setting. In 2012, the NZ government began a reform of the HDECs due to the perception that NZ was not providing a welcoming environment for clinical trials and therefore losing out on an important source of revenue. It was at this time that the government cut certain forms of research from the review process.¹⁴⁷ This narrowing of the HDEC remit for ethical review meant that those organisations conducting health research outside of the university who lack their own ethics committee, and who are not funded by the HRC and not classified as clinical/observational research, have no recourse for ethical review. Also, in devising the online application system, the format and content of questions and permissions focus almost solely on the biomedical.¹⁴⁸ These changes have a

¹⁴⁷ Interestingly the submissions for the Parliamentary review were mixed between pharmaceutical companies, university health researchers (of varying types) and concerned citizens. Their concerns were around processing time, but their suggestion was that review was robust, but resourcing insufficient (this from commercial and university submitters). Ambiguity around Māori consultation processes were raised and problems with projects that required multiple committee approvals. Changes that were implemented did not clearly map to these concerns: the narrowing of the scope of the committee, an electronic submission process, narrowing of committee membership, and shortening of processing time, as well as an explicit removal of review of scientific validity, and formal ethical process for accessing New Zealand bloodspot cards for secondary research. (Tolich & Smith, 2015)

¹⁴⁸ Even though some qualitative work can be reviewed by an ethics committee, filling in the application form would constantly reinforce that their kind of work is not the norm for the committee.

silencing effect; it sends a message to those conducting certain types of research about what their value is in the system.

Application forms (ethics, funding) in many settings are not flexibly designed to accommodate different kinds of research. By this, I mean, that while there are spaces within these forms for researchers to describe their work, explanatory notes provided are biomedically-focussed, or section headings align with biomedical practice rather than other more mixed or iterative practices. Iterative practices especially are disadvantaged in a system that does not deal with flexibility. This lack of flexibility can be directly connected back to managerialism – auditing, bureaucracy, and the like require conformity to pre-established standards and ideals for system efficiency.

This emphasis on the biomedical, the evidence-based, the commercial or economically beneficial, naturally disadvantages those looking at marginalised populations because the issues for these populations are largely not biomedical. Instead, the issues are social and complex. The methods to address these kinds of issues are rarely RCTs. The interventions researchers working with marginalised populations create, are unlikely to generate commercial revenue. Some interventions might be more clinical (pharmaceutical, medical), but most will fall within issues of access, intervention or delivery.

Not only are the marginalised disadvantaged through circumstances in society, but research that would improve their situations is itself marginalised by systems that approve, fund, and use research and its outcomes.

4. 5. Summary

Institutional ethnographic practice in New Zealand is rare and while work exploring the effects of neoliberalism and performance measurement on the academy (and more specifically women) exists (Cupples & Pawson, 2012; Lõhkivi et al., 2013;

London et al., 2012; Reay, 2000; Reiners, 2014; Shore, 2010a; Teelken, 2012; Wylie, 2011) my work here extends these analyses to understand how the health research system works for researchers that affect health inequity.

More specifically, in this chapter, I described the ruling relations of health research for those working with marginalised populations and their experiences. The tensions of support and stress from the communities informants work with, and the organisations they work for are distinct. Informants enjoyed their work and gained satisfaction from it. For many, their work as a researcher expands to advocate and champion for the populations they serve. The burden of this role is evident in the barriers that these researchers overcome and address when conducting research within systems that neither privilege their population of interest or recognise their questions (and the means of answering them) as valid or important research practice. These systems are a part of the ruling relations that, within a neoliberal framework, direct academic pursuits towards the free market with a biomedical bias. There is a commodification of research (and teaching) as processes of product creation for economic benefit within a knowledge economy.

Teaching has not been part of this enquiry because not all informants were within tertiary institutions. The knowledge economy commodifies teaching through the valuing of courses that generate the most revenue and the devaluing of courses that conversely do not. The commodification of teaching impacts the informants by creating both some of the precarity they felt and some of the burnout (where teaching commitments add to their workload burden). It is also the case that given the premise of research informed teaching (that universities are mandated to address by legislation), that where diverse research is not occurring or is silenced, teaching becomes and is limited in what it conveys to students. Further work in this area is required.

Within this theory of the ruling relations, those working specifically with populations that suffer injustice, are themselves disadvantaged by not only focusing on a group that rarely leads to any form of economic benefit but a group that fails to participate in the neoliberal ideal of a self-regulating market that creates well-being for the self-interested individual. Also, the constant emphasis on the biomedical

and evidence-based health research practices fail as epistemologies to address the full scope of health knowledge and as such fail to address all health research questions, specifically those pertaining to the marginalised and disadvantaged.

I posit that this failing is an epistemic injustice for the researchers working with marginalised populations, insofar as their knowledge and knowledge practices are devalued or silenced within the larger health research system. This original application of epistemic injustice will be explored further in the next chapter where I discuss conflicting epistemological frameworks.

Chapter 5: Epistemic injustice, research practice, evidence and decision-making

"A wise man proportions his belief to the evidence."
David Hume

"Scientific standards themselves are always already actively politically engaged, whether or not those who support and follow such standards intend the particular politics that the standards promote."
Sandra Harding

The previous chapter finished with the claim that epistemic injustice occurs for researchers working with marginalised populations (and the populations themselves). This chapter must now explore this assertion. To that end, I explain epistemic injustice, an unfair dismissal or failure to recognise certain knowers and certain types of knowledge as valid using measures of rational authority and credibility (Fricker, 1998). I link this in part to the research environment which is dominated by a biomedical bias and evidence-based standards (Chapter 4). Evidence-based medicine (EBM) has become the status-quo model for decision-making across health services and health policy settings.

The history and rationale of EBM are explained, including the hierarchy of evidence. The hierarchy of evidence is used to evaluate and classify information. I explain the assumptions that underpin this evaluation and some critiques of EBM, are put forward. Based on the findings of Chapter 2 and 4, I then make the novel claim that our health research environment and the dominant EBM framework create epistemic injustice for marginalised population researchers. This injustice is achieved by denying researchers working with marginalised populations rational authority and credibility. I explain that this occurs through the concepts of objectivity and generalisability used in the health research environment. I conclude by considering possible solutions to this problem of epistemic injustice.

5.1. What is epistemic injustice?

Miranda Fricker explains epistemic injustice as a dismissal of or failure to recognise certain "knowers and knowledges" enacted through social power of either agents or structures, passively or actively (Fricker, 2007). There is a here an epistemic injustice for both the marginalised population and for the researchers who work

with marginalised populations. Epistemic injustice could be said to occur for marginalised populations in that their cultural, or social, or gendered¹⁴⁹ experiences and needs are missing from the dominant discourse of health and largely ignored in considerations regarding health. They are, in other words, invisible. Fricker calls this a hermeneutic injustice (Fricker, 2007). A hermeneutical injustice is one of communication, where a person/group lacks access to a significant part of their social experiences, because of socially dominant ways of interpreting and communicating (Fricker, 2007; Medina, 2012).

Therefore, in undertaking research that focuses on experiences and conditions that the dominant health research culture does not recognise as significant or different from those of the general population, marginalised population researchers start from a point that is already deemed less valuable within that dominant discourse.

However, the discussion in this chapter focuses on the direct dismissal of knowledge generated by researchers working with marginalised populations rather than the hermeneutic injustice experienced by the populations themselves. For an epistemic injustice to occur at the level of knowledge creators or knowers¹⁵⁰, one has first to understand that the definition of knower is someone who possesses both rational authority (competence and trustworthiness) and credibility (ability to be believed to have rational authority)(Fricker, 1998). Rational authority is recognised when we consider the knower to be someone who tells the truth (trustworthiness) and has the right way of determining it (competence); credibility occurs when we recognise that a knower has rational authority based on socially determined characteristics or consistent external confirmation of knowledge claims (Fricker, 1998).

5.1.1. Epistemic injustice within the Aotearoa New Zealand health research environment

The research environment as a structure enacts social power that discredits both aspects of rational authority and credibility required for a marginalised population researcher to be a knower. In Chapter 4, marginalised population researchers

¹⁴⁹ This could be any axis of potential discrimination or marginalisation and as mentioned earlier can also be the intersection of multiple axes of discrimination or marginalisation.

¹⁵⁰ Fricker calls these informants, but given our use of informants in Chapter 5 in line with the ethnographic method, it was felt that using an alternative term would be clearer.

appeared to have differing perspectives from other health researchers and/or methodologies and pay attention to different phenomena in the world. They may, for example, use a traditional quantitative method, but apply it to mapping the social causes of phenomena, where the dominant framework is focussed on the behaviour of individuals. Alternatively, they may have a 'traditional' perspective of the individual but use 'non-traditional' methodologies, such as participatory action research. They may have both a 'non-traditional' perspective and methodology. The fact that they are delineated here as 'non-traditional', and this conveys a shared understanding to the reader evidences a certain dominance of perspective within the health research environment. These interests, perspectives, and methodologies are either altogether dismissed, or ranked lower within the health research knowledge environment that currently exists. Their dismissal is partly created by the privileging of "objective" priorities and perspectives in health knowledge creation, and also partly due to the "positivistic" standard by which we assess healthcare research methodologies.

Within the academic environment, given the forces described in Chapter 4, there is a tendency to favour research that generates either government interest, international acclaim or has a commercial output/economic benefit. As was explained in Chapter 4, researchers working with marginalised populations conduct a range of research using qualitative, quantitative, and mixed methods. Their work ranged from small, interventional studies to larger descriptive studies, observational studies, including various exploratory and theoretical research; all focused on distinct and small populations. Research of this type does not generate commercial outcomes (it may generate economic outcomes, i.e. cost savings, but these are often comparatively small). Research of this type rarely attracts international acclaim and when it does, it is generally within a small international community dedicated to an equally small and specific area. Government interest is mixed (as described below). Therefore, the work of marginalised population researchers, with the knowledge they create, is less valued and less valuable within the greater health research environment. Researchers working with marginalised populations create work that fails to conform to the standards of evidence and value

that exist in the system.¹⁵¹ They fail to meet these standards in part because of the perspectives they start from (credibility/rational authority), in part based on the devaluing of methods they use (rational authority), and in part based on the greater systems lack of interest in their topics and populations (credibility).

5.1.2. Epistemic injustice within the government evidence environment

Government research use is applied. It has a purpose and therefore must meet criteria to qualify as a specific kind of information. Sometimes research is commissioned by the government to fill an information gap; sometimes governments use research information already in existence and sift it through an evidence evaluation framework to use that which fills their information gap.¹⁵² The government health sector mostly uses evidence assessment frameworks adapted from evidence-based medicine's hierarchy of evidence (GRADE Working Group, n.d.) with a strong focus on RCTs.¹⁵³ It will become clear in this chapter that the work of our informants and other researchers working with marginalised populations is often outright ignored because it fails to meet the criteria established by evidence evaluation frameworks.

This dismissal of research completed with marginalised populations creates or contributes to the injustice of health inequity by excluding information relevant to those that decisions may apply to, failing to also address their needs.

5.1.3. Epistemic injustice and its relation to health inequity

As outlined in Chapter 1, health inequity is a complex phenomenon with many contributing factors, including the social determinants of health. The fact that the groups that suffer inequity are also the groups, least well represented in clinical trials and health research would seem to be a contributing factor given that information from these activities informs services, clinical guidelines, and policy, in an evidence-based decision-making environment (Chapter 2).

¹⁵¹ Biomedical knowledge that is patentable or in some way commercialisable is also valuable in the system, but the work done with marginalised populations is hardly ever this type of work.

¹⁵² Funding bodies value the kinds of research that are seen as valuable within the system. So research conducted outside of government interest is still to some degree aiming for these same standards (if not aiming for reputational impact or commercial output).

¹⁵³ As we saw in Chapter 3, the GRADE framework is often used – a tool that rates evidence robustness and relevance to question under consideration.

The disadvantages caused by invisibility in health research *minimally* have two negative aspects:

- 1) Issues of interest, clinical measures (from diagnostic trials for example.), well-being measures, quality of life measures, and the like may be less generalisable to you, i.e. the problems focussed on may not apply to you or are measured in a way that does not accurately address your need or context.
- 2) Research outcomes are less likely to apply to you – therefore the projected health outcomes are undetermined, i.e. they may be less successful, or not successful at all, and in some cases, they may be harmful.¹⁵⁴

Research used as a source of evidence for service and priority decision-making does not include work that is representative of issues within marginalised populations. This exclusion of certain work is in part due to the dominance of one perspective of health and the privileging of particular priorities and methodologies to explore health. The priorities, perspectives, and methodologies are described as “objective” and therefore fair. To explore this further, I now clarify terms.

5.2. Research, evidence and their evaluation

The terms “knowledge” and “evidence” have been used in very distinct ways within this thesis¹⁵⁵.

Knowledge and evidence are precise terms when used in the philosophical literature. Philosophy of Science, which is a philosophical branch that deals with the nature of truth and knowing, has a rich history of theories that attempt to designate these terms and their meanings.¹⁵⁶ This philosophical usage of the words is not quite how I am using them here. While my focus is epistemological: what counts as

¹⁵⁴ Remember in Chapter 3, one of the causes of injury for Pasifika peoples was adverse reaction to medication not resulting from misuse. It is just as plausible that service design or delivery evidence could be less applicable based on cultural issues or socio-economic issues, for example, where these were not considered in the research.

¹⁵⁵ In Chapter 1, we described this as a distinction between knowledge generated from research and evidence as it was defined by Sackett within the EBM framework, this is now made somewhat more clear.

¹⁵⁶ Philosophy of Science occupies itself with the definitions of science and knowledge and covers theories that are reductionist, positivist, constructionist, coherentist, etc.

knowledge, what counts as evidence; this only applies to the specific environment of health and health research. Rather than the weightier question of what are the requisite conditions to count anything in any context as being true or as knowledge. It is, therefore, important to make clear how I am using them in this chapter.

5.2.1. Definitions

In this specific context of the relationship between health research and health inequity, I am using “knowledge” to denote information generated by health research not classified as evidence.¹⁵⁷ Knowledge is “knowledge about” something. Knowledge can be produced using the full range of research methods about the full scope of health research topics. Information is classed as knowledge when created within the standards of the particular methodology used, i.e. there are different methodologies, but each provides a different kind of “knowledge about” something. Whether the information is knowledge or not is decided based on whether it adheres to internal standards within a given methodological framework. The community of knowers then accepts that framework as knowledge-producing.¹⁵⁸

Evidence is being used here as a term to denote that information classified as vigorously arrived at within the dominant evaluation framework, i.e. information arrived at in the *right* way to inform questions in a very specific way. Evidence is “evidence for” something (within this thesis). This evaluation of information predominantly measures methodologies against each other, rather measuring internal consistency within a methodological standard (i.e. this methodology provides better “evidence for” something than that one). Evaluation of methodological rigour for any given piece of evidence occurs after the evaluation of whether it is the right kind of methodology in the first place (i.e. we pick RCTs over case studies before we determine whether the RCT was well-conducted).

It is also important to note that “evidence” is evidence even if not yet used, i.e. something that would be evaluated highly within the epistemological framework is still “evidence for” even if not yet explicitly used within a decision-making exercise.

¹⁵⁷ Knowledge in its more traditional sense can be gained through experience or deduction, of course, but for the purposes of this chapter, it is being specified as above in the context of the health research environment.

¹⁵⁸ In effect within this thesis for the purpose of making distinctions between the information created by different kinds of researchers, I’m using the following system: evidence, is knowledge that is rated as valuable, knowledge is research/information that is rated as valid research, but not evidence.

Governments, academia, and industry generate evidence (Figure 19).

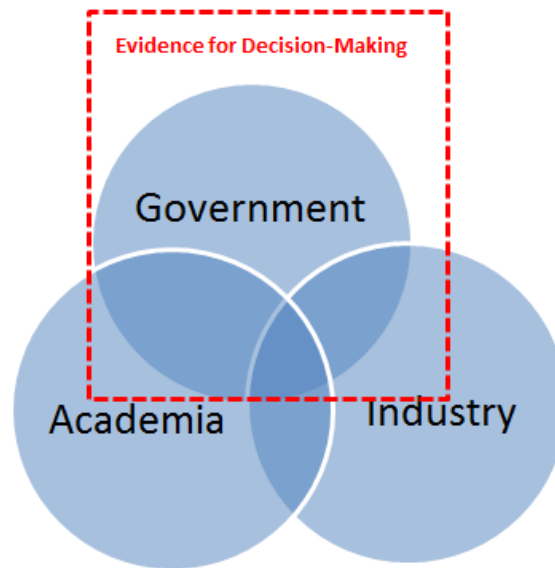


Figure 19 - Research Drivers & Evidence Sources¹⁵⁹

Evidence is used largely by governments for decision-making (based on the working definition within this chapter), but also of course by industry and academia for particular kinds of activities (for example product creation, product marketing, or research planning). The focus here is on evidence used by governments, nevertheless acknowledging that industry and academia have overlapping roles within these activities and all three are mutually influencing.

It is important to understand the how of “evidence-based” decision making whether for clinical guidelines, or in service, or policy design, to see how this affects knowledge generation. To do this, we must understand the emergence of evidence-based medicine, its original goals, how it is now employed, some contemporary critiques generally, and then more specifically regarding health inequity.

5.3. Why do we need evidence?

¹⁵⁹ Circles overlap unevenly as the relationships between these three entities are not balanced.

Decision-makers use evidence in multiple ways (Figure 20). Not only does it inform the question to be addressed (scoping of the problem), it helps set parameters, finding potential solutions and choosing between those solutions (Majone, 1989).

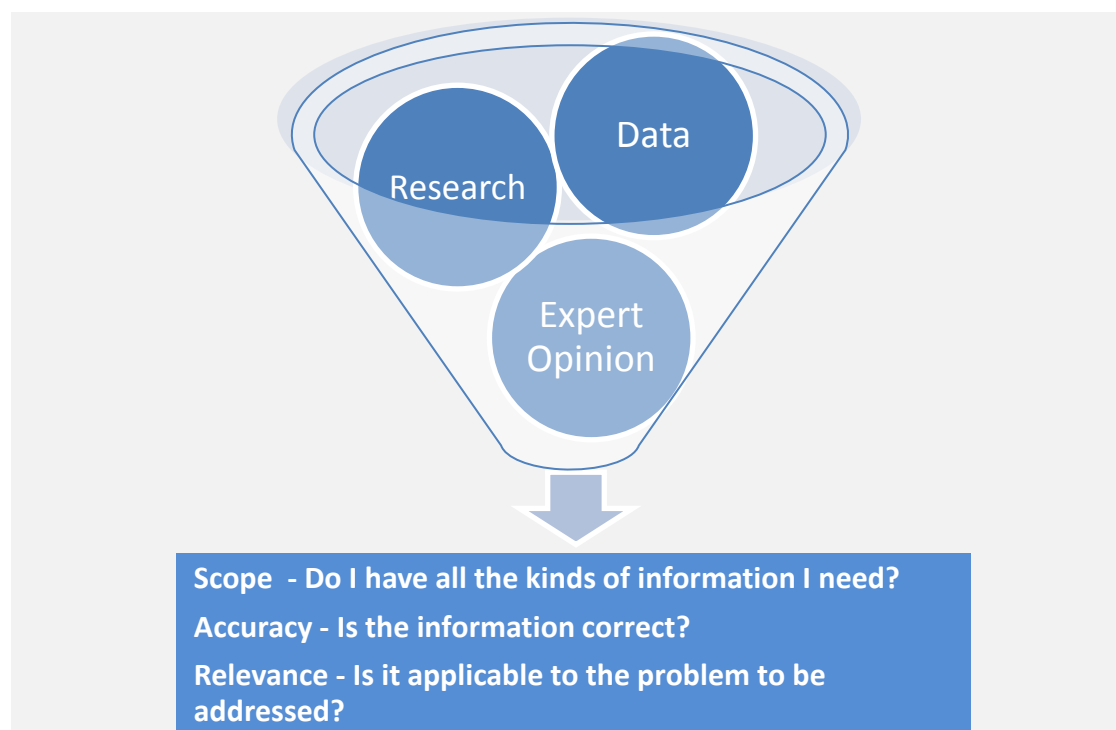


Figure 20 - Information for Decision-Making¹⁶⁰

Evidence in decision-making can come in many forms (Figure 20). Data is the data collected by government agencies or researchers in establishing the size of a problem (epidemiology) or the use/costs of services (cost-benefit analysis/cost-utility analysis). Various government organisations and services collect this data for purposes unrelated to a particular research problem (for example services record-keeping or the census). Although it *can* be created specifically to answer a question (national surveys, such as those for health or mental health), and then used by government agencies or researchers to quantify issues.

Research results provide a range of information, yet research that delivers “evidence” is ranked highest with regards to soundness (as explained in 5.4.3. below). Research can offer information that helps us understand a problem, as well

¹⁶⁰ This diagram represents decision-making at the policy and service design level not the patient-clinician level, where evidence-based decision-making specifically states that patient values be included (how they can be is not clear, and is discussed further in this chapter).

as showing the efficacy of potential solutions.¹⁶¹ Expert opinion is used in combination with data and research and is relied on more heavily where research evidence is lacking. Expert opinion provides a link between practice and theory (Baker, Lovell, & Harris, 2006; Majone, 1989; Orton, Lloyd-Williams, Taylor-Robinson, O’Flaherty, & Capewell, 2011) in an ideal setting. It is the accumulation of relevant experience and knowledge. What is important to all decision-making is whether or not these sources of information are comprehensive, accurate and relevant (Cartwright, Goldfinch, & Howick, 2009; Hunter et al., 2016; K. Oliver et al., 2014; Wye et al., 2015). Inequities in health research, evidence of which was found in Chapter 2, lead to inequities in decision-making (also found in Chapter 2), which in turn lead to policy, provision, and services that are not response to those that suffer health inequities.

In many government decision-making settings, not all the necessary information relevant to a problem or decision or a solution is available. Ideally, most of the questions one would want answers to are listed below (Table 15):

Table 15 - Information required for decision-making

- What is the size and nature of the problem?
 - How many people does it affect?
 - Which people does it affect?
 - How does it affect those people?
- What are the key contributing factors to the problem?
 - What are medical factors contributing to the problem?
 - Are there other factors contributing to the problem?
- What is the impact of the problem?
 - What is the impact on individuals and their families?
 - What is the impact on communities and society?
 - What is the impact on the health systems and services?
- What solutions can address the problem?
 - What can prevent the problem?

¹⁶¹ The distinction between efficacy and effectiveness is one of internal/external validity, i.e. something is efficacious if it is shown to work within a controlled environment, something is effective, if it has a high probability that it will work in the real world, based on evaluation or trials mimicking the real environment. Internal and external validity are described further in 5.4.4.

- What can treat the problem?
- Which solutions address the problem best considering all factors, where factors are:
 - biomedical,
 - individual acceptability,
 - social acceptability,
 - health system feasibility (financial, practical, political, etc.)?

All of this information must come from data, research, or expert opinion. The information sourced must be as complete as possible, relevant to the posed questions, and accurate to provide the best possible support for decision-making.¹⁶²

5.3.1. The Evaluation of Information

For the system to work, we need to know how to evaluate the cogency of information relevant to our questions. Current evaluations use a ranking system that assesses information based on one-dimension: accuracy. This system defines accuracy narrowly as the ability of a methodology to make valid claims about the cause and effect of a particular course of action. Decision-makers informally assess the completeness and relevancy in the picking-and-choosing of information (Cartwright et al., 2009; Majone, 1989). This evaluation applies across a range of decision-making but originated in EBM.

The argument for the use of evidence in decision-making is that it serves to increase fairness and efficiency by making decisions that are based on “objective” evidence to ensure best outcomes for given situations (Bluhm, 2005; Borgerson, 2009; Buetow, Upshur, Miles, & Loughlin, 2006; Timmermans & Mauck, 2005). The question is, however, whether the evidence determines the decision, and whether the evidence generated is truly objective. Both the assumption of objectivity and the assumed connection of objectivity to fairness are taken up in this chapter, but first an explanation of evidence-based medicine.

¹⁶² It is important to note here, that the literature is clear that best use of research in decision-making currently does not occur. What is important for the argument here however is not whether research is used optimally, but that the value of research is determined by the degree to which it is “useful” and for our researchers specifically the reference for usefulness is government decision-making.

5.4. What is evidence-based medicine & evidence-based decision-making?

5.4.1. What is it?

Evidence-based medicine is the evolution of clinical epidemiology, which came about in the late 1940s early 1950s (Burch, 2009). Post World War II, physicians on both sides of the Atlantic (Archibald Cochrane, UK (Cochrane, 1989) and Austin Bradford-Hill, USA (A. B. Hill, 1965)) were making efforts to make medical decisions dependent upon evidence rather than individual clinical experience, beliefs, or clinical judgement (Burch, 2009). These efforts led to the creation of the formal randomised controlled trial and called for a greater use of their results in decision-making. This work continued throughout the 1960s and 1970s in an environment where communicable diseases were the *raison d'être* of medical research. Evidence-based decision-making was introduced in the 1980s by Eddy to ensure that policy and guidelines were tied to appropriate evidence (Eddy, 2011). The term itself, however, arose at McMaster University in the early 1990s from a student of Daniel Sackett's (Rogers & Ballantyne, 2009; Sur & Dahm, 2011), although Sackett's definition is the most commonly known (from 1996):

Evidence-based medicine, (...), is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. (Sackett et al., 1996)

Sackett's definition did receive some criticisms for failing to consider other elements in decision-making and was later revised to include clinical expertise and patient values:

(...) a systematic approach to clinical problem-solving which allows the integration of the best available research evidence with clinical expertise and patient values. (Sackett, Richardson, Rosenberg, & Haynes, 2000)

5.4.2. What does it claim?

The reason EBM in part¹⁶³ became popular is that it resonates, i.e. the idea that matters of health should be decided by robustly gathered evidence rather than *mere* opinion, was attractive to many. It implied a level of fairness and objectivity that would nullify waste or discrimination – decisions could be made based on, *good, solid facts* (Rogers, 2004a; Sackett et al., 1996). Everyone, regardless of age, gender, sex, or colour, should receive the same treatment for the same condition, while equally, nobody ought to get a treatment that is ineffective (causing personal, public and financial costs). These were laudable goals. No discrimination, no waste, a system that guarantees fair and efficient healthcare.

The problem is that EBM oversells what it can deliver. The evaluative framework used does not necessarily fulfil its mandate and it is not clear that objectivity is by default fair. I investigate these assumptions further below, but first, it is necessary to explain some of the constituent parts of EBM and decision-making.

5.4.3. Hierarchy of Evidence

To determine what qualifies as “best available evidence”, EBM endorses a hierarchy of evidence. The hierarchy of evidence rests on the premises that not all evidence is equal and that some forms of evidence are more robust than others. Variance in robustness is due to the ability of a method to isolate a causal connection between the effect measured and the intervention, while simultaneously removing bias (Lewis & Warlow, 2004; Sibbald & Roland, 1998). The hierarchy moves up and down a range of methodologies. The least robust methods are at the base: basic science, expert opinion, case studies, and case series. Methods attributed to the peak are RCTs and meta-analyses/systematic reviews (Figure 21) (SUNY Downstate, n.d.). Systematic reviews and RCTs are rated the highest within this hierarchy, because proponents of EBM believe that these methodologies, when conducted properly, are robust enough to remove the likelihood of bias and confounding factors (for RCTs through practices such as randomisation and blinding and controlling for placebo-effect)(Lewis & Warlow, 2004; Sackett et al., 2000; Sibbald &

¹⁶³ EBM fits well with the overall managerialism in the health system discussed in Chapter 4. Benchmarking, auditing, standardisation, etc. occurs more readily in an environment with guidelines and prediction models. It is also fair to say that it was not broadly popular and accepted - clinicians objecting particularly to the prescription of decision-making.

Roland, 1998). Various statistical analyses are additionally used to minimise unwanted effects further.

The ranking (Figure 21) emerges clinically and in policy settings, as seen in Chapter 2 (e.g. the GRADE tool or similar adaptations conflate levels, but keep overall framework, i.e. A-D grades).

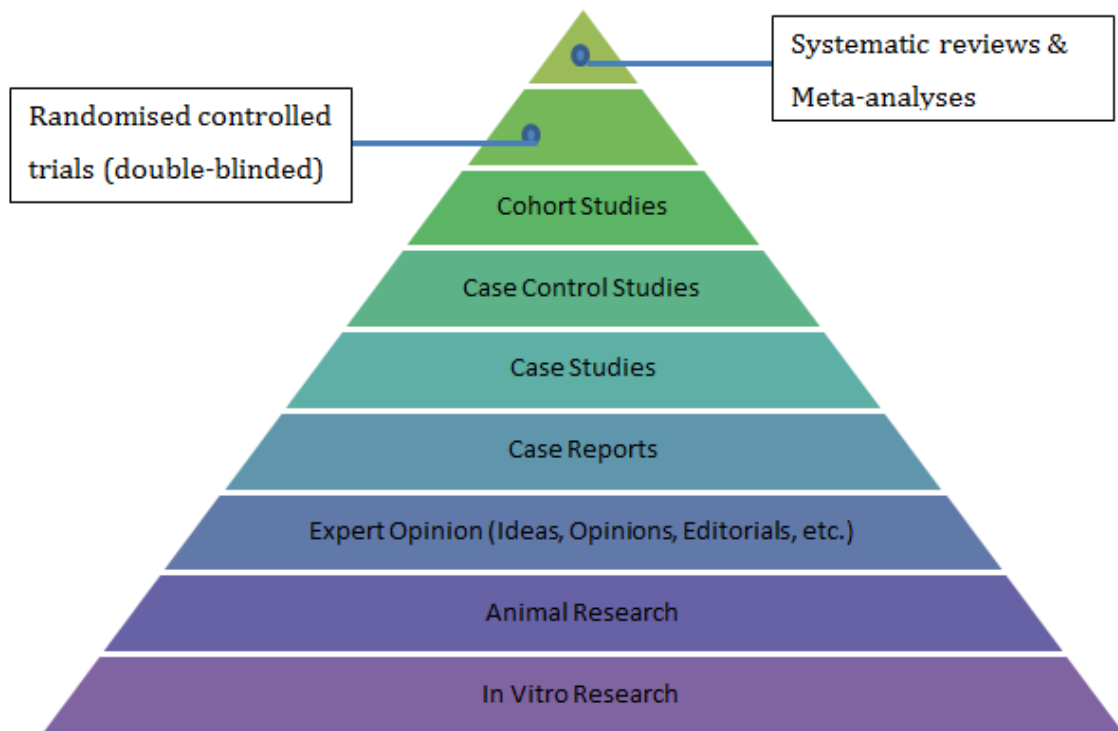


Figure 21 - Hierarchy of Evidence

5.4.4. Internal versus External Validity

Researchers are asked to pay attention to internal and external validity when conducting an RCT. Internal validity describes how accurately the trial can assess whether the cause and effect relationship between intervention and outcome is valid; external validity describes how well the trial can map to real life situations, i.e. be generalizable (Louis & Shapiro, 1983). As many confounding factors as possible and bias need to be removed from the trial protocol to improve internal validity. Researchers remove confounding factors and bias by using randomisation, blinding, and controlling as many of the conditions in which the trial operates as possible. Researchers may also consider excluding subjects who are likely to have other factors that will influence the outcome of the study. Improving external validity

requires almost the opposite strategy, as the truer the trial protocol maps to real world conditions and actual patients, the better. Good internal validity conveys high scientific rigour, whereas good external validity conveys high clinical applicability. Ideally, a trial should aim to get some form of equilibrium between internal and external validity, so that if the results are positive, statements can be made both about the effectiveness of the intervention (internal validity), as well as its applicability/acceptability in the real world (external validity). Where a trial does not reach a balance between internal validity and external validity, researchers should undertake successive trials moving from internal validity to external validity (i.e. later stages of Phase 1-5 research, (Portney & Watkins, 2015)). In other words, a researcher may begin with perfectly controlled conditions, and then move to RCTs in more “real-world” settings with the same intervention. To capture the “real-world” setting, researchers use such methods or analyses as Intention-to-Treat (analysis uses all participants’ data including those participants who withdrew or discontinued the trial) or pragmatic protocols (clinician researchers assigned participants to intervention arms or control arms based on participant characteristics, similar to clinical decision-making in the typical clinician-patient scenario).

When applying the evidence hierarchy, internal validity is taken above external validity, at least implicitly, during the assessment of methodologies. Those with less confounding factors are ranked higher than those with confounding factors, those things that make a trial more externally valid are often confounding. No extra work is done in the ranking level of trials to distinguish, for example, between two trials that are both conducted rigorously but with different degrees of external validity. Explanatory trials (higher degree of internal validity) are more prevalent than pragmatic trials (greater degree of external validity) in the literature (Borgerson, 2013; Schwartz & Lellouch, 2009). Prevalence of one type of validity over the other means that decision-making must rely on internally valid, but less externally valid evidence most of the time.

5.4.5. Generalisability

One of the claims of EBM is that gold standard RCTs produce generalizable evidence (Rothwell, 2005). If researchers undertake trials with sufficient samples and use

robust methods (i.e. blinding, randomisation.), then this means that the results of those trials will successfully transfer to the general public. Blinding removes investigator and participant bias; if neither the investigators nor the participants know which intervention the patients are receiving, then this piece of knowledge cannot have an effect on the intervention. Randomisation removes the ability of investigators to assign those more likely to show significant change within the trial to the intervention arm. Cohort size and characteristics (inclusion/exclusion criteria) are used to account for potential confounding factors based on participant variables.

With this in mind, it is not clear that the current assumptions of generalisability are in fact valid. I explore this further below (5.4.6.1).

5.4.6. Problems with Evidence-Based Frameworks

EBM and evidence-based decision-making is now widespread and mostly seen as “best practice” across many disciplines. Government agencies responsible for social welfare or education, for example, conduct RCTs when assessing new initiatives.¹⁶⁴ Third sector organisations incorporate these EBM-based methodologies in their justification for ongoing funding (Samson et al., 2015). The justification of dominant practices by way of evidence-based rhetoric attempts a sleight of hand. When we say something is evidence-based, it evokes the idea of objectivity (and fairness) derived from facts (seen as value neutral). Value is always seen as subjective, and therefore prone to prejudice and bias, whereas we treat facts (whether correctly or not) as immune to prejudice and bias (Douglas, 2007). However, despite intentions, EBM decision-making processes remain value-laden. The ruse of evidence-based rhetoric masks values that are embedded within this framework.

5.4.6.1. EBM & Evidence-Based Decision-Making – The Assumptions

The definition of EBM is laden with epistemological presuppositions and these are inextricable from the intentions of the model. In this section, these assumptions are shown to be problematic, but even if they were not, the definition itself still fails because of the difference between its conception and implementation.

¹⁶⁴ Ibid 135

Decision-makers in health source evidence from robustly conducted clinical trials or systematic reviews (an analysed collection of clinical trials). Decision-making also includes Cost-Benefit or Cost-Effectiveness Analyses (CBA/CEA). I focus here for now solely on evidence related to interventions (and therefore traditional EBM), because evidence regarding interventions is part of what is used in these kinds of economic analyses.¹⁶⁵ They are generally conducted using a mixture of government service or economic data and intervention evidence. A discussion about the measures of effectiveness or benefits, etc. will be included later in this chapter.

The information gained from a positive clinical trial rests on some key factors. In the clinical trial setting, a result is deemed to be positive when:

- a. A significant change is detected between the intervention group and the control group, where that significant change is determined by a difference in outcomes measures and decided to be a result of the intervention rather than mere chance (based on statistical probability).
 - i. The “power calculation” is a fundamental element of these statistical tools. It tells triallists the number of people required in each group to be able to establish a statistically significant difference between groups on the chosen outcome measure scale.
 - ii. A statistically significant change can be measured in multiple ways. It can be purely physical (the difference between anti-inflammatory markers pre- and post-intervention for example), clinical (difference in swelling pre- and post-intervention, for instance), or patient-focused (Minimally Important Clinical Difference (MICD) in pain, for example).
- b. Generalisability is the assumption that if a trial has the correct number of people in it then the results will be generalisable to the population. This is because the sample, by sheer numbers alone, will have a diversity of variables, that cannot be controlled for within the

¹⁶⁵ See New Zealand’s Treasury’s CBA worksheets for District Health Board use:
<http://www.treasury.govt.nz/publications/guidance/planning/costbenefitanalysis/cbax>

trial, meaning that a positive result should mostly translate to the diversity of variables present in the population.

- i. Sample size is where representation is considered (or not). For example, if as a researcher, I know that an equal number of men and women suffer from the condition I have an intervention for, then I should aim to recruit a proportionate sample of each within my trial cohort to be truly generalizable to the disease population (and conduct a subgroup analysis). Prevalent variables such as gender, or variables of interest such disease-related variables (blood pressure or BMI for example)) are controlled for and included in the analysis.

So a trial result is positive and reliable, where a researcher detects a significant clinical difference between intervention group and control group, based on robust design in a generalisable sample, where the researcher has considered relevant variables.

Decision-making using health research and clinical trial data is assumed to be fair because it does not take into account specific characteristics of trial participants; it is ostensibly fair because it is methodologically “blind”¹⁶⁶ to the differences in people. Paradoxically, this so-called blindness is precisely what is *unfair*. Full recognition of the disadvantages or complexities of some groups is necessary to provide them with good health outcomes, part of that begins with research. Not only that but this “blindness” is a myth - to say it is objective is to assume that representation was fair in the first place. If we consider the lack of representation of various minorities in trials then actually, trial data, baseline data, outcome data, all of it is far from objective¹⁶⁷, it is skewed and skewed to the dominant group in society. Outcome measures have been determined using skewed populations, not only for biomedical parameters but also when considering what outcomes to value (Berger et al., 2009; Graham, 1992; Heiat, Gross, & Krumholz, 2002; Pearce et al., 2004; Rogers, 2004b; Rogers & Ballantyne, 2009; Sharpe, 2002).

¹⁶⁶ “blind” is the terminology generally used within EBM and would not be a terminology I would use in other circumstances

¹⁶⁷ These non-objective measures once set are used within the health system and the research environment, compounding the problem.

5.4.6.1.1 Assumption 1: Evidence generation is objective

Objectivity is assumed a solution to different kinds of bias. First a counter to favouritism or prejudice in selecting priorities and second, a counter to bias in science, where those conducting research either consciously or unconsciously skew the results of a piece of work to their preferred outcome. These are two very different considerations. One concerns justice, while the second is an issue of best practices in research.

Objectivity, as a tool of justice at the deliberative level (what is a priority), is discussed further below (5.7.1.2. and in the next chapter). Here it is important to note, that values determine the various key factors of any given project. What kind of intervention is chosen to test, how it should be delivered, what an outcome is, how it is measured, are all questions that involve a particular perspective or position. Researchers are mainly designing evidence-generating activities in a biomedical setting with little input from patients, families, and communities. What we often refer to as the objective or neutral position, is, in fact, the tacitly accepted values and practices of a socially (i.e. morally) dominant group (Harding, 2006; Haslanger & Haslanger, 2012). When researchers in a socially dominant group talk about objectivity, they are talking about removing their personal preferences, not letting their emotions or feelings cloud their judgment. They are not talking about suspending their particular social position from influencing the decisions made during a given evidence-generating activity. It is this latter that would be truly objective, but arguably quite impossible (Haslanger & Haslanger, 2012). The only way therefore to be “neutral” is to consider and include multiple perspectives as a form of equalising any particular bias. Actions to remove this type of bias are not discussed, reviewed, or promoted within the EBM framework.¹⁶⁸

5.4.6.1.2. Assumption 2: Evidence is Generalisable

Generalisability is only assumed when trials meet certain requirements. These requirements are based largely on external validity measures (internal validity tests

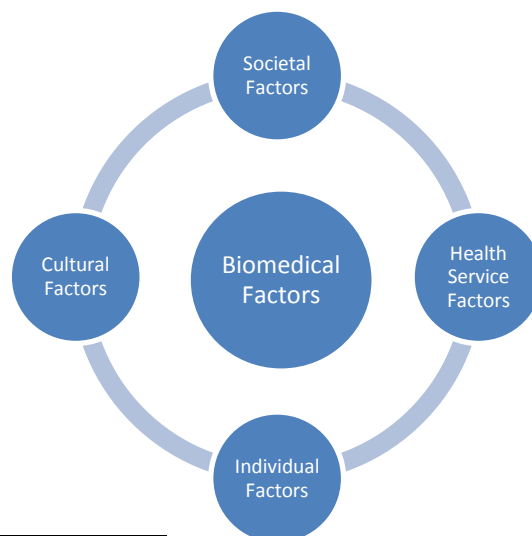
¹⁶⁸ It is discussed in evidence-based decision-making exercises to a degree through the inclusion of “lay people” or stakeholder groups in the process. However, there is no explicit recognition of this point, rather a softer recognition that people should be included in decisions that affect them (these people are not always very representative as is noted in Chapter 4).

tell us whether we can trust an outcome; external validity tells us whether it will work outside of the trial). It is generalizable if:

- The delivery method was similar or identical to that used in the clinical setting
- The sample was either appropriately sized or specific (sample included suitable subgroupings mirroring real-world disease population).

Literature (Graham, 1992; Heiat et al., 2002; Rogers, 2004b; Rogers & Ballantyne, 2009; Sharpe, 2002) and the work done in Chapter 2 indicates that researchers choose samples based on size to eliminate “noise” (noise, defined as interference from uncontrolled variables), rather than specifications based on disease-population (not that this does not also happen).

The underlying problem is the assumption that blindness to difference can solve matters of representation. In the current system, problems of diversity in the population for the outcome are solved by volume rather than degree, that is, large trial cohorts rather than specific trial cohorts. If we consider any one person, he or she has some factors that influence their health (Figure 22). Factors vary in the degree to which they affect health depending on the health problem¹⁶⁹ (in this Figure 22, they are broadly balanced, with the biomedical being somewhat bigger and central, as an example).



¹⁶⁹ Some health problems like appendicitis for example have very little influence from other factors, while others such as diabetes may have varying influences for multiple factors.

Figure 22 - Factors influencing health

Typically in a clinical trial, cohort numbers are used to overemphasise the factor of interest and to minimise the other factors (variables) (Figure 23). Considering the figure seen below, if the purpose of a trial is to intervene on, and measure a biomedical factor, by using a large cohort the central factor (biomedical) becomes more prominent, while the other factors– in theory – are thought to become less confounding (Figure 23).



Figure 23 - Factor of interest magnified within larger cohorts that dilute other factors

One issue here is that regardless of size, trial cohorts tend to be largely homogenous (Graham, 1992; Rogers, 2004a; Rogers & Ballantyne, 2009; Symonds et al., 2012). Furthermore, they also represent the “best of patients” insofar as people enrolling in trials are often more motivated with flexible circumstances (i.e. can fit trial visits in), which makes them more likely to successfully comply with intervention requirements than the group representing the general disease population. This phenomenon is not unrecognised (Blakely & Woodward, 1999; Phillips, 2003). The health research community is well aware that trial effects should be considered as

ideal with drop off expected in the 'general' population (Liang, 2007). What remains unconsidered is that the spread of "drop off" falls much more heavily on those who are already marginalised based on their heterogeneity, based on age, ethnicity, complexity, or disadvantage, because they are the least like the "generalizable" sample and have to account for more complexity.

The literature also shows that delivery methods used in trials are often unlike those used in the clinical setting. In fact, as was mentioned earlier, trial stages theoretically could move from internal to external validity to ensure generalisability to negate this issue. Phased testing of this kind moves from mechanistic disease/intervention understanding and testing, through to intervention/delivery testing. However, again literature would indicate that the majority of work done and funded in the clinical trials space prefers practices that test internal validity over those that test external validity (Schwartz & Lellouch, 2009).

The attention paid to internal validity over external validity is in part based on a reductionism that focuses solely on the intervention-outcome mechanism of a trial and nothing else. An RCT itself does not tell you, if you designed your intervention appropriately for the setting in which patients will later receive it. It does not tell you whether the intervention is acceptable to those who have the disease. It does not tell you why something worked or failed, neither biomedically or subjectively. In addition to ignoring all the factors that our informants deemed to be important (see Chapter 4), RCTs also ignore factors such as pathophysiological explanations (Ashcroft, 2004; Solomon, 2015).

In essence, RCTs ignore confounding factors to ensure that the results are "clean" because there is recognition that these factors play a part in outcomes, but no work is done to address these very factors when translating results to the real world, where they matter in achieving outcomes. Between the trial situation and the practice situation, there is an information gap regarding complexity (of situation, of patient, of system) that researchers and decision-makers are not addressing.

At present, policy-makers and health providers are expected to address this complexity gap in practice. The only recourse they have to do this is through experience (trial and error) and information-sharing (about trial and error). Little

research or evidence is provided to help them consider interventions in the contexts in which they may have to apply them.¹⁷⁰ The missing complexity might be, for instance, multi-morbidity, where the patient has multiple conditions at once, and various interventions for their conditions may be contraindicated or require careful management. It might be cultural: the patient has beliefs that mean the clinician cannot provide the intervention as designed in the trial in the same way. There are many variations of complexity than can be imagined, but it is apparent that marginalised groups will almost always include some variation of complexity based on their “difference” to the general population. The majority of researchers who work with marginalised populations recognise this essential complexity in their identification of problems, in their connection to communities when deciding courses of action, and in their selection of methods used to evince the best information within the given circumstances.

5.4.6.2. Critiques of EBM

Despite the influence of EBM, there are vocal opponents. Criticisms are either philosophical or practical. The former, take issue with either the hierarchy of evidence or the very way in which EBM is meant to influence decision-making at the clinical level, rejecting the dominance of evidence, over other considerations such as clinical expertise and patient values. The latter believe that within the current environment that entails high volumes of information (but with a narrow range) and poorly created information (through fraud, time/funding constraints, or incompetence), it is impossible to parse evidence usefully.

5.4.6.2.1. Philosophical Critiques

EBM works together with such things as prediction rules, or scoring tools, to create standardisation (Niessen, Grijseels, & Rutten, 2000; Pronovost et al., 2006; Timmermans & Berg, 2010). Standardisation implies fairness and consistency. Robust evidence leads to essential relationships: if x, then y. Thus, for *all* situations

¹⁷⁰ Some of course do exist.

of x, we will *always*, for all people do y.¹⁷¹ A counter-argument against this is that x is not always so very alike and therefore, “when y” will require more input. As noted earlier in this chapter, arguments for the incorporation of clinical expertise and patient values were made so forcefully, that they revised the definition of EBM.

Second, critics of EBM have pointed out that the clearest results come from the simplest trials, trials that ask simple questions within homogenous populations (Rogers & Ballantyne, 2009; Sharpe, 2002). A preference for simplicity returns us to our discussion of internal validity versus external validity but requires that we extend it. It is, therefore, better for those conducting trials to keep a trial simple, by paying more attention to internal validity than external validity since the latter requires the management of many confounding factors. It is also better to avoid multi-factorial solutions or questions in complex health conditions/contexts. This avoidance of complexity is because the ability to isolate a causal mechanism within a trial format is hindered significantly when either the cause (intervention) creates too much “noise,” or the environment in which the cause takes place is already too noisy. Remembering that, because EBM largely ignores pathophysiological (or other) reasoning (Ashcroft, 2004; Solomon, 2015), it has no way of assessing what might be influencing the cause-effect mechanism. It can only indicate when it has been successful, unsuccessful, or that the results are unclear. Some argue that this is why RCTs are entirely unsuitable for social interventions because social interventions are more likely to be multifactorial and in complex environments (Jackson & Waters, 2005; Rychetnik, Frommer, Hawe, & Shiell, 2002; Slowther, Ford, & Schofield, 2004).

Complexity either in the cause or the effect environment dilutes information in such a way as to make clear statements impossible. EBM, therefore, is a limited tool in creating evidence. Once again, it is clear that it fails to address complexity and it does this philosophically.¹⁷²

¹⁷¹ There are exceptions in practice based on the degree to which “y” is likely to be successful for a particular patient, in a particular situation at a given time – but this is not based on evidence.

¹⁷² There are other philosophical objections to EBM based on how it views both doctors and patients within the decision-making process, but these are not important to our discussion here at the level of research. For a selection of these views, please see (Buetow, Upshur, Miles, & Loughlin, 2006; Hay et al., 2008; Tonelli, 2006)

5.4.6.2.2. Practical Critiques

Clinical trials are very expensive because overseeing the provision of a new intervention and monitoring people receiving the intervention (or an alternative) requires a lot of resources. Resource constraints mean two things: first, trials run for shorter periods of time than would be ideal for assessing outcomes. Second, only trials that attract someone to fund the activity happen.

Industry and academia are the dominant players in clinical trial activity (governments, usually contract one or the other to do their trials). They are often carried out in environments that are time-poor and resource limited. Funding sources can create significant bias, not only in what work is chosen to be done but also in the outcomes reported from that work (Goldacre, 2012).

It is critical to draw attention to the “best available evidence” phrasing used in the definition of EBM. Most often, people discussing EBM focus on “best” in this definition. However, it is essential that we not to overlook “available.” Decision-makers, health professionals, and researchers are not able to review evidence for all options when ranking evidence that informs decision-making. Rather, pertinent are those options that have evidence and more accurately, published evidence. It can also be said, that within the ranking system, where we know of other interventions but have no highly ranked evidence, our final decision is unlikely to recommend that option.

Therefore, decision-making is dependent on a selection of positive evidence available in the literature on selection of interventions. Of course, no situation would exist where we have all the available evidence, for all possible options, on any particular topic. If we consider reports of *poor* research practices, and biased publishing (Bosch, 2014; Elliott, 2010; Fanelli, 2010; Fang, Steen, & Casadevall, 2012; Goldacre, 2012; Jones et al., 2013; Simes, 1986; Trinquart, Ioannidis, Chatellier, & Ravaud, 2014), then evidence-based decision-making starts to look much less robust given this informational base.¹⁷³

¹⁷³ Trial data fraud, post-trial outcome selection (i.e. secondary outcome if more significant), positive publication bias, etc. – these things come to light only when someone points them out, but with the

5.6. What are the alternatives?

What I have shown so far in the discussion of evidence is:

- a) The health research environment values research that either has an economic impact (through economic output or policy/service savings), has (international) reputational impact, or can be classified as evidence (for policy/service decision-making).
- b) Evidence in these situations is defined using the Evidence-Based-Medicine framework of ranking (the hierarchy of evidence).
- c) The hierarchy of evidence ranks methodologies against each other based on their ability to determine cause and effect for a given intervention.
- d) Evidence-based practices make claims to:
 - i. Objectivity, which I have argued, fails based on chosen topics of interest, and the tacit perspectives that influence the choice of interventions, measures, and outcomes.
 - ii. Generalisability, which I have argued fails, based on widespread practices of homogenous trial cohort recruitment (which is likely to be based on drivers in the research environment such as publication pressures, amongst others).
- e) Researchers working with marginalised population do not generate research classed as valuable because it is rarely of a commercial nature, lacks an international audience (impact), and is not classed as evidence.
 - i. Their work fails to be classed as evidence since it does not meet the standards of generalisability or objectivity.

Researchers working with marginalised populations suffer an epistemic injustice in that the model used for assessing research as evidence (largely) excludes their work. Their work is not valuable in the other ways available to researchers as described in Chapter 4 (commercial/economic or international value).¹⁷⁴ The epistemic injustice occurs because objectivity and generalisability establish rational authority within the health research environment, and researchers that do not

sheer volume of work being published now, discovery often lags behind, meaning decision-making activities can occur with faulty information without knowing it.

¹⁷⁴ Which can be the case for other researchers who do not generate “evidence” in this sense, if we think of geneticists or historians for example.

abide by the epistemic claims that structure this environment, fail to establish credibility.

Any evidence framework will need to recognise and address the complexity discussed thus far to amend this injustice.

5.7. Integrating complexity

Complexity describes the various factors associated with individuals that influence their ability to benefit from an intervention. Assessing issues of complexity include, but are not limited to, normative judgments. What you pay attention to, and how you pay attention to it, is based on what you think is the right thing to do - what is fair.

So what a researcher first chooses to research is itself a value judgment, and I discuss this further below. However, once a researcher decides what to research, other issues of justice arise. Complexity increases in the health research environment as you move from pilot work through to implementation and evaluation work (Figure 24).

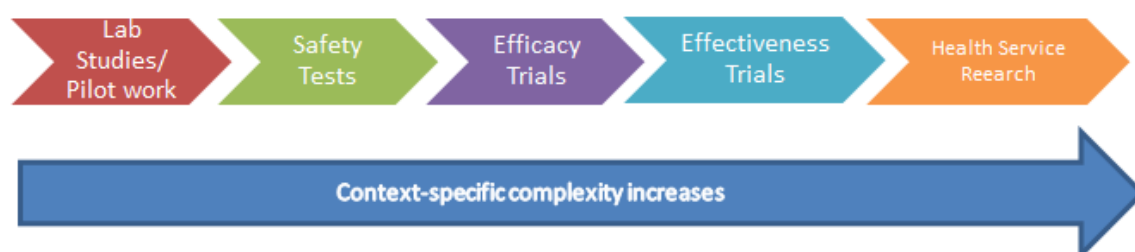


Figure 24 - Research stages and complexity

In Figure 24, the diagram uses stages that combine various other models that exist such as Phases 1-5 or Translational Research's staged model (Committee to Review the Clinical and Translational Science Awards Program at the National Center for Advancing Translational Sciences, 2013) to illustrate the pathway of research while indicating the degree of complexity along the pathway. Here interventions can be pharmaceutical or behavioural, where lab studies/pilot work are exploratory or safety tests that test the basic assumptions; efficacy trials test whether it works; effectiveness trials test whether it works in the real world setting and better/worse

than other interventions; and finally health service research covers a range of implementation and evaluation work happening both in the health system and the NGO setting relating to health and intervention outcomes, or service evaluation. Evidence can be generated at any given stage without completing all five; it is just evidence of a different kind. Community researchers would likely conflate these stages (i.e. 1&2 together, or 2&3 together) for the kind of work they do and it would be called different things at each stage.

In the current environment, complexity generally and specifically as it relates to marginalised populations is mostly considered outside of the research process. Complexity, if discussed at all, takes place during decision-making, at policy level, service level, or at the doctor-patient level (Figure 25)

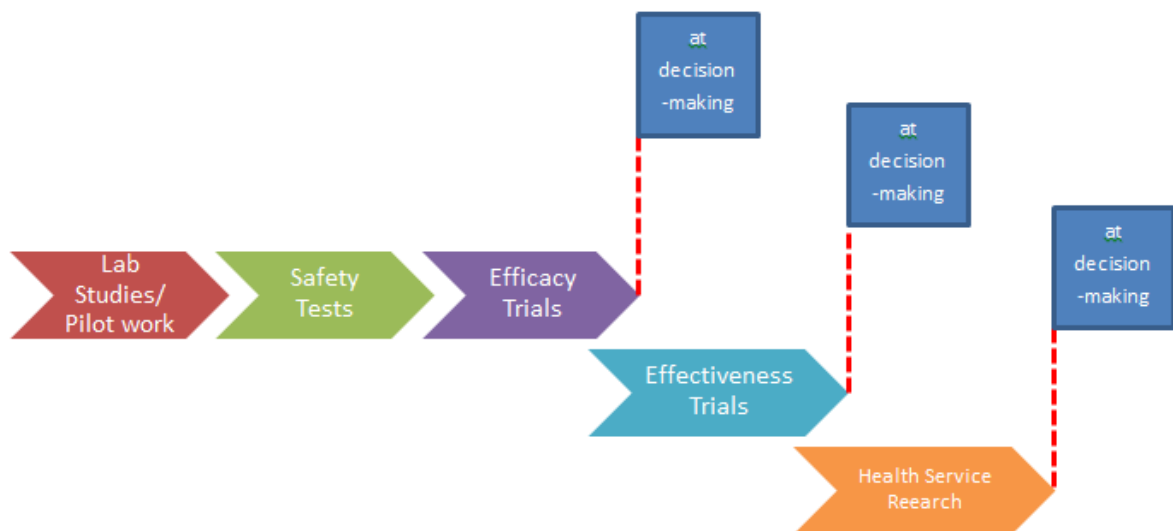


Figure 25 - Current practice for considering complexity

One way to add complexity into the research-evidence pathway is to incorporate it at critical stages. Adding complexity in this way includes recommendations to incorporate stakeholders or focus group input at design points of the research-to-evidence pathway to ensure appropriate decisions in both research design and delivery are made (Figure 26)(Greenhalgh, 2014).

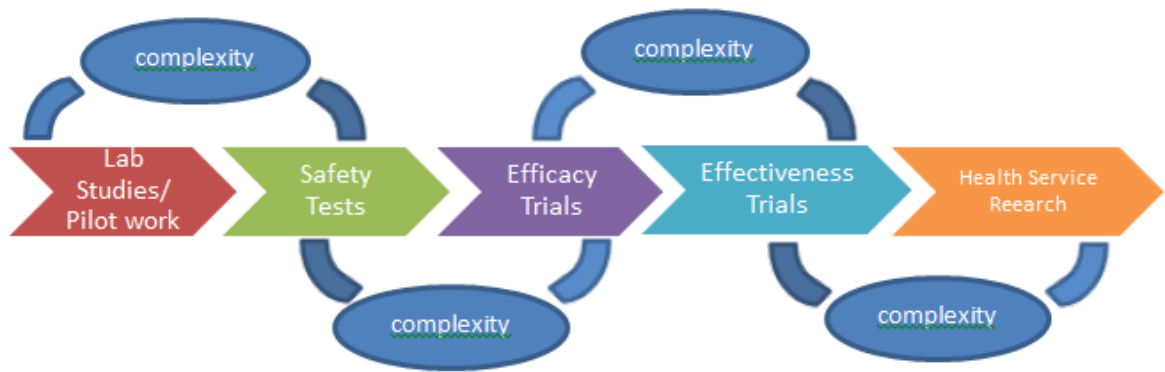


Figure 26 - Incorporating complexity

For the researchers interviewed in Chapter 4, the incorporation of complexity was unnecessary since it was entirely embedded. There was no separation, no critical points at which it could be considered since for them it was simply the process itself (Figure 27).

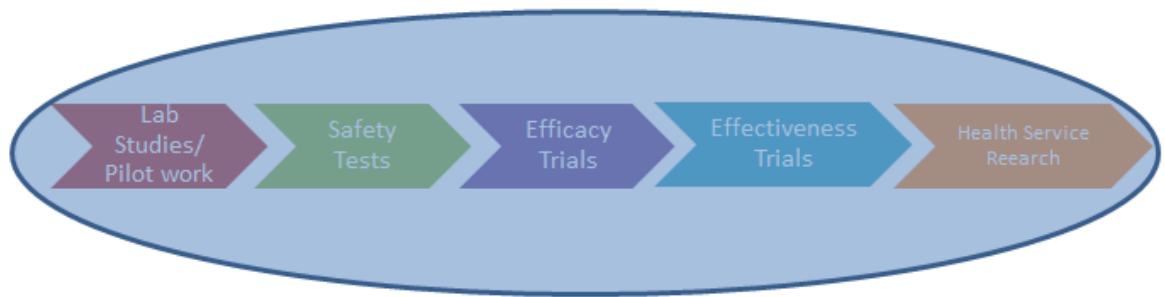


Figure 27 - Researchers working marginalised populations - Complexity and Research Practice

All of our informants in Chapter 4 practised research where their point of focus was always the marginalised group and how their position was affected by the larger system. This positioning was the case regardless of methodology or question, i.e. a researcher may have been investigating a very typical quantitative epidemiological question of cardiovascular disease-related death as an example, but the researcher did it from the position of a particular group, with an interest in bettering the situation for *that* group. The analysis was conducted considering the group's culture (i.e. does death at a certain age, mean something different than at another age for example) or world view, or socio-economic status, or any other important characteristic.

This paying attention needs to be more widely adopted for interventions to benefit those marginalised populations, but what does this require?

5.7.1. Change of Epistemology or Change of Values?

The proceeding sections have argued:

- Evidence *generation* includes values/bias
- Evidence *evaluation* includes values/bias
- These values/biases currently favour the majority and do not consider marginalised populations

Evidence-based decision-making is said to be fair because decisions are made based on the facts of the matter (evidence). If, however, as has been argued, the facts are heavily weighted in favour of one group over another, then this is the very opposite of fair. How do we resolve this issue? There are two potential ways of addressing it:

- 1) A shift in the evaluation framework – what we consider to be the right type of evidence (and means of generating it)
- 2) A shift in justice theory – what we consider is important and fair

5.7.1.1. Evidence

It is not clear that a total and fundamental epistemic shift is needed, such that everyone should conform to a feminist-inspired standpoint theory¹⁷⁵, for example (Harding, 1987). Rather the issue is one of deciding “what is evidence” within the health research environment, and that an epistemological pluralism could provide a more thorough picture in making decisions. To broaden our informational base, we require a different evaluation framework for evidence.

Some scholars have called for the hierarchy of evidence to be fundamentally revised. Walach has suggested a circular approach, that is, that there are multiple types of information required to decide whether an intervention both works and is appropriate (Walach, Falkenberg, Fønnebo, Lewith, & Jonas, 2006). Other suggestions include a web, again suggesting the connection of multiple

¹⁷⁵ that privileges the viewpoint of the oppressed in understanding power and social relations (Harding, 1987)

strands/kinds of evidence supporting each other (much like a Quinian web¹⁷⁶) (Bluhm, 2005; Sehon & Stanley, 2003). I agree with these calls for a broader inclusion of information types into the evidence definition to provide a better foundation for decision-making.

There are, however, two more things to consider:

- 1) Evaluation of research within its particular methodological framework
- 2) Evaluation of different research within a decision-making exercise.

The first point is a distinction made earlier in the chapter, namely that something can be knowledge only if it meets internal methodological standards. We must establish that a piece of work meets these standards before we can count that piece of work as evidence. The second point applies to the evaluation of knowledge as evidence within the decision-making setting. If we consider Table 16, certain kinds of information are more pertinent to different aspects of this list. It, therefore, makes much more sense to evaluate information about the question we are asking and the methodological rigour.

5.7.1.2. Justice

Theories of justice provide us with the means of establishing what we think is fair in providing and relating to our fellow humans. In health, what we believe is fair underpins all decision-making, insofar as we make decisions in line with beliefs about what is the “right” thing to do, and then direct our enquiries based on this.

Two things create injustice, as has been argued in this chapter:

- 1) What we consider evidence when decision-making¹⁷⁷
- 2) What we think is fair as the goal of decision-making

To change how we generate and evaluate evidence, I believe we have to change what we deem to be fair in the decision-making process. By doing this, the effects flow on to how we conduct research, based on what we then need to pay attention

¹⁷⁶ Quine argued for a holism in epistemology based on an ontological relativism – the web, meaning that each belief was dependent on others, no single belief of any kind being able to stand alone (Putnam, 2002).

¹⁷⁷ Where our evaluation framework to judge evidence always excludes information of a certain kind that pertains to a certain people/groups.

to in exploring issues. This shift in what we consider and how we measure fair is crucial to make change and a novel solution to a long-standing problem.

If we consider it necessary to improve the situation of disadvantaged/ marginalised populations in health, then the information we require for decision-making must incorporate appropriate evidence concerning these groups. To have these facts, we have to include them in our research processes.

To do this, a Capabilities Approach (CA), which focuses on the capabilities a person requires to achieve their desired functioning (Sen, 1992), explicitly opts for the very opposite of the blindness I have described here. It is a person-centered approach that values intrinsic goods (well-being and freedom) and uses democratic public deliberation to arrive at priorities (i.e. a set of capabilities) (discussed more fully in the next Chapter). By setting what capabilities are relevant and necessary and then ensuring that ALL people meet them, we can address the health research aspect of health inequities in two ways:

- 1) We can take stock on where inequities exist at a population level and set priorities accordingly (top-down approach) both for health services and research within a capabilities framework (much like the UN Health Development use of capabilities).
- 2) We can also deliberate on what capabilities are necessary to flourish within the health service context and then embed these capabilities not only in services but also in research processes. For example health literacy, self-advocacy (meant in its broadest sense to incorporate family/whānau), peer support perhaps. (Bottom-up approach)

What does this mean for health research and clinical trial research?

Evidence to inform decisions around health inequity will sometimes be of the clinical trial kind and sometimes be of methodologically different kind. Quantitative methods are a measure of magnitude, whether this is the size of an effect, the number of people or the rate of change, for example. Qualitative methods explore people's understandings/ opinions about/experiences of "something" so that researchers can better understand that "something". Both of these things are

necessary for addressing health issues. These methods are complementary, and questions roll from one to the other in dealing with an issue.

The epistemological paradigms within which they sit can also be varied. Whether one adopts a positivist paradigm or a social constructionist paradigm, reflects something about the knowledge you generate, but not whether you generated it appropriately. The information from different paradigms tells us different things about the world and can inform decision-making in various ways. It is, for example, not inconceivable to imagine a decision-making process regarding public health interventions for smoking that included biomedical evidence relating to the efficacy of a particular nicotine patch and a grounded theory approach to understanding teenage self-image in rural towns related to smoking. Both of these pieces of information from varying epistemological frameworks can provide useful information in deciding how to implement a nicotine patch intervention for teenagers in the rural setting. What counts in the assessment of whether that information is useful, whether we can say it *is* evidence, are the internal standards of the method rather than an external ranking of different methods against each other. We must tease apart the conflation of methodological rigour with objectivity associated with EBM.

Not only is a diversity of methods necessary, but also a diversity of research populations is required to make sure that we make decisions based on information that applies to the actual disease population. We cannot design interventions that work well amongst the disadvantaged if we do not include them in the research itself, as well as the discussions about what might work in the first place, not to mention what counts as “working” (i.e. measures of benefits and harms).

In the next chapter, we explore further how the capabilities approach might be used to direct our inquiries in a fairer manner to all groups within the population

5.8. Summary

In this chapter, I argued that evidence-based decision-making creates an epistemic injustice for marginalised population researchers and inadvertently disadvantages marginalised populations due to the privileging of an objective viewpoint considered fair, but blind to difference (and therefore varying need). I explained

that evidence-based decision-making promotes the idea of fairness based on objectivity and generalisability. Researchers working with marginalised populations are transparent about their values and their work is directed to a specific group, meaning that they do not meet the EBM measures of objectivity and generalisability and so are dismissed as knowers within the dominant culture. I then argued that EBM's definitions and standards related to objectivity and generalisability are inaccurate and rarely achieved in research that currently counts as evidence. From here I showed that there is a need to for appropriate information to feed into decision-making, for decision-making to be fair and that includes a recognition of complexity, which EBM practices fail to incorporate. Reform is therefore required.

Various forms of epistemologies can generate different kinds of evidence; I therefore argue rather than adopt a new epistemology across all evidence-based decision-making a change in focus through a theory of justice (Capabilities Approach) that requires an informational base more responsive to inequity for its evaluative space would allow a broader acceptance of evidence types and underpinning epistemological paradigms.

Chapter 6 – Justice Framework as a Horizon of Significance

*“It is manifest that the actual availability of information can affect the possibility of using specific moral approaches.”
Amartya Sen (Dewey Lectures, 1984)*

Sen’s point above lies at the heart of this thesis. The argument here has been that disadvantage is created by what information we pay attention to and use to make decisions. Information available in the health decision-making environment (from research and data) provides us with a limited base from which to make fair decisions. Therefore, people in the system make decisions with a certain moral approach¹⁷⁸, which the system further reinforces through information-gathering exercises, creating a mutually supporting narrow field of justice and inquiry. As such, the only way to reform the system is to explicitly reformulate what is fair, which requires a new informational base, thus driving the circular relationship between justice and evidence in the health research environment into a broader cycle.

In a system that focuses on a very distinct idea of evidence (as discussed in Chapter 5) and cost-benefit or cost-utility analyses, those who lack representation in either the evidence or analyses will necessarily lose out. The current decision-making system in New Zealand relies on ad hoc methods to address considerations of social value or justice. The majority of information considered in these decision-making exercises is clinical and/or economic in nature and fails to represent the complex picture of society accurately. It is poorly representative in two distinct ways: evidence of effectiveness is not generalizable to marginalised populations, but more importantly, measures of burden, risk, and benefit, are not generalizable to marginalised populations.

To understand why this is the case, first I explain some of the ways in which resources are distributed within NZ’s health system, how they reinforce what information is used to make resource decisions, and how decision-makers consider

¹⁷⁸ It is hard to say what comes first in this relationship, obviously when gathering information we do so with the intention of addressing something we find significant therefore we already start from a particular point of view, but what is clear, is that once the relationship between values/justice and information/evidence begins, it does create a somewhat mutually-reinforcing closed system.

health inequity or marginalised groups. I then make a distinctive move, by discussing informational bases and theories of justice that determine them. Sen (2009) articulated that all theories of justice rely on an evaluative space that requires an information base. That is, to weigh what is fair, first requires identification of the thing that is important to equalise or maximise (utility, primary goods, capabilities for example) and then requires information about how different actions will affect the thing of importance (Sen, 2009).

I introduce Sen's Capabilities Approach (CA) as a potential solution to this problem, including its key elements: intrinsic value (well-being and freedom), person-centeredness, and public deliberation; and its relationship to social choice theory (Sen, 1992). I then discuss what information would be necessary to implement a CA in the NZ system (stating that research is required to fill this gap) and what benefits this would have while outlining some possible limitations of this approach.

6.1. Decision-making for health inequity in NZ

Chapter 1 argued that New Zealand has committed itself to the goal of health equity and that the government has made some progress in reducing health disparities, especially within Māori communities. However, there is still considerable work to be done, some of which is currently being undone (Human Rights Commission NZ, n.d). Prioritisation decisions in health affect health inequity, not only through access to services but to the kinds of services prioritised and funded over others. Priorities in the health system directly change priorities in the research funding system. This connection is evident in research data regarding rheumatic fever and rheumatic heart disease discussed in Chapter 2. During 2006-2010, before a raised awareness of the impact of rheumatic fever on Māori communities (especially), there was a single research grant related to this disease awarded. In 2011, 2012, and 2013, there was one grant per year. While these figures may appear insignificant given rheumatic fever affects a small group of a minority population, moving from one grant in five years before national discussion of the issue up to one grant per year post-discussion is noteworthy.¹⁷⁹ Increased attention on rheumatic fever and its

¹⁷⁹ It is difficult to do this kind of analysis with other diseases that are less specifically focused, i.e. rheumatic fever is seen as a problem that largely affects Māori or Pasifika people. Other government

outcomes was not a result of decision-making processes (i.e. it did not become a priority through the ranking systems currently used) but was rather directly achieved through advocacy, as was emphasised earlier.

6.1.1. Health budget distribution

VoteHealth is the budget managed by New Zealand's Ministry of Health (provided by Treasury) to fund the country's health and disability services. The Treasury distributes this money to the Ministry of Health who distributes it further across the health system, including to PHARMAC¹⁸⁰, the twenty regional district health boards (DHBs)¹⁸¹, and national disability and maternity services. (Ministry of Health, n.d.-l). A description of the different ways the Ministry of Health distributes these funds is useful to understand what information the Ministry uses and what considerations it makes.

6.1.1.1. Allocation to District Health Boards and Primary Health Organisations

The Ministry of Health distributes funding to DHBs and Primary Health Organisations (PHOs) (who are responsible for subsidising primary care visits with a private GP) based on two different models, which both employ some of the same assumptions.

For DHBs, the "population-based funding formula" is used to distribute the health funding allocation to each DHB. This formula takes into account age, ethnicity, sex, NZ deprivation index, rurality and an adjustment for unmet need, all based on historical data (Ministry of Health, n.d.-i). Therefore, if the DHB has a greater degree of deprivation, rurality, populations that are ageing or diverse, it receives more funding because these factors correlate with a higher level of service need.

PHOs work on an enrolled capitation model. A capitation model distributes funds to primary healthcare practices based on the number of people enrolled at said

priorities remain relatively stable over blocks of time, and so picking out another example of this kind either for the wider population or for a specific minority is not possible.

¹⁸⁰ NZ's Pharmaceutical Management Agency – responsible for the funding/subsidising of various medications and some medical devices. It undertakes health technology assessments in deciding what should be funded and negotiates with pharmaceutical companies to get the best possible prices, to ensure the budget provides as much as possible. www.pharmac.govt.nz

¹⁸¹ District Health Boards are responsible for tertiary and secondary care, but also distribute funding to Primary Health Organisations who in turn distribute funding (based on a capitation formula) and support to private general practitioners providing primary care. District Health Boards also contract community services from private suppliers and non-governmental organisations.

practice. Therefore to receive subsidised primary care, people who live in NZ must register with a general practitioner of their choice.¹⁸² A patient is eligible to receive greater subsidies should they have a defined high need (determined at an appointment and applied for by the general practitioner to the PHO). The capitation formula is used by DHBs and their related PHOs to distribute money at the level of primary care for enrolled patients. This capitation formula distributes partly according to weighted demographics (age, sex, ethnicity, deprivation, rurality), some according to need (Higher-User, CarePlus (for multimorbidity)), and then further funding can be shared for health promotion activities (Ministry of Health, 2016b).¹⁸³ Explaining the capitation-based funding model, the Ministry explains weightings in the following:

In general, people need more care when they are very young and as they get older.

Women in their child-bearing years tend to need services more frequently than men.

The formula for calculating capitation payments takes into account the demographic make-up of the population (Ministry of Health, n.d.-b).

The weightings provide more for Māori and Pasifika patients, more for those living in social deprivation, and more still, for Māori or Pasifika living in higher social deprivation (an example below from the weighted allocations).

Table 16 - Services to Improve Access for High Need Groups (Ministry of Health, 2016b)

¹⁸² General practitioners are private and set their own fees, however these are generally similar between individual practices for purposes of competition in the market.

¹⁸³ There are additional capitation rates for children, certain management activities, and vaccine administration. (Ministry of Health, n.d.-c)

| Services to Improve Access | | Non High Use Health Card Holders | | | |
|----------------------------|--------|----------------------------------|--------------------------|-------------------------|--------------------------|
| | | Māori/Pacific | | Non Māori/Non Pacific | |
| Age Group | Gender | Deprivation deciles 1–8 | Deprivation deciles 9–10 | Deprivation deciles 1–8 | Deprivation deciles 9–10 |
| 00–04 | F | \$75.8232 | \$151.6460 | \$0.0000 | \$75.8232 |
| | M | \$79.8304 | \$159.6620 | \$0.0000 | \$79.8304 |
| 05–14 | F | \$23.9996 | \$48.0004 | \$0.0000 | \$23.9996 |
| | M | \$22.4648 | \$44.9292 | \$0.0000 | \$22.4648 |
| 15–24 | F | \$22.1460 | \$44.2916 | \$0.0000 | \$22.1460 |
| | M | \$12.1884 | \$24.3772 | \$0.0000 | \$12.1884 |
| 25–44 | F | \$19.4608 | \$38.9216 | \$0.0000 | \$19.4608 |
| | M | \$12.5796 | \$25.1596 | \$0.0000 | \$12.5796 |
| 45–64 | F | \$26.6548 | \$53.3104 | \$0.0000 | \$26.6548 |
| | M | \$19.9084 | \$39.8172 | \$0.0000 | \$19.9084 |
| 65+ | F | \$45.9344 | \$91.8696 | \$0.0000 | \$45.9344 |
| | M | \$39.6140 | \$79.2268 | \$0.0000 | \$39.6140 |

Health inequities are addressed at the highest level of resource allocation by demographic-stipulated need, i.e. subgroups within the population of a particular demographic ‘kind’ generally, suffer poorer health (or are more expensive – e.g. pregnant women). Therefore, a higher degree of funding is required to cover that population. The information used here is historical demographic data and historical service utilisation data.¹⁸⁴

6.1.1.2. Allocation decisions between services and interventions

Health technology assessments are the general tool by which governments decide whether it will be worthwhile to fund a particular service or intervention (what “worthwhile” means is discussed below). It also allows for a comparison of the relative merits and disadvantages of different kinds of interventions used for the same conditions. These prioritisation exercises use a mixture of need/benefit cost analysis or social value information. For example, PHARMAC, which is the most prominent agency making funding decisions in a formulated way,¹⁸⁵ has different

¹⁸⁴ Remembering that PHOs distribute money based on enrolled patients. Information about low-service users (for which there is some extra funding) is minimal and largely old.

¹⁸⁵ The National Health Committee referred to in Chapter 2 has been disestablished, this means that there is no centre of expertise in the MoH for HTA but rather that this is spread throughout the

types of criterion subjected to its considerations. PHARMAC lists its assessment criteria as clinical, economic and commercial ('Making funding decisions | PHARMAC', n.d.). The clinical criteria cover aspects related to the effectiveness of a drug, the evidence that exists to support it, the alternative options, and the size of the affected population. The economic criteria measure cost-benefit analysis type assessments using quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs).¹⁸⁶ "Commercial" refers to PHARMAC's ability to negotiate drug prices with large pharmaceutical companies on account of being a conduit for injecting pharmaceuticals into the health system (i.e. people can pay privately to have other medications in NZ, but PHARMAC provides all publically funded or subsidised medications). PHARMAC has also implemented something called "Factors for Consideration" which reference five distinct dimensions: need, health benefit, costs and savings, and suitability ('Making funding decisions | PHARMAC', n.d.). These are relatively self-explanatory, except suitability, which captures the non-clinical aspects of the medicine under consideration and what impacts it might have on outcomes.

Once a draft decision has been made on a drug (or device), PHARMAC posts this document on their website and allows a period of submissions from not only clinicians but also the general public. It is worth noting, however, that PHARMAC does not promote these publications widely, so unless there already exists a particular interest, through which one is aware that a consultation is open (i.e. by checking their webpage regularly), then it remains unlikely that these submissions will generate broad interest or response. Based on PHARMAC's website, the informational base that supports their decision-making is primarily demographic, service utilisation data, clinical research, and economic data.

6.1.1.3. Allocation decisions within a given service or intervention

Health providers make service allocation decisions also using cost-benefit analyses calculations. However they also use "clinical priority assessment criteria" for

ministry with differing departments either undertaking HTA independently or contracting private companies or academics to do this work.

¹⁸⁶ QALYs and DALYs are economic tools used to quantify burden of disease (mortality and morbidity) in a dollar amount based on quality of life measures and overall life expectancy. They are widely used, but philosophically contested in terms of the fairness of how they measure quality of life (Brock, 2004)

decision-making on a case-by-case basis where they have established a threshold to receive care (i.e. based on limitations of resourcing). These tools are developed nationally but not exclusively, as some regions create their own. They are intended to help public sector clinicians evaluate a patient for a particular type of intervention, such as surgery or fertility treatment, for instance. Clinicians and stakeholders decide the tool using a Delphi process,¹⁸⁷ and use five categories to determine priority scores: “pain, personal functional limitation, social limitation, potential to benefit from operation and consequences of delay” (Gillett, Peek, & Herbison, 2012). Each of these categories is weighted differently and has a variety of criteria to help determine the score. The users of the tool determine a threshold above which the intervention is offered, based on knowledge of what is possible with the resources available – i.e. it rations. The information used here is a mixture of service funding data, clinical expertise, including reference to the evidence-base, and some explicitly normative considerations around the social limitation. These tools have been criticised, not only for their rationing but because it fails to account for specialist bias when scoring a patient.¹⁸⁸ They also suffer access issues for those who are subject to health inequity (Dew et al., 2005; McLeod, Dew, et al., 2004; McLeod, Morgan, et al., 2004).

6.1.2. Information used in Health Resourcing Decisions

The above outlines what information is being used to make distribution decisions:

- 1) Need - based on population-level demographic data and retrospective health data
- 2) Clinical information – such as effectiveness and ability to benefit
- 3) Cost-effectiveness using estimated QALYs and DALYs referenced to NZ demographics and service use data
- 4) Social values – vaguely determined about the impact on family/communities (as seen in PHARMAC) or social limitations (as seen in CPAC).

¹⁸⁷ Some have included a consumer representative, but in the mid-2000s rather than use a Delphi method and discussion, CPACs were created using 1000minds (a software programme) where those taking part are asked to rank statements against each other in order to determine preferences/weightings. For more information, see: <https://www.1000minds.com/>

¹⁸⁸ That is, as a rationing tool, it can be used unfairly, as a surgeon can score one patient differently than another, even if their need is the same, based on preference, or what is called the “squeaky wheel” problem (some patients are better at complaining than others).

The limitations of information collection mean that these are the best measures we currently have to assess need and distribute funding appropriately (within the current framework). However, when we explicitly consider marginalised groups, it becomes apparent that the following problems emerge:

- 1) Service utilisation data – shown in Chapter 2 to be problematic based on use and accuracy of data; therefore is non-representative.
- 2) Clinical information is mostly prevalence and efficacy information based on research data, which again in Chapter 2, was seen to be non-representative
- 3) Cost-effectiveness data using QALYs and DALYs which have long been contested on their applicability to subgroups of the population – so non-representative¹⁸⁹
- 4) Social values are those of participating decision-makers, if decision-makers are not representative, then social values are unlikely to be.

These decision-making practices and their informational base focus on a fair distribution of goods (health services), or maximisation of clinical outcomes based on a distribution of goods (where health is determined by clinical predictions of benefit). It fails to consider the conversion of goods into actual well-being (i.e. the focus is on the distribution of goods or a form of utility).

I now explore how these practices relate to theories of justice, what informational bases different theories of justice have and the problem of goods conversion further.

6.2 Foci of current models

Sen argues that all theories of justice aim to equalise some factor of importance, whether it is primary goods, utility, or freedom. (Sen, 2011). The overarching theory of justice used within our health system is a distributive one (in a Rawlsian form (Rawls, 2001)), where the aim is to distribute goods fairly amongst all, taking into account the position of the worst off in allocating resources at the highest level (that is in distributing it across the entire system). The current system uses a modified

¹⁸⁹ Various work exists on this front considering equity, disability, etc., for a selection see: (Bevan & Hollinghurst, 2003; Brock, 2004; Chamberlain, 1985; Starfield, 2001)

or weak utilitarianism¹⁹⁰ combined with a distributive model when allocating limited access to resources at the lower level (that is within the system for specific services).¹⁹¹ Utilitarianism seeks to maximise utility for the majority in any given decision, where utility is often defined as a well-being or happiness. It is weak in this system because, in some cases, decisions take particular account of inequity in maximising utility (i.e. decision-makers may choose a slightly less maximising option if it improves equity, rather than just the option that maximises utility ideally).



Figure 28 - Points of Measurement & Distribution at Present

Neither of these foci (Figure 28) ensures well-being. For example, if the municipal council of a small, impoverished town could provide its citizens with seeds for vegetable growing, it might reasonably allocate larger families with more seeds. However, a family’s ability to grow vegetables and be nourished by them depends on a network of factors, such as land available to them, material resources required for nurturing the vegetables, time to tend to the vegetables, and basic levels of knowledge about vegetable growing. In principle, the distribution process was fair, as the council gave those with the greatest need more. This provision did not necessarily ensure well-being. Over time, families may psychologically adapt to being undernourished to the extent that they may well rate their well-being relatively well, despite being undernourished. Similarly, they might even report high well-being from receiving a significant amount of seeds, even though they are unable to use them for nourishment. Thus, this stark example highlights that, in

¹⁹⁰ Utilitarianism in this sense – greatest benefit to the greatest number based on QALYs/DALYs as measure of utility.

¹⁹¹ This discussion is limited to the distributive and utilitarian justice models as these are most pertinent in the NZ setting. While a libertarian/rights-based approach could also be justified, it is less clear how they factor in health decision-making beyond the fundamental provision of healthcare questions.

trying to distribute seeds based on distributive or utility measures, we still fail to address the problem of undernourishment and the effect had on a person's life.

Sen calls this a conversion problem (Sen, 1992, 1999). It is this space of conversion (i.e. receiving a "good" and converting it to well-being) that is the proper site for evaluation. Theories of justice that distribute resources "fairly" or maximise utility are not capable of capturing whether people are better off or ensuring those with the most need are better off.

6.3. What is the Capabilities Approach?

In the last section, I described the view of health and resource allocation as one focused on resources and utility. Attention was given to the way they fail to efficiently and justly address problems of both health and health inequity.

Here I describe the Capabilities Approach (CA) to resolve the issue of conversion by focusing on a person's capabilities to "achieve functionings they value and have reason to value" (Alkire, 2005). What is of particular importance in a CA is the focus on individuals, intrinsic goods (freedom and well-being) and public deliberation (in determining what capabilities are valuable) and the implications for the required informational base, which I will show links us back to Chapter 5 and the need for more diverse information.

6.3.1. Capabilities and Functioning

Capabilities are those things that we need to achieve valuable functionings. That is, capabilities are the factors required to turn a resource into functioning, where the desired functioning is one an individual values and has reason to value (Alkire, 2005; Robeyns, 2005; Sen, 1992, 1999). "Functionings" are things we want to do with our lives, whether it is to nourish ourselves or to read, or to be politically engaged, perhaps have a career. Sen and Alkire describe functionings as a capability set - like a menu that opens up possible functionings, from which I can then achieve those I desire (Alkire, 2005; Sen, 1992). Capabilities are functionings that people have real access to, and functionings are those they choose to achieve. Converting resources into functionings depends on factors that limit one's capabilities. These can be personal factors that are physiological or social in nature. For example, a valued functioning might be walking in the park. My capability to achieve that

functioning will depend on whether I am capable of walking very far, whether I live in a society where a female-identifying person can walk in the park, whether I have access to a park (i.e. it may have an entry fee, that is prohibitive for those on my income, or requires transport costs to get there). Sen's focus is on the real opportunities people have access to, not just the nominal opportunities they have access to (Sen, 1992). To take another example, I might live in a country with free Wi-Fi for all, but if I do not have access to a computer or smartphone, then the opportunity of Wi-Fi (and the further functionings this entails) is closed to me (Figure 29).

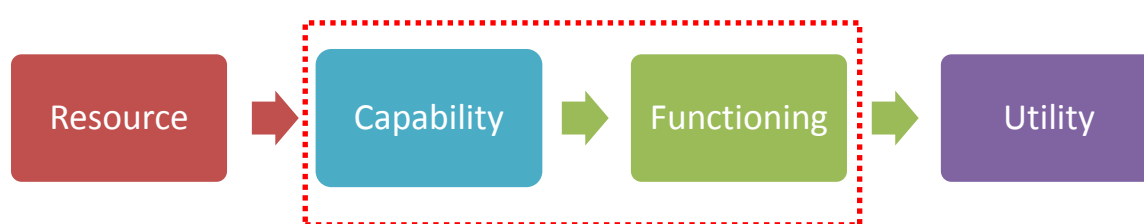


Figure 29 - Points of focus within CA for distribution

One of the unique things about the CA is that it combines well-being and agency, whereas utilitarianism focuses on well-being, and Rawls begins with agency as the starting point for the distributive model in determining the principles (Rawls, 2001; Robeyns, 2005; Sen, 1985).¹⁹² Sen argues that theories that focus only on one aspect i.e. well-being or agency, are missing relevant information (Sen, 1985, 2011). Both well-being and agency are important in determining whether someone is leading a good life (Sen, 1985, 2011).¹⁹³ Importantly, though, well-being and agency cannot be conflated. There are times when increased agency could negatively impact on well-being and vice-versa (Sen, 1985). Sen illustrates why well-being and agency are both important factors for assessing justice and equality if we consider two people who are starving, where one starves due to lack of access to food and the other due to religious commitment (Sen, 1985, 1992, 1999). The former is both lacking in well-being and has little opportunity to rectify it; he has diminished agency in what he can choose and achieve. The person starving for religious reasons

¹⁹² In Rawls "Original Position", rational beings objectively decide the principles of a fair society without knowing what position they may have in that society (Rawls, 2001)

¹⁹³ Sen sees freedom as both a factor of well-being or agency (i.e. you can have agency freedom or well-being freedom or both) (Sen, 1985)

has a different set of opportunities available to him despite his similar state of well-being. This difference between the two cases is important.

To then evaluate capabilities and opportunities people have access to, the functionings people have reason to value must be determined. For Sen, public discourse and democratic processes are used to decide these (Alkire & Black, 1997; Robeyns, 2006; Sen, 1992, 1999). Through consultative processes that determines what functionings are important to people, considering those who have access to the least functionings first, one can arrive at information required to make fair decisions. A real world example best illustrates this practice.

Burchardt and Vizard aimed to use a capability approach to monitor human rights in Britain (Burchardt & Vizard, 2011). To do this, they decided that four 'building blocks' were necessary:

- 1) they focussed on substantive freedoms and opportunities (i.e. those things people could actually do);
- 2) the evaluation had to include: functionings (what people were doing), treatment (what discrimination/challenges people faced in society), and autonomy (people's choice and control);
- 3) they disaggregated population data by subgroups to move away from the generic to the specific, and
- 4) through public consultation, they determined a capability list using the human rights framework as a starter for discussions (Burchardt & Vizard, 2011).

Through this, they have created a sophisticated evaluation matrix requiring a broad informational base (indicators determined through consultation) to conduct monitoring. Both the capabilities list and the indicators in assessments were informed by deliberative processes (Burchardt & Vizard, 2011), meaning criteria and measures are relevant and representational. Monitoring using CA is now being implemented to measure human rights in this instance; it requires ongoing research in refining metrics and seeking means to access the information needed. This project illustrates the need to create an entirely new informational base to use this particular evaluative framework. It also shows that to implement both the

framework and determine the base consultation is required. In making decisions between capabilities to prioritise there will necessarily be times where options come into conflict. It is, therefore, necessary to consider how decision-makers can resolve these.

6.3.2. Weighing up conflicts

Sen's CA uses Kenneth Arrow's Social Choice theory as a framework for combining various people's deliberatively decided capabilities into a collective decision for priority setting (Arrow, 2012). What this does is allow a ranking without specifications of weights, i.e. rather than saying this is valuable to this degree and we should weigh it accordingly, people stipulate that they prefer x, over y, and y over z for example. Different people may rank these in a variety of ways, but a collective decision based on rankings of compared options is possible without assigning specific weights to specific options. Preference ranking and compromise is counterintuitive to most of our current practices and the place where most people struggle with the CA in practice. Our society is set up on a social contract theory approach where much is seen as a zero-sum game: for someone to benefit someone has to lose out. An adversarial position, where someone has to lose out, does not necessarily have to be the case within a social choice theory framework, where people may agree through rankings of an outcome that they do not agree on directly.¹⁹⁴

For example, I might prefer apples to oranges and oranges over grapes. Judith may prefer oranges over grapes and grapes over apples. Moreover, Sally may like mangoes over oranges and oranges over grapes. We can provide everyone with oranges, and no-one specifically loses out, although Judith will be happier than Sally or I. This, of course, is a very basic example that does not take into account outcomes (i.e. what the various fruit achieves) or well-being at all and does not consider need. This example does illustrate that there is an option for improving everyone's situation through preference ranking rather than a distribution based on weightings of particular elements or factors against each other.

¹⁹⁴ Extensive work has been done by Jennifer Prah Ruger to outline how conflicts within these situations can be ameliorated using the incompletely theorised arguments approach. She shows that it is possible to combine conflicting preferences into a satisfactory solution (Ruger, 2010).

If we consider this in health, most discussions about redistribution of funding within the system focus on the fact that someone has to lose out. However, it is not clear that that has to be the case if we work within a capabilities model. It may be the case that some people do not receive additional benefits that they currently receive, while others begin to equal out, but it is not necessarily true that some people would be worse off. Designing and choosing interventions that work for the groups currently disadvantaged does not necessarily entail a lack of responsiveness to those for whom the current system is sufficient. It is also worth noting that the current system is not necessarily that responsive to the “general” public, but that due to the relative advantages they have access to they can overcome this lack of responsiveness. After all, trial cohorts do not map to the variety of people that make up the general population any more than they do to the people who are the focus here. As a woman in her late 30s, there would be little evidence that pertains to me in the system based on the literature referenced in Chapter 1, 2, and 5.

6.4. Capabilities Approach in Health and Health Research

So far we have discussed the CA in very broad terms. Often when used overseas, in developing countries, for example, it is used to focus on the very minimum of things required to achieve functioning, food, water, shelter, education, and so on.

Alternatively, as was shown in the example above, to evaluate a particular aspect of society. It is important now to focus on health and health research specifically.

If the assumption that the health research system influences the health system (and vice versa) is correct, then to implement a CA requires action in the health system as well as the health research system. Considering the health system first, if we were to use the CA as an evaluative framework in health in NZ, we would need to:

- 1) Establish a capability set of interest in health through deliberative practices, where these deliberations include membership more strongly weighted to those who currently suffer health inequity.¹⁹⁵
- 2) Take stock of the degree to which inequalities in this capability set exists (i.e. where are the gaps, how big are they) at present.
- 3) Devise measures for assessing and monitoring them.

¹⁹⁵ This is the high level capability set; it is conceivable that within different conditions or situations different capability sets will exist.

Implementing the CA would require better processes for public involvement and deliberation between the Ministry of Health and the populace. It also means that the priorities the Ministry of Health sets will be somewhat different, i.e. they focus first on equalising health for everyone and then on improving health beyond that.¹⁹⁶

There are two levels at which capabilities sets needs to be determined. Firstly, the set of capabilities (related to health) that are required to achieve functioning in everyday life. Secondly, the set of capabilities required to convert health services into health functionings. One addresses the overall relationship health has to well-being, the other addresses how people benefit from the health services that governments provide.

This first level: these are the capabilities needed to achieve functioning determined as being healthy – these may include mobility, or pain-free living, longevity, or quality of life. They could be any number of things, but this would need to be determined in public deliberation and mapped to conditions, i.e. if people see these things as most valuable, which conditions hinder them, which services support them, and how do we prioritise them. It is possible that the public deliberation would result in a similar set of priorities as currently exists, but these current priorities are not openly discussed and become contentious whenever the public contests a funding decision.¹⁹⁷ It is also possible that different groups within the population prioritise different things such as quality of life over longevity or vice versa, and some flexibility within the system for recognising that is necessary. The NZ population currently engages in these discussions on a case-by-case basis based on advocacy and the ability of a group to get attention for an issue. Completing, this process within CA framework would mean that the public have an open deliberation (and have ongoing input) facilitated by governments who then set priorities which were informed by these processes. Furthermore, in this type of CA process, the voices of those who currently suffer health inequity are explicitly

¹⁹⁶ This is somewhat controversial given the reference to neoliberal policies in the last chapter, but could be justified under the NZ Public Health and Disability Act (NZ Public Health & Disability Act, 2000)

¹⁹⁷ Examples of this can be seen in New Zealand around PHARMAC decisions for cancer drugs (Herceptin and Ecluzimab both caused public backlash) and surgery access.

considered in contrast to the present where the only input is from those who have well-developed voices in the civic and market square.

For the latter, i.e. the capabilities required to achieve functionings within a given health service type. One would imagine that such things as transport, health literacy, self-advocacy, cultural and religious recognition, and so on, may come up on this list, as those things that hinder a person's ability to convert a health intervention into a positive outcome. Once these are determined, however, they can be embedded in health services and in the design of new interventions that researchers investigate.

The informational base required to address these capabilities must be particularly responsive to those who have a capabilities deficit, i.e. current measures fail to capture much more than very basic differences between groups and the accuracy can be called into question (as was shown in 6.1.).

6.4.1. Health Research Priorities and Practice

Again there are two ways in which a CA framework affects health research. One is the needs of the health system for information to answer its questions, the redefining of the informational base described above. The second is in the actual practice and prioritisation of health research itself.

A CA focused health system would require a different informational base. This informational base would include some of the traditional elements, but would additionally need to understand what things people value and what things help them achieve the things they value.

For health research, this would mean there are three distinct domains of information required to proceed:

- 1) Capability preferences
- 2) Capability gaps
- 3) Interventions/supports/contexts that help people achieve capabilities

These will require different methodological approaches to determine them and will need close connections with people (and specifically people who suffer disadvantage) to set relevant frames of inquiry and measurement.

This connection to people is worth noting for other reasons. Both Māori, Pasifika and the disability movement have made strong calls for self-determination (Tino Rangatiratanga)(Bickenbach, 2013; Bishop, 1999; Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009; Field, Martin, Miller, Ward, & Wehmeyer, 1998; McDougall, Evans, & Baldwin, 2010; Smith, 2000). A CA allows this to occur through the stipulation of person-centered (and deliberated) valuable functionings and measures. Person-centered care is described as the goal for providing successful healthcare to people and a CA that explicitly promotes this would seem beneficial (Entwistle & Watt, 2013).

Another benefit of the CA is that it allows recognition of the various factors that constitute health capability, i.e. the social determinants of health. A CA opens broader avenues for investigation and supports the Health in All Policies approach promoted by the World Health Organization.¹⁹⁸

At the research prioritisation level, there is a requirement for more public involvement in decision-making. In part, this can come from prioritisation at the health service level, but it can also come from direct participation in the setting of priorities at the research level. One could imagine for instance the HRC creating a public or patient panel to inform their investment stream priorities. Models exist overseas of public involvement in research priority setting such as the Patient Centred Outcomes Research Institute¹⁹⁹ in the USA or the James Lind Alliance²⁰⁰ in the UK, both of which use public input to inform research goals and activities. The National Institute of Health Research (NIHR) in the UK also has extensive processes for including the public, patients and carers in setting research priorities, informing research design, taking part as researchers in research and being participants in research.²⁰¹ These organisations have ways for the public, patients and stakeholders to have direct input into what research is done and how it is done. At present in New Zealand this kind of involvement is dependent on individual researchers and their philosophies, and it would be fair to say that while these

¹⁹⁸ Health in All Policies recognises that the social determinants of health play a real role in the health of populations and as such health policy alone cannot affect health outcomes. For more information see: http://who.int/social_determinants/publications/health-policies-manual/en/

¹⁹⁹ For more information see: <http://www.pcori.org/>

²⁰⁰ For more information see: <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>

²⁰¹ For more information: <http://www.nihr.ac.uk/patients-and-public/opportunities/>

organisations exist in other countries they are not necessarily a model of how all relevant health research related activity is occurring in those countries. By explicitly underpinning health, health services and health research with a CA framework, it is hoped this kind of activity would be seen as necessary rather than desirable.

6.4.1.1. Project Level

At the individual project level, a CA also requires some changes. Researchers need to consider within any given project, patient-informed priorities and outcome measures (to achieve full functioning in the service setting; a conversion of resource into outcome), as well as what capabilities, are required to take part in research. Many of the informants described in Chapter 5 begin with their populations, they start from what their communities consider issues. A CA framework would support other researchers to recognise this need to consider populations and appropriate measures from the beginning and acknowledge those researchers already working in this way.

Consider, for example, Outcome Measures in Rheumatology (OMERACT).²⁰² Before their consultation with patients, OMERACT focused on a core set of outcome measures that did not include fatigue. The measures focused mostly on pain and joint swelling. OMERACT and others promoted these measures as those that researchers should be using in clinical trials as the most relevant and to gain the most from combining data from various trials. Once OMERACT began consulting with patients, however, they found that patients worried most about fatigue rather than those in the core set (Kirwan et al., 2003) and so fatigue measures were added to the core set. Trials often do not include patient-focused measures in their outcomes measures (i.e. just clinical measures), and this is problematic when deciding what things are worth implementing to achieve patient well-being (Wieseler et al., 2013).

Another aspect related to this would be to develop more patient-relevant measures such as the Patient-Specific Functional Scale (PSFS) (Nicholas, Hefford, & Tumilty, 2012). This tool asks patients within a physiotherapist appointment to list three (or

²⁰² OMERACT is a group that focuses on rheumatology research, specifically outcome measures in rheumatology research. See: <http://www.med.uottawa.ca/research/omeract/about/about.html>

more) activities that they would normally do but cannot do due to their injury/illness and rate them as to their current ability to perform them. Patients then repeat this exercise at the end of treatment. The PSFS is the perfect tool within a CA, in that it focuses on a person's ability to achieve functionings they value (and the effects of treatment on that functioning). More of these kinds of measures and tools would ensure that health services and treatments provide patients with meaningful outcomes.

These kinds of measures could also be included in health data systems along with typical measures such as blood pressure if designed in a manner that makes reporting simple. The utilisation of this kind of data alongside typical biomedical data would go some way in providing a broader range of information in decision-making. This kind of data would provide both decision-makers with the real world outcomes for patients aside from changes in a specific clinical measure.

Research systems at the highest level (priorities and funding) and the project level would need to reconsider practices in light of the informational base required for CA framework decisions in health.

6.5. Limitations

The CA is an incomplete theory of justice and as such requires analytical support on a number of fronts. These gaps can create avenues for distortion. The weighing of different factors as discussed earlier is still somewhat underdeveloped but is possible to implement (Fukuda-Parr, 2011). One could imagine a CA-distributive hybrid model – that is a system where the point of focus is capabilities but another system is used to ensure their effective weighing/distribution.²⁰³ Using key elements of the CA such as public deliberation and person-centeredness combined with the distributive model, which focuses on procedural fairness in combination with CA evaluative framework may be useful for ethical decision-making, i.e. capabilities/functionings are the evaluative space, rather than goods, and public deliberation is used to inform the ground rules of distributive decision-making.

²⁰³ Other hybrids or models of CA have been suggested by Ruger (Ruger, 2010) and Ventakapuram (Venkatapuram, 2013) specifically within the health service system rather than the health research system.

Secondly, Sen's CA relies on extensive and extended processes of public consultation and deliberation. These kinds of discussion exercises are fraught with practical issues. Issues include:

- a) upskilling of both those leading the discussions and those involved as representatives in the discussion needs to occur, if meaningful outcomes are to be achieved
- b) some form of infrastructure and system development for ongoing dialogue and relationship building to reduce costs and improve knowledge acquisition and transfer
- c) ensuring transparency and meaningful representation (i.e. for representation to be meaningful it needs to be authentic, comprehensive and accurate to the community and people it represents (Hunter et al., 2016)).

People are already using the CA in development settings (Sen, 1999; Venkatapuram, 2013) and other discrete projects, and so it is not too theoretical for a practical setting. What is important is to ensure those using CA retain the key concepts of intrinsic goods (i.e. a focus on the interconnected goals of well-being and freedom), public deliberation, and person-centredness in whatever way they operationalise CA.

6.6. Summary

In this chapter, I described the distribution of funding within the NZ health system and what information is used to decide that funding. I argued that the information used was lacking and contributes to the epistemic injustice for marginalised researchers and inequity suffered by marginalised populations described earlier in the thesis. I have then argued that the introduction of a CA in the NZ health decision-making environment and the health research system would be useful in addressing the health inequity and the epistemic injustice that occurs within that environment for researchers working with marginalised populations.

The CA is helpful because it focuses our attention first on those that are not achieving their full functionings (i.e. the most disadvantaged). The informational base the CA requires to evaluate justice requires a broader set of information, and

there is an emphasis on intrinsic goods, person-centeredness, public discussion and participation. Not only that, but it can help reform our systems both on the larger scale, by making explicit the link between other social policy areas and health, and the smallest scale, in conducting research in a way that is patient/participant responsive.

Chapter 7: Implications

"I may not have gone where I intended to go, but I think I ended up where I needed to be"

Douglas Adams

7.1. The Story so Far

This work began with the intuition that one of the many causes of health inequity was the invisibility of marginalised populations in health research, both within research studies and across all research activity. The literature supported this intuition of a lack of representation as was shown in Chapter 1. It was, however, necessary to also verify this within the NZ health research environment. Adequate representation of various marginalised groups in research that informs decision-making is lacking. Novel work exploring this across trial registries, ethics committee records, and health funding records indicated this was the case (Chapter 2). While some projects specifically aimed to address health inequity or the social determinants of health, or even distinct populations, the magnitude of this work, appeared to be out of balance with the size of the marginalised populations and their need (Curtis et al., 2015; S. Hill et al., 2010, 2013; Leeder & Dominello, 2005; Linton et al., 2011; McCormack et al., 2012; Meredith, Sarfati, Ikeda, & Blakely, 2012; Ministry of Health, 2013; Talamaivao et al., 2010; Waldon, 2003).²⁰⁴ Lack of inclusion means we are not discovering or creating knowledge that can help us address the health of these marginalised populations and the disparities they face. It also means decisions currently made by the health system and health researchers are based on limited information. I found evidence of this limitation based on a lack of representation of marginalised populations in a review of health guidelines for the major causes of morbidity and mortality for marginalised groups available from the Ministry of Health and in decision-making exercises that were publicly available from the National Health Committee and PHARMAC. What this work shows is that there is a lack of representation not only in the research itself, but in the use of information from research that informs decisions, and in the decision-making.

To understand the reasons for this disparity, I undertook further work. First, I conducted a survey of ethics committees in NZ who review the majority of research that would likely make its way into decision-making. In NZ, National Ethics

²⁰⁴ Remembering only three particular marginalised groups were investigated here and that others are likely to be less well represented.

Advisory Committee (NEAC) guidelines make very wide-ranging claims about justice, including reference to representation and health inequity among others (NEAC, 2012a, 2012b). These documents are in place to guide both researchers and committees in their considerations of justice. I wanted to understand how ethics committees felt about justice requirements given justice is not apparent in the research activity reviewed in this thesis, despite clear statements about justice in the guidelines.

I, therefore, surveyed committees to ask what they thought of the definition of justice, whether they thought applicants addressed the various elements of justice described in the guidelines and what their responses were to applications that did not address them. Did they make recommendations, or if not, did they feel like they could? The survey also asked about certain practices in the literature described as being likely to aid health inequity improvements (big data, open data, collaborative partnerships and stakeholder engagement). The initial thought in undertaking this work was that with a wide-reaching definition of justice available in the guidelines, an ability to enforce this might be lacking. I based this presumed inability to enforce justice on the conjecture that if applicants were not embedding the idea of justice provided in the guidelines in their projects, then projects that fell short would likely require changes that had resource implications. Such changes were likely to be contested based on funding and time pressures. Alternatively, reasons for the lack of justice in the research environment could be that applicants addressed justice in applications, but in practice fall short; or ethics committees could disagree with the definitions. While this enquiry was the first of this kind in NZ, unfortunately, the response to the survey was low, and so results cannot be considered representative. From those participants who did provide input and comment, some points of interest were found.

There appeared to be an ambiguity of what justice (specifically around health inequity) should look like in ethics review, other than when it was definitively laid out in regards to Treaty obligations. Even where justice was a detailed requirement for Māori populations, the survey respondents noted tokenism and a lack of real

engagement, which is supported by informants reports in Chapter 4 and the literature (Hudson & Russell, 2009; Tolich & Smith, 2015).

I further asked respondents about practices that in the literature have been suggested as ways to either ameliorate the burden of research participation on communities and especially vulnerable communities, fill knowledge gaps where information is lacking, or ensure that researchers and decision-makers included.

Answers to questions regarding big data showed that those participants that responded felt that it could be useful in improving health inequity, but that there were many things to be considered in dealing with the data sensitively and that ethics committees were not necessarily equipped to do this. Big data practices are powering ahead in NZ with initiatives such as Statistics New Zealand's Integrated Data Infrastructure and the HRC funded programme "Burden of Disease Epidemiology, Equity and Cost-Effectiveness Programme (BODE³)" to name but two, using large datasets and integrating them together.²⁰⁵ As previously mentioned, worries about data privacy, safety and ownership are rife both here and internationally, but for marginalised groups specifically the question of power is crucial (Bollier & Firestone, 2010; Boyd & Crawford, 2012). By this I mean, who decides the questions being asked of data and who interprets the data, with what perspective and with what outcome in mind? These are points discussed further below (7.2.3).

Responses to open data were more mixed with some favouring these practices and others reporting that they did not believe people should be made to share data. Open data in contrast to big data is that collected by researchers. Concerns from respondents were largely in consideration of the researcher and their potential loss of intellectual property, rather than towards either participants from whom researchers collected the data or communities that future analysis of the data might impact. In Chapter 4, talking with informants a Māori participant described one of a

²⁰⁵ Stats NZ IDI available at: http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure.aspx BODE³ available at: <http://www.otago.ac.nz/wellington/departments/publichealth/research/bode3/>

few Kaitiaki²⁰⁶ groups that manage a research data set, deciding and guiding how others may access it. These Kaitiaki groups exist for a number of datasets (both from research and government services), the National Kaitiaki Group being the most well-known.²⁰⁷ This group governs Māori women's cervical smear data, which is part of the national cervical screening registry in NZ (i.e. all cervical smear results are forwarded to the registry) ensuring that researcher's use of this data is responsive to Māori and Māori women and does not impact them negatively. It is more accurate to describe this kind of management as semi-open and whether this should be the model for all research data sets or only those affecting populations that face marginalisation is something to be considered. Data management and ownership is discussed further in 7.2.3.

Respondents agreed in principle that both collaborative partnerships and stakeholder engagement were positive and necessary models of conducting research but did see that they were potentially, ethically challenging. A CA to health and health research would require more of this type of work, based on the need for direct input on the prioritisation of capabilities required for functioning (discussed further in 7.2). It would therefore, seem that researchers and ethics committees will require support to be able to undertake and review such practices appropriately.

The next step was to move from ethics committees to the research environment itself. Does the research environment promote the inclusion of marginalised populations in research and marginalised populations' research in general? I therefore, spoke to those working with marginalised populations, this again is a first in Aotearoa New Zealand (others have spoken to Māori academics as described in Chapter 4; Asmar et al.,2009; Mercier et al.,2011). What is it like being a marginalised population researcher? What work gets done and why? I used an institutional ethnographic method to explore this. This feminist sociological method starts from the experiences of people in their everyday lives and uses these

²⁰⁶ "Kaitiaki" translated means guardian and while this traditionally may have been associated with the land in this context it means guardianship over the data collected. This serves to both ensure that future users use it with appropriate consideration to Māori, but also provides participants with peace-of-mind about their data and its future use.

²⁰⁷ For more information on the National Kaitiaki Group, please see: <http://www.health.govt.nz/our-work/populations/maori-health/national-kaitiaki-group>

experiences as entry points, in combination with institutional texts, to understand the ruling relations in the given problematic (the health research environment in NZ) (Smith, 1987). I found that these researchers and their populations suffered an injustice within a health research environment governed by neoliberal policies and a biomedical bias: the ruling relations. These ruling relations were evident in the way different kinds of research was valued and supported. This environment impacted on our informants through the way people thought about health problems and their solutions in NZ when making decisions about policies and services. The environment also impacted on these researchers through the prioritisation of research, i.e. what was more advantageous within the system to conduct, given pressures for international recognition or economic benefit and continuous performance measurement requirements. The researchers working with marginalised populations in this study are distinguishable from other health researchers by their ties to specific communities and populations; these ties often being personal. They utilised various methods but did so with an emphasis on small groups and with a perspective that recognised the social processes that created their populations' disadvantage. Their practice was at odds with what the ruling relations valued regarding answers and ways at arriving at them. I explained this was an epistemic injustice.

An epistemic injustice, as theorised by Miranda Fricker, is one where a dominant group denies members of another group the status of knowers and dismisses their knowledge. The definition of "knower" is someone who possesses both rational authority and credibility. This work is the first to make a connection between the health research environment and researchers working with marginalised populations positing that the health research environment in NZ creates an epistemic injustice for these researchers. I argued that the system denies these researchers working with marginalised populations both rational authority and credibility within exercises that evaluate research and evidence. These researchers are denied the definition of "knower" by the system because they are upfront about their perspective (one of empowering their disadvantage community) when undertaking research and their commitment to a particular group. The system sees this avowal by these researchers as a bias that undermines their knowledge because

this knowledge creation lacks objectivity and generalisability. The biomedical and evidence environment is one that privileges objectivity and generalisability.

I then argued that the concept of objectivity prized within the health research and decision-making environment was first, a conflation between the objectivity of values and objectivity within the scientific method for those within the dominant paradigm; and secondly, was a misunderstanding of objectivity's relationship to ensuring fairness. I explained these problems of objectivity by showing that there are a variety of values always present within research. Regardless of these values, however, what was important was an internal objectivity²⁰⁸ within the method regarding standards of rigour when determining the significance of a piece of information. Points of interest, outcome measures and the like are always chosen within a particular normative framework. Removing bias within a study for the purposes of generating robust information (or evidence) was not in the selection of a measurement, but in measuring the world against that dimension, if the original selection of measures was clearly explained within a normative framework (making it clear what the biases are). Therefore, to address the problem does not require a privileging of one epistemology over another but recognition of the kinds of information multiple epistemologies provide, along with attention to methodological rigour within individual research projects, and explicit statements of perspectives in the assessment of knowledge and evidence.

I argue that the best position in decision-making is one where one has this diversity of evidence from different methodologies and normative viewpoints. This diversity only occurs in a pluralistic epistemological environment. However, to ensure the marginalised are considered appropriately in a pluralistic epistemological environment, a theory of justice that robustly underpins this environment is necessary. This theory of justice must privilege the perspectives of those with the least power.

²⁰⁸ Of course, objectivity makes little sense at all within some qualitative methodologies, but even within these methodologies, reference is made to rigour, and subjectivity within a project either has to be clearly explained separately or as part of the analysis.

To that end, the Capabilities Approach (CA) is explained and suggested as the appropriate framework for justice in the health research and health decision-making environment. The CA is rarely discussed in the NZ setting. While NZ geographers and community activists have explored the CA as a way to make sense of well-being in policy discussions or consider post-neoliberal models of society (Larner & Craig, 2005; Fleuret & Atkinson, 2007) little else exists that directly applies CA to health in the NZ setting. The CA is an evaluative framework of justice that aims to equalise capabilities as means of achieving functionings one values and has reason to value (Alkire, 2005; Sen, 1992). These capabilities and functionings are prioritised through public discourse but focus on those populations where a gap in capabilities exists. I explained Sen's CA, and its key elements for this argument – person-centeredness, intrinsic goods (rather than instrumental goods) and public deliberation (for capability definitions and priority setting) before arguing why Sen's approach was the most suited to creating our pluralistic epistemological environment and ensuring an appropriate focus on health inequity.

7.2. Where to with the next?

7.2.1. Research activity – prioritisation and representation

Our systems for ranking and evaluating research require review. The lack of representation found in Chapter 2 is a direct result of the systems described in Chapter 4. These systems create both demand and supply issues.

The demand issue arises in a system that privileges work that does not include or seek to improve the lives of marginalised populations. This privileging means that the kinds of research done by people like the informants in Chapter 4 are less “desirable” within the existing research systems. This desirability is in part based on the outcomes not being “valuable” and in part based on the perception that problems they address are not “significant” enough (where significance is either international acclaim or economic outcomes).

The supply issue is in part created by the demand issue (i.e. fewer people seek to do work for which there is less demand) but is also created through the current funding and research support mechanisms failing to fund and support the work in these areas adequately. General clinical trials lack representation because within

the timelines and funding available it is more realistic to pick the easiest population to recruit rather than the most relevant (which might require outreach activities, more time, more research locations, and so on). Specific research for these communities currently is often of a methodological type that is judged to cost less and therefore research funders rarely fund work that may be expensive in this area without extensive justification.²⁰⁹ The structures and mechanisms that review and support research activity rarely recognise other forms of undertaking research that include co-production or iterative processes.²¹⁰ This lack of recognition means work done for marginalised groups is either done within a narrow field of “what will a research funder fund” or is done outside of the research system and with little recognition of the work.

This interrelated demand and supply issue requires concerted efforts and strategies to counteract it. General promotion of inclusion will not fix these problems. I say this based on the evidence of current inclusion of Māori, despite the degree of discourse that occurs about Māori as the Tangata Whenua, to whom we have special obligations based on the Treaty. Universities and the health system include cultural workshops or cultural competence training, there is the stipulation in research to consult with Māori, there is specific funding for Māori, and yet a lack of representation was still found (Chapter 2). Further work is required to understand the best way to use a CA to appropriately modify the research environment to foster greater recognition of marginalised groups in relevant research and promote more research for these groups to address health inequity. Factors in the research environment that require considerations are:

- 1) The Performance-Based Research Fund (PBRF)
- 2) Health Research Council funding
- 3) Tertiary Education Infrastructure and Support
- 4) Ethics Committee review (discussed in 7.2.4. below)

²⁰⁹ Unlike justifications for other expensive research that can generally convince a reviewer of the need for an expensive laboratory or piece of equipment, researchers working with marginalised groups generally have to convince reviewers to fund more time and travel, which reviewers with limited experiences of working with marginalised populations can easily dismiss or reduce (i.e. it can be done with less visits or trips, etc., where as they rarely edit a budget for equipment – recommend different/cheaper equipment for example).

²¹⁰ University and ethics systems struggle to deal with projects of this kind for funding, ethics approval, and other research governance issues.

7.2.1.1. The Performance-Based Research Fund (PBRF)

I explained in Chapter 4, as with other international research performance measuring exercises, the PBRF aims to assess research quality and impact based on the submission of individual researcher portfolios within departments at universities and polytechnics. These portfolios²¹¹ are then used along with research degree completions (i.e. Masters and PhDs) to distribute money to universities and polytechnics based on their research performance. Some have argued that these kinds of exercises (along with funding mechanisms) create the “publish or perish” culture, which fosters stress and pressures, that lead to less than ideal research practices (Ashcroft, 2006; Fanelli, 2010; Gendron, 2008; Herndon, 2016; Ivancheva, 2015; Lund, 2012; S. Wright et al., 2015). Again, what a metric focuses on drives behaviours. If we, therefore, want to change behaviours we have to improve our metrics or what they mean.²¹² More radically, we could abolish the system of measurement altogether, if one reads blogs or Twitter this discussion is happening almost constantly between academics and has led to research largely on the adverse effects of measurement exercises such as PBRF mentioned in Chapter 4 (Ashcroft, 2006; Ivancheva, 2015; Reay, 2004; Waitere, Wright, Tremaine, Brown, & Pausé, 2011; Waitere et al., 2011).²¹³

What is especially interesting with the PBRF is that its goals are broader than unidimensional publication impact. If one looks back at the Working Party Report from 2002 published just before the first measurement exercise occurred in 2003 in NZ, it clearly states that impact should be broader than publication. The purpose of the fund goes beyond ensuring quality in research in the simplest terms to also recognise the support of students into research, and broader dissemination of work beyond academia, including references to diversity and community (TEC, 2002). One is asked to include a lot more in a portfolio than just publications and their citations. The metrics created for portfolio evaluation, however, mainly focus on

²¹¹ Individual researcher scores are private, departments receive a public ranking. Researchers receive their scores, as well as various layers of management within the institution.

²¹² Recognising of course that a metric is only ever an indicator of behaviour and that people can “cheat” the system, and for some it will not affect their behaviours at all.

²¹³ The London School of Economics has a number of blogposts relating to research impact and performance measurement for example.

outputs, funding and academic reputation (measured in multiple ways), but these latter two are somewhat dependent on outputs (TEC, 2013).²¹⁴ An interesting exercise beyond the scope of this project would be to assess portfolios elements separately to determine whether publications are a stronger indicator of performance than funding and academic reputation (i.e. would people score higher based on one element over another, or are they generally even across all three domains) . It would also be interesting to compare the content of curricular documents from different institutions considering staff PBRF scores, i.e. does the PBRF actually ensure that teaching is research-led (as stated in its goals). Both of these projects would be difficult to gain ethical approval for (given the private status of individual scores) and neither solves the problem of measuring impact and quality, but they would provide a better understanding of the current system and whether it is meeting its goals.

For health inequity specifically, recognition of community impact of research applications would be useful. Recognition of community impact is worthwhile beyond the health sphere, in helping communities and institutions come together. While universities should be aiming for impact on the global stage, they should also be trying to make a direct local impact.²¹⁵ A measurement of this is likely to be difficult, proven through narratives rather than numbers in some cases; although as discussed in Chapter 6 patient and community specified outcomes could be developed. As I tried to argue in Chapters 5 and 6, picking something to value because it is the easiest to measure, does not necessarily provide the best outcomes. Measuring something purely in a narrative form may not be useful, but the combination of quantitative/standard metrics and other non-traditional signs of impact can together build a more accurate picture.

²¹⁴ That is you do not get invited to speak at conferences if you are not widely published, you fail to attract funding if you have not published in the area your seeking funding for, etc.

²¹⁵ Later revisions of PBRF for the 2018 evaluation have introduced a recognition of broader impact, but it remains to be seen, how this will score in relation to other more traditional forms of impact.(TEC, 2016)

7.2.1.2. Health Research Council Funding

The Health Research Council of New Zealand as New Zealand's primary health research funder must do more to address health inequity.²¹⁶ While funding of career awards for Māori and Pasifika were vital and necessary, as well as the funding of Hui Whakapiripiri (Annual Conference), some other processes require review.

For example, I raised in Chapter 3 and 4, that sections in applications that require applicants to address their project's "responsiveness to Māori" are often seen to be completed perfunctorily or in a tokenistic fashion. The research community and funders (especially HRC) need to have further discussion about what are valuable indicators of genuine engagement and consideration²¹⁷ and how reviewers should deal with applications that do not meet these indicators. The development of a more suitable scoring framework within applications and with weightings that reflect the importance of different elements is needed. A scoring framework would require some research to ensure metrics measured desired behaviours (one issue, of course, being that forms only ever provide a proxy of the engagement rather than the knowledge of the relationships itself) and testing of weightings to ensure the sought outcomes.

Similarly, the HRC must either revise the definition of the current Health Significance score that grants receive based on their impact on the health of New Zealanders or add a further score for health inequity. Currently, applications can score highly across all other domains, but due to addressing the needs of a small population receive a very low health significance score and therefore not get funded. If revision is not possible, a second score reflecting health inequity is required to balance out when a grant addresses significant issues for small but marginalised populations. This health inequity score would have to be appropriately weighted against health significance to achieve the desired

²¹⁶ I made reference to the Haldane principles in early chapters, which as a simple translation is one of academic freedom. It could be argued, that a move to focus on inequity is inhibiting to academic freedom. I of course, disagree; I think this would be no different than the current limits on academic freedom within a resource-constrained environment.

²¹⁷ I would suspect that these are known by senior Māori reviewers already, but their current ability to critique or score poor responses is limited.

outcome.²¹⁸ Again, any revisions to include an appropriate response to health inequity would require some work to investigate appropriate metrics and weightings.

Currently, the HRC splits funding between investment streams in the following way²¹⁹:

| | | |
|------|---|---|
| 70 % | } | 1) Health and Well-being |
| | | 2) Improving Outcomes for Acute and Chronic Conditions In New Zealand |
| 20% | | 3) Health Service Delivery |
| 10% | | 4) Rangahau Hauora Māori |

Anecdotally, there is discussion at HRC workshops that streams 3) and 4) are constantly undersubscribed, and yet arguably this is where a lot of the work regarding health inequity could be improved. Matters of health inequity are often, but not always, matters of service access and delivery, rather than the biomedical aspects of the intervention (although this can also be the case) (Devaux, 2013; Hill et al., 2013; Mladovsky & Bâ, 2016; O'Connor, 2011; *The uneven playing field: ethnic inequalities in cancer outcomes in NZ*, Sarfati, 2013). It would, therefore, seem that a greater balance across these funds could be called for (with an explicit statement regarding inequity) or it may be more useful to disregard these existing categories and begin again.

Categories such as Exploratory, Descriptive, and Interventional²²⁰ could be argued for as more useful, as long as the scoring of applications in each took appropriate account of responsiveness to Māori and health inequity. Alternatively, these three categories plus the current 4) Rangahau Haora Māori could be maintained, but 4) could be modified slightly to only fund Māori-led research as a natural progression

²¹⁸ It would be useful to explore whether a separate score would create more representation both within and across studies, which I suspect might be the case rather than just changing the criteria for health significance (i.e. from great impact on health of New Zealanders, to equity improving or large impact).

²¹⁹ This information is in the general guidelines for 2016/2017, available from: <http://www.hrc.govt.nz/news-and-publications/publications/investment-signals>

²²⁰ This is by no means a final list, Evaluative for example could also be included, but this would be decided in consultation.

from the career awards for further development. These changes to funding mechanisms require some thought and modelling and require rigorous consultation with stakeholders (where consultation membership favours those stakeholders who represent the interests of those who suffer inequity).

Funding panels must become more diverse both regarding methodological expertise²²¹, but also regarding the interests they represent. Our current primary funding mechanism in New Zealand does not address health inequity appropriately. If we were to change to a CA framework then, capability deficits would be apparent, and funding mechanisms would have to concentrate on these. An emphasis on capability deficits would require changes to both the weightings funders give to various factors when reviewing a grant and the way they divide the money between areas of importance.

Lastly as mentioned in Chapter 6, a CA framework would require input from public and marginalised groups in research. As I suggested, models such as the PCORI, the James Lind Alliance or the NIHR show that public involvement in decision-making is not only possible but beneficial. It would seem that the Health Research Council of New Zealand would be the obvious place from which to organise or support these activities given its status as New Zealand's main health research funder.

Alternatively, the Ministry of Health may be better suited and could use such an infrastructure for questions beyond health research, in deciding other priorities in service planning or policy activities.

7.2.1.3. Tertiary Education Infrastructure and Support

As we saw in Chapter 4, tertiary institutions provide little in the way of support for community outreach and fail to recognise activities by their staff that do this despite the lack of support. A CA framework could be used to make tertiary institutions directly show their influence and impact on the capabilities of communities locally, nationally and globally. We should not dismiss international acclaim for research, but we must balance this acclaim with other impact if we want to address health inequity. Some Polytechnics are better at this than universities, because of their

²²¹ Fieldnotes from a HRC funding workshops with input from a previous panel member, discussed one panel as having four biostatisticians and one qualitative researcher for example. A diversity of experts, including those who undertake economic analyses, etc. would seem more appropriate.

previous applied focus rather than research focus. It requires the building of relationships with communities, discussing need, and attempting to address it.²²² This relationship building with communities prior to any specific projects would make the practice of research with marginalised groups potentially less challenging. Relationship building requires funding prioritisation within the institutions, and for that to be successful, again more work is needed to understand what kind of models and systems might be useful.²²³

7.2.2. Research practice – What questions? What answers?

I argued in Chapter 5 that a pluralistic epistemological environment was necessary as we require various information from diverse perspectives to ensure appropriate consideration of those who have the least capabilities. It is still necessary to understand purely physiological processes such as mechanotransduction²²⁴ for example, which requires lab-based methods and little in the way of consultation and outreach. Nevertheless, at the same time, if I were wanting to trial an intervention for balance (the processes of balance being ones that involve mechanotransduction), then I need to talk to people who suffer the particular balance problem to design a responsive intervention before beginning my work and throughout it. Designing and testing of the intervention will require a variety of methodologies to provide the information necessary to know that it works, how it works, and that it works for people in the real world. Every single researcher cannot be an expert in a variety of methodologies, and so the multidisciplinary team approach is an obvious one (and one already promoted to some extent).

Part of this “talking to people” is ensuring appropriate consideration, choice of questions and metrics and so forth, which can only happen if there is real representational participation in decision-making (as argued in Chapter 6). Designing infrastructure within universities that supported participatory decision-

²²² See for example: Otago Polytechnic <http://www.op.ac.nz/about-us/governance-and-management/our-partnerships/> or Unitec <http://www.unitec.ac.nz/about-us/our-partnerships/community>

²²³ New Zealand can learn from international examples of these and adapt. It must be said of course, that various institutions have varying relationships with their local iwi and marae (meetinghouse) and so some community relationships exist. They also exist sometimes through student placement programmes in the community in health programmes, but these need to be strengthened and supported in the same way that innovation is currently supported.

²²⁴ Process by which cells transfer mechanical stimulation into a biochemical response.

making at the macro- and micro-levels²²⁵ would be helpful. This infrastructure could then support researcher relationship-building with communities, as currently exists for commercial and innovation activities.

Importantly, we also need to consider a different way of supporting research in various forms as informing evidence-based medicine and decision-making. Of course, these discussions are already happening and have been for some time along with the critiques of EBM discussed in Chapter 5. Calls for science-based medicine (broadening the base), as well as the development by GRADE of an evaluative approach for qualitative research and Cochrane's inclusion of qualitative method tools, are positive examples of moves towards a different way of recognising valuable information.

There is discussion now in policy circles²²⁶ of "post-normal" science (Funtowicz & Ravetz, 1993) and the need to incorporate different kinds of methods and information into decision-making. However, my experience of these discussions to date have shown them to be still relatively STEM-focused (as the "hard sciences"), and when people do mention social sciences (as the "soft sciences"), they only refer to them when discussing big data (so the work is still quantitative). These discussions focus on the difference in the types of questions now posed that need answers and on multidisciplinary teams and scientists as "knowledge brokers", where these are defined as experts who present the evidence available objectively (Gluckman, 2016). Where these developments may lead is not yet clear, but it would seem that they are likely to continue as is without a powerful impetus to focus on health inequity.

In a tight funding environment, in a small country where minority populations live spread across a vast geographical area, it would make sense for institutions to

²²⁵ This distinction is between individual project level and programme or research strategy level.

²²⁶ Peter Gluckman (Chief Scientific Advisor) travelled the country in 2016 discussing this "Post-normal" science at universities, which contrasts to the first meeting of Global Science Advice in Policy, which I attended in 2014 and was STEM based and the meeting itself completely lacked diversity (which was questioned in the sessions and tweeted about), so there is some progress. However it was also clearly stated that in this new era knowledge brokers (objective presenters of information) were what government wanted and not researcher activists/advocates (promoting a position).

collaborate more. The current systems, again, do not support this collaboration, fostering competition instead. Further work, to discover better ways of ensuring research excellence without creating an environment that undermines useful practices, is needed.

7.2.3. Data

I mentioned in Chapter 3 and Chapter 4, the literature references to big data and health inequity. These come in two forms. Firstly, data already existent in systems if it were to be combined, could provide answers to questions, for which there has been no funding or no practical way of collecting data in the past (Bollier & Firestone, 2010; Lohr, 2012; Raghupathi & Raghupathi, 2014). Where this may fall short, as also mentioned in Chapter 5, is the service utilisation of marginalised communities, i.e. if they use services less, records about them will only provide an incomplete picture. In addition, even where service utilisation data might provide some information, if data classification is poor and inaccurate, then this information source is likely to be more harmful than useful. In using this data, we come across the problem of questions asked and measures used. If those using the data only consider marginalised groups within the larger questions investigated in the data, then answers are unlikely to apply. There is a risk of the marginalised becoming invisible within big data as they currently do in the research and decision-making setting. The Kaitiaki groups mentioned earlier would seem to be a well-functioning model for Māori data. How do we consider this for other groups? Any solution will need to provide two things: 1) a means of ensuring that the way data is combined and analysed considers those who suffer the most disadvantage first and foremost, and 2) conveys to research participants or service users that information they have provided is being used by researchers in their best interests.

Secondly, the call from Ben Goldacre for the collection of new research data at the point of care which (Goldacre, 2012) also existed in the literature beforehand in slightly different forms such as evidence-farming (Hay et al., 2008), again comes down to service utilisation. Collecting data at the point of care means people could do research in the clinical setting for such things as comparative trials (testing effectiveness where evidence exist for efficacy). Goldacre suggested this for pharmaceutical research, but there is here also the opportunity to create

deconstructed RCTs, i.e. a collection of n=1 like trials based on a set protocol and with specified outcome measures collected across national clinics, where patients meet criteria for the trial. The trial protocol would need to be some form of AB trial design (i.e. ABA, or ABAB)²²⁷ to ensure treatment efficacy in the patient, while also providing data to be collated with other single-patient data sets. There are advantages to this, insofar as that while service utilisation for marginalised groups is lower than majority groups, it is higher than trial participation. Therefore, this data use would at least provide more information than currently available. It allows for a much more externally valid form of data collection: standard point of care. Moreover, one could conceivably add adjunct research to collect other data using other methods (such as qualitative methods) to assess differences in responders and non-responders.

Disadvantages include the possibility of greater distrust in the health services based on the breaking down of the separation between therapy and research. This separation was created based on past transgressions of clinicians experimenting on patients without their knowledge. Clinician transgression is a particularly poignant topic in New Zealand where Dr Green conducted research using women with abnormal cervical smears without their knowledge (Manning, 2009). Some of these women died, and it would be fair to say it was not immediately recognised or addressed by the medical establishment of the time. Green's actions and the establishment's response led to the Cartwright Inquiry in NZ. It is from this inquiry that the government established NZ's ethical review system and in so doing made clear that research required ethical approval and patient informed consent. In tying research closer to clinical practice, two things would be necessary: a) ethical approval of trial protocols for clinical practice; and b) some form of public consciousness raising to avoid the fear of being 'experimented' on. This latter needs efforts to educate the public that much trial and error already occurs in medical practice, in finding the right intervention for the right person (i.e. consider current

²²⁷ A or B designate receiving the treatment or not receiving the treatment. Typical N=1 trials, have a period of taking measures prior to intervention/ during intervention, or during intervention/after interventions. Depending on the type of illness or intervention, one can explore more robust testing methods, for example where the intervention is trialled (A), removed (B), and trialled again (A) to see if it induces the same effect. Effectively, the one patient acts as their own control group during the trial.

polypharmacy, self-management interventions for smoking, diabetes, or mental health issues). This type of research would only introduce a process to formalise that regular course of action and by doing so make it rigorous, ensuring the right information is used to make decisions.

Open data is a movement asking for researchers to share their results openly as soon as they are available. The argument here is that often this data is publicly funded and so should be publicly shared. Sharing of data improves transparency, reduces research fraud, and should reduce waste by allowing people to use different datasets for questions they have without having first to collect the same data, someone else has already collected (Doshi, Groves, & Loder, 2014; Gurstein, 2011; Molloy, 2011; Saito & Gill, 2014). It also means that decision-makers can use all relevant information in their deliberations, rather than all information published in a journal.

Objections to this do exist. Those researchers who work in resource-limited funding environments worry that if they are made to make their data accessible after collection and primary analysis that someone in a higher resource setting may trump them on future secondary analyses. They see data ownership solely in regards to their rights, i.e. it is their intellectual property and labour. They own that data. I think this is, in part, is a sign of the environment in which they conduct research and the measures by which we review performance. Changes to what counts as having an impact (i.e. substantially used datasets versus widely cited publications) and how a researcher's reputation is built, directly thwart the idea of the researcher as "seeker of truth". If collaboration and discovery were more lauded rather than individual status, then this could balance these instincts and objections somewhat. In many fields, it is also the case that it is somewhat archaic to discuss research as if it was the result of one person's thinking, even though we refer to it in that kind of way. After all, for the basic sciences, there are often huge research teams, in social sciences, this can also be the case. Researchers in academia also have to remember that all of their time is publicly funded.²²⁸ Issues of data

²²⁸ As is noted in the Appendices related to Chapter 2, I have made the unanalysed datasets from my research available to all. The information shared was already publicly available, but in a cumbersome fashion, through sharing the collated information in a usable format, this work may help someone else in future.

analysis such as those raised above for big data, could similarly be managed with Kaitiaki groups or the like. Participants would need to be made aware of what taking part in a trial means in terms of the data collected and its future use. Making sure these various mechanisms are sufficient and participants are appropriately informed requires oversight.

7.2.4. Ethics Committees

An obvious question here would be “What is the role of the ethics committee?”, and others have debated this (Holm, 2016; Moore & Donnelly, 2015; Schaefer, 2016). Their discussion focused on whether the role of committees was “code-consistent review” that involved no ethical deliberation (i.e. rule-following)(Moore & Donnelly, 2015), a denial of this view suggesting their role is ethical deliberation (Holm, 2016), or the hybrid – their role is ethical deliberation in applying the rules (Schaefer, 2016). I am inclined to agree with Holm and Schaefer that more occurs than basic code-consistent review. However, I do not think that this is what the issue is here, based on the findings in Chapter 3.

In my view, the question is one of ethical authority. It is not whether committees take part in ethical deliberation or code-consistent review, but the fact that the current tasks of ethics committees are both ethical consideration of standards in relation to codes and code-consistent review, at the one point of review. To state this more clearly: ethics committees are tasked with both setting and maintaining standards of ethical practice and enforcing those standards at the one point of reviewing an application. Each committee when it decides whether a certain practice sufficiently meets their conception of informed consent as prescribed in the guidelines, for example, is deciding a standard, but they are each doing this independently. This one-point of contact²²⁹ for both standard setting and reviewing seems wrong to me.

Incorporating ethical practice into a project happens at the design phase, not at the application stage. If the role of committees is to approve a piece of work that meets

²²⁹ One could argue that standards are set over multiple reviews, i.e. that most researchers will apply for ethics more than once and share their experience with other researchers, so that standards are spread through an academic “osmosis” type phenomenon.

the agreed standards (which requires more than a code-consistent review), then we need some other body that first sets those standards, provides other information on what meets those standards and promotes them. Considering work in Chapter 3, what is just research practice, what are the key elements and how should committees assess it? Who is promoting what the standards of just research practice are?²³⁰ The promotion of justice as a fundamental principle in research is not at all evident. Generic guidelines exist and are available. They underpin all committee guidelines. However, what I think is needed is ongoing support material regarding topics, such as “things to consider when managing consent in context ‘x’”, or “ethical recruitment in the clinic setting”, for example. The body that oversaw this would also have to have some authority with institutions so that they could easily disseminate and encourage the use of material. These resources would then also be available to ethics committees. In NZ, the obvious choices for this would either be the National Ethics Advisory Committee, the Health Research Council Ethics Committee or the Royal Society of New Zealand (in recognition that more research occurs than just health research). The former is preferable as any work in this area should cover more than accredited committees²³¹. This body could then set and disseminate the standards for “justice” or innovative research practices such as photovoice methodologies²³², or working with the learning disabled (based on consultation).

This norm or standard setting should not sit with individual ethics committees (i.e. it would then be disparate between committees). Currently, it does with each committee making these decisions in their review practices (and precedent setting). What informs these norms and standards are usually academics publishing papers of an ethical practice or conundrum. Committees use these and their knowledge of legislation or research experience to make decisions. For example, committees assessing big data practices might consider legislation and international research

²³⁰ If these were set, then funding bodies and institutions would have to take note of them.

²³¹ NEAC does create advisory documents occasionally across a broader domain than just health research. And the Health Research Council was directly responsible for the creation of Te Ara Tika for Māori research. The idea here is for something more active.

²³² Photovoice methodologies are those that use participants taking photos and discussing those images as research data. These kind of projects are often ethically fraught in relation to the various consents that might be needed in taking and using, and sharing images.

literature. This use of information in decision-making is by no means systematic or comprehensive. Ethics Committees in NZ do not meet each other regularly²³³ other than when Chairs or members attend conferences or the like, so dissemination and standard setting between committees occurs sporadically.

There is here a gap that requires filling beyond the ethics committee itself in setting standards, promoting them, providing training and ensuring committees and research organisations meet them. This task again needs funding support for the body tasked with doing this work.²³⁴

7.3. The Good and the Bad

The three studies completed within this thesis and the theoretical argument made are limited but novel with the NZ environment.

The survey of representation in research activity in public records while being the first of its kind in New Zealand was restricted insofar as the sources themselves were limited. I wrote about this in 2013 when conducting the review (Tumilty, 2013) suggesting that a national database of research activity would be useful not only for purposes such as my own, but more generally for researchers, clinicians, government policy-makers, and the general public. The records used had errors, were incomplete, provided limited information and did not exist in a way that searching or analysis was easily possible. This lack of information means that NZ decision-makers in various situations (research or the health system), can quantify activity in its simplest forms (numbers of applications, numbers of grants and dollars spent, types of grants) but cannot analyse it meaningfully to plan activities and fill strategic gaps. My work here shows that in research activity representation was extremely poor (less than 5% combined) between 2006-2013, for three groups, one of whom are Tangata Whenua. It also shows that inclusion of research related to these three groups in a selection of clinical guidelines (for diseases of importance) and in health technology assessments/decision-making documents that were publically available (PHARMAC and National Health Committee) was also

²³³ HDECs Chairs communicate and individual Chairs may informally communicate with each other, but no formalised mechanism of ethics committee communication exists.

²³⁴ It should be noted, that if this were the case, then this would move committees further to either Schaefer's conception of them or Moore's and away from Holm's.

extremely poor. Others have done a more detailed analysis of one related aspect of this part of the work – Jull and colleagues went through ethics records and analysed how many were registered with a clinical trial registry (Currie & Jull, 2012; Jull et al., 2005). Heather Came reviewed public health documentation between 2009 and 2011 for inclusion of Māori scholarship (Came, 2012, 2014), which my work here has extended, finding a similar lack of inclusion. Other groups have sought evidence of representation within specific countries or conditions (Berger et al., 2009; Graham, 1992; Heiat et al., 2002; Sharpe, 2002; Symonds et al., 2012).

My work is the first of its kind to seek representation in NZ across multiple sources about the representation of marginalised groups and sets a baseline for future inquiries. With greater time, funding and technological skill, a cross comparison of sources to create a “master list” of research activity that pulled data from websites for ongoing updates would be possible in a format that could be shared online for open use by anyone. The creation of this resource was not possible within the parameters of this study. However, it was important for me as researcher who believes in an open scholarly community to share my data and so raw data related to Chapter 2 is available on figshare²³⁵ (address links are included in the relevant sections of the Appendices).

The survey of ethics committees did not reach an adequate response rate and focus groups would have been more productive, especially given participant feedback. The survey was also too long and should have remained focused on the questions related only to justice. There is relatively little research work done with ethics committees in New Zealand. As referred to earlier, Gillett has commented on the reforms of 2012 (Gillett & Douglass, 2012) and some commentaries exist regarding these reforms. Moore has commented on the role of committees as discussed above, but not in the particular NZ context (Moore & Donnelly, 2015). Pieper and Thomson from Australia have written theoretically on justice in ethics review in the Australian context of the National Statement (Pieper & Thomson, 2013). Others have questioned specific practices of NZ ethics committee about children and youth (Allen, 2009; Powell & Smith, 2006), and ethical review and methods have been

²³⁵ www.figshare.com is an open repository for the sharing of research artefacts, whether it is data, reports, figures, etc.w

described for Māori by Māori (Hudson, 2004, 2009; Hudson & Russell, 2009; Hudson, Milne, Reynolds, Russell, & Smith, 2010)

By far the most work done on the New Zealand ethics environment has been undertaken by Tolich; and more recently Tolich and Smith, both Chairs of HDEC committees pre-2012 and still very prominent in the ethics review space in New Zealand (Tolich & Smith, 2015). Aside from this book, Tolich has in collaboration with other authors written numerous papers on specific elements of ethics review in NZ (Gremillion, Tolich, & Bathurst, 2015; Tolich et al., 2016; Tolich, 2002, 2015; Tolich & Fitzgerald, 2006). He has also written with other committee members about an unorthodox committee he founded to fill an ethics gap post the 2012 ethic committee reforms (Flanagan & Tumilty, 2015; Marlowe & Tolich, 2015; Tolich & Marlowe, 2016). None of this work has addressed justice in ethics review specifically.

My work here was the first attempt in the NZ context to consider ethics committee review of justice. It was obviously limited in what it provides in relation to the thesis due to the low response rate, but what it does do, is provide valuable information to researchers in how to approach committees for their views in future. I also think it provides motivation to explore:

- a) The practice of ethical review in New Zealand. What are ethics committee assessing exactly? Is it purely risk assessment, as was suggested? I would think not, but this requires investigation.
- b) Big Data Ethics – what do we need to do, whose responsibility should it be, what is currently happening, who “owns” data, and so forth? Big data activity is rising, and ethics committees require support and information to deal with this.
- c) Research regarding the relationship between information provided in applications and desired behaviours, i.e. whether applications are the best indicator of desired practice. If not, what novel forms of ethics review could we institute instead? There are those who think that ethics review requires a total reform, thinking about it in new and dynamic ways (van den Hoonaard

& Hamilton, 2016). To do this well more information and discussion is required.

- d) The relationship between committee membership, committee guidelines and review outcomes. Some work in this area has been done²³⁶, but not extensively and not in the New Zealand context.

An institutional ethnographic method is a rare tool in NZ – Ellen Pence, would be its most prominent advocate here (Pence 2001; Edleson 2010).²³⁷ It is the only piece of work speaking to researchers working with people who suffer health inequities in New Zealand. Work in the UK has included researchers and advocates and their views regarding health inequalities research (Smith & Garthwaite, 2015). There are projects (referenced throughout this thesis) on people’s perspectives of the PBRF or Māori research practice, but my work here is original in that it examines a group of researchers and their experiences within the research system and specifically those working with marginalised populations. As this thesis was nearing submission, work from the assessment of the UK’s Research Evaluation Framework (REF), similar to NZ’s PBRF, was published and also drew conclusions regarding the discrimination of women, ethnic minorities, and people with declared disabilities within the process, as well as the focus on marketisation (some positives were also noted)(Stern, 2016). What this work adds to these kinds of findings, is that not only are marginalised researchers disadvantaged, but researchers working with marginalised populations are, too. And in fact, that researchers working with marginalised populations are often themselves those marginalised researchers in the first place. There is here a compounding of their discrimination in the system.

Further work, would seek to talk to junior academics in this area and understand how they experience the research system. Also, it would be interesting to speak to those who started in this area and did not continue, although their recruitment would likely be very challenging.

²³⁶ For example see: (Dal-Ré, Espada, & Ortega, 1999; Savulescu, Chalmers, & Blunt, 1996; Stark, 2012)

²³⁷ Pence is known for immensely valuable work in domestic abuse and violence against women and children. She has sadly passed away.

The theoretical thinking in this thesis sought to connect epistemology and justice more explicitly. While every first year philosophy student can recite “no is from an ought”, fewer are aware of Putnam’s work on fact/value entanglement (incorporating Sen’s early economics) (Putnam, 2002) and feminist thought in Philosophy of Science (Harding, 2006; Harding, 1987, 1991; Hartsock, 1983; Haslanger & Haslanger, 2012; Smith, 1999). These works provide valuable entry points to reform evidence-based medicine, which has long been criticised (Buetow, 2008; Buetow & Kenealy, 2000; Buetow et al., 2006; Cartwright, 2010, 2011, 2013; Greenhalgh, Howick, Maskrey, & for the Evidence Based Medicine Renaissance Group, 2014; Greenhalgh, 2012; Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015; Hay et al., 2008; Hunter, 1998; Kerridge, Carter, & Lipworth, 2008; Rogers, 2004b; Rogers & Ballantyne, 2009; Tonelli, 2006), but is still prominent, partly based on the idea that impartiality equals fairness. I have proposed that embedding the CA that stresses intrinsic goods (rather than instrumental goods), person-centredness, and public participation may go some way to transforming knowledge generation exercises, by explicitly linking them to people and outcomes, changing the variety of questions that can be asked and answered.

The work done here shows that if we use an evaluative framework (the CA) that makes explicit reference to its informational base, we can more clearly link values and facts and engage with them in public deliberation and discussion. This explicit linking of fact and value in the health system and health research space provides a new avenue for addressing inequities. The connection of the CA to evidence-generation allows for explicit arguments for the connection with research populations at the beginning of research activities and throughout. While public involvement in research decision-making happens in some places around the world, it is by no means standard practice globally or locally in NZ. A CA would help to provide a voice to these populations in health research, and it is my feeling that the NZ government should also incorporate it at the service and policy level. Health research is not sufficient to address health inequity but it is necessary to address health inequity.

7.4. Conclusion

I sought to understand the representation of marginalised populations in research and the systems that use that research. I found a lack of representation to be indicated and then set out to understand why. This involved surveying ethics committees in NZ to find out how they consider justice in their reviews (defined as both representation and fair distribution of risks/benefits). This survey, while not reaching a response rate to draw conclusions, provided interesting information for discussion. I then used an institutional ethnographic method to understand the research environment for researchers who work with marginalised populations to determine whether there were factors in the research environment that created this lack of representation. I found that an epistemic injustice occurs for researchers working with marginalised populations, insofar as neoliberal health and educational policies, and a bias towards the biomedical in health research means that their work is rarely rated as evidence or as valuable.

From here, I argued that the policy and service exercises of rating research as evidence, influence what work people in the research setting perceive as valuable. Our method for evaluating research as evidence was found to be lacking: it focusses too narrowly on efficacy, thus excluding other work that could provide useful information for decision-making. Our evaluative framework also fails to determine the quality of efficacy in relation to connections with real world settings. I then argued that this dominant epistemology restricts our ability to make ethical decisions, by limiting the information with which we make them.

Based on this limitation, I introduced Sen's CA as an evaluative framework that focuses on well-being and freedom in an important way. I explained the CA with its focus on the capabilities people need to achieve functionings they value and have reason to value. By focusing on intrinsic rather than instrumental goods, incorporating public deliberation in determining capabilities, and actual achievement of well-being and freedoms, the CA requires a broader informational base. This informational base supports the pluralistic epistemological environment argued for in Chapter 5 and does so while involving public engagement.

Development of prioritisation tools, consultation/engagement infrastructure, evidence matrices²³⁸, as well a reform of ethical review and research evaluation are needed, but a CA framework in the health decision-making setting and the health research setting could go some way to addressing health inequities in Aotearoa New Zealand.

²³⁸ These are not insurmountable if tools are developed incrementally and build off each other.

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Appendix A: Health Research Funding data

Health Research Council funding data is available on their website. This list is not complete, as those investigators who do not wish to have their grants added to the website (embargoed) for commercial or sensitive reasons can choose to do so. I am also aware of some grants that were not asked to be kept from the site, which were not in the list based on my previous professional roles in research administration. Therefore the data from this website is incomplete. However, it is suggested only marginally so.

Methodology

Annual reports' (in PDF/Word format) include tables of applications. I copied tables from documents and then converted them to Excel. These were then searched using multiple methods:

- 1) Electronic search using "Find" option in Excel searching for terminology related to Māori (Māori, Māori, whenua, kaupapa, whanau, Whānau Ora, nga*, whan*, whak*,*ori , tanga*), Pasifika (Pacific*, Pasifik*, Samoa*, Tonga*, Fiji*, Cook*, Niue*, Kiri*) and Learning Disability (intellectual, learning, Down*, Prada*, fetal*, disability) groups. These provided lists that were then scrutinised for those that pertained to our groups (i.e. some results with *ori or fetal* were not related our case groups, but these were then excluded). A fourth group was created that included those projects related to equity or that involved two of our groups or that included studies that relate to rheumatic fever which has been a particular health issue for Māori and Pasifika children and adults. These terms included: equity, disparity, rheum*, equality, determinants. This was completed by the primary investigator.
- 2) Additionally, manual checking (i.e. checking in each item in the list) was completed by the primary investigator and an external checker (medically trained). Filtering of titles was thrice-checked by the author on three separate occasions each multiple days apart, and by the external checker (medically trained). The principle of charity was used between checkers and searches, insofar as the largest list was taken as the final list.
- 3) All titles that were an acronym rather than a title such as "SPRINT Trial" or that were considered ambiguous in the larger list were searched online to check the nature of the study before being included or excluded.

A full dataset (without analysis) has been posted openly for future use by others in the spirit of collaboration and collegiality. This data is available from www.figshare.com

Tumilty, Emma (2016): Health Research Council of New Zealand Funding 2006-2013 (Open).xlsx. figshare.

<https://dx.doi.org/10.6084/m9.figshare.2062068.v2>

| | |
|--|--------------------------------|
| | Māori |
| | Pasifika |
| | Learning Disability |
| | Equity or Multiple case groups |

| Year | Title | Investigator | Organisation/Institution | Amount (\$) | Duration (mnts) |
|------|--|--------------------|---|-------------|-----------------|
| 2009 | Exploring whanau based strategies and communication employed to reduce violence | Mere Balzer | Te Runanga o Kirikiriroa Charitable Trust | \$4,000 | 3 |
| 2013 | The Tangata Whenua and Tangata Tiriti of the New Zealand coalition to end homelessness: National Homelessness Strategy | Hulita Tauveli | University of Auckland | \$5,000 | 10 |
| 2012 | Māori housing-related potentially avoidable hospitalisation in Waitemata DHB | Zarah Allport | University of Auckland | \$5,000 | 4 |
| 2012 | The use of rongoa in contemporary physiotherapy practise: An exploratory study | Kelly Gray | AUT University | \$5,000 | 3 |
| 2012 | Māori conceptions of health in ultimate relationships: An exploration of health and intimacy | Pita King | University of Waikato | \$5,000 | 3 |
| 2012 | Indigenous women, problem gambling and the care of their children: A literature review | Patricia Grogan | AUT University | \$5,000 | 3 |
| 2013 | Māori and palliative care | Diane Koti | Massey University | \$5,000 | 2 |
| 2013 | Literature review of cultural safety pertaining to foot-care with Māori | Cynthia Otene | AUT University | \$5,000 | 2 |
| 2009 | Resilient Whanau: Well-being through innovation and traditional practice | Tania Ruana | Te Hauora O Turanganui a Kiwa Ltd | \$10,000 | 3 |
| 2011 | Sport as a forum for capacity building and self-determination in Indigenous communities | Renei Ngawati | AUT University | \$11,600 | 36 |
| 2011 | How do different populations define Whānau Ora? | Te Moana Rolleston | Massey University | \$11,600 | 18 |

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|------|--|--------------------|--------------------------------------|----------|----|
| 2010 | Porirua Harbour and the relationship to Tangata Whenua - Working towards a healthy built environment | Stephen Kenny | HRC | \$11,873 | 13 |
| 2012 | Best outcomes for Māori with cancers | Jacqueline Lumsden | Massey University | \$11,970 | 12 |
| 2011 | He Kura Aro Huango: Primary Schools & Māori Children with Asthma - A Pilot | Anne Webster | Tu Kotahi Māori Asthmas Trust | \$11,997 | 7 |
| 2012 | A Kaupapa Māori approach to Cardiac Risk Reduction | Josephine Church | The Cardiac Clinic | \$12,000 | 12 |
| 2013 | Supporting Māori tamariki/whanau with chronic asthmas: A health literacy approach | Maraea Nathan | Tu Kotahi Māori Asthma Trust | \$12,000 | 6 |
| 2011 | Ngaitai Papkainga Toiora: Sustainable Housing Development for Ngaitai Whanau | Leah Redstone | Ngaitai Iwi Authority | \$12,000 | 6 |
| 2006 | He Arorangi Whakamua - A Ngati hauiti tobacco control intervention | Gillian Pirikahu | Whakauae Research Services | \$12,000 | 6 |
| 2009 | Mauri Ora Growing healthy tamariki, whanau, and hapu in Tuhoe communities | Haromi Williams | Education Authority Charitable Trust | \$12,000 | 3 |
| 2007 | Exploring resiliency factors for prevention and management of Chlamydia in young Māori women | Catherine Waetford | AUT University | \$13,900 | 12 |
| 2010 | Do whanau Māori in Taranaki support community-based breastfeeding initiatives? | Marnie Reinfelds | Massey University | \$15,600 | 12 |
| 2008 | Why are mental health services failing Māori homeless | Diana Johnson | University of Waikato | \$16,066 | 12 |
| 2012 | Optimising Māori women's breastfeeding | Isabel Tui Edwards | AUT University | \$17,600 | 24 |
| 2009 | Ko taku iwi tuaroa tena: Key factors in decision-making on immunisation among Māori - extension | Stephanie Palmer | Tumana Research Services | \$32,315 | 4 |
| 2013 | The secret happiness: Narratives from Māori elders in the Bay of Plenty | Marama McDonald | University of Auckland | \$37,303 | 12 |
| 2007 | Oranga Kaumatua - Taranaki | William Edwards | Massey University | \$47,627 | 24 |
| 2006 | Workplace safety for Māori nurses | Victoria Simon | Massey University | \$50,690 | 18 |
| 2011 | SICK TO DEATH: Māori Access to Quality Healthcare in | Jennifer Reid | University of Otago | \$60,550 | 21 |

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|------|--|--------------------|-----------------------------------|-----------|----|
| | Christchurch | | | | |
| 2011 | The impact of whakapapa exchange on the therapeutic alliance in therapy with Māori clients | Arna Mitchell | Massey University | \$65,550 | 24 |
| 2007 | A Māori-centred inquiry into health governance: Māori directors on DHBs | Joy Panoho | Massey University | \$65,740 | 30 |
| 2006 | Kia ngawari ki te awatea: a psychological journey toward wairuatanga and Māori well-being | Hakarere Valentine | Massey University | \$66,039 | 32 |
| 2006 | Whanau bioethical decision-making - genetic disorders and Māori Health | Hope Tuapara | Massey University | \$74,650 | 24 |
| 2012 | Collaboration with and for rural Māori with addiction and related problems | Andre McLachlan | University of Otago | \$80,278 | 36 |
| 2012 | A Māori-centred grounded theory study of Māori with addiction and related problems | Maria Baker | Massey University | \$85,050 | 48 |
| 2006 | Insulin resistance & Māori health - repeated measures study | Isaac Warbrick | Massey University | \$95,050 | 36 |
| 2008 | Pilot intervention study to improve the oral health of rangatahi in Taranaki | Kate Morgaine | University of Otago | \$100,000 | 36 |
| 2008 | Māori with disabilities and their whanau navigating complex support systems | Adelaide Collins | Māori Development Research Centre | \$100,000 | 36 |
| 2006 | Acceptable child/adolescent Mental Health Services for New Zealand Māori | Kahu McClintock | University of Auckland | \$101,050 | 36 |
| 2006 | Māori and Indigenous health initiatives: blood-borne viral and sexually transmitted infections | Mera Penehira | University of Waikato | \$102,550 | 47 |
| 2010 | He Kaakano ahau I ruia mai I Rangaiaatea: engaging Māori in Child an Adolescent Mental Health Services | Pikihuia Pomare | University of Auckland | \$104,738 | 36 |
| 2010 | Whānau Ora: Māori motherhood, cultural identity, and mental well-being | Reena Kainamu | University of Auckland | \$107,602 | 36 |

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|------|--|---------------------|---|-----------|----|
| 2011 | Whakapapa: An Interpretation of Indigenous Theory for Postvention of Suicide for Whanau Māori Experiencing Whakamomori | Pania Renati | University of Waikato | \$108,095 | 36 |
| 2013 | Whanau kopepe: Young Māori parents experiences of raising a family | Felicity Ware | Massey University | \$108,402 | 36 |
| 2013 | Māori elders resilience and arthritis: Measuring home health outcomes | Sharon Awatere | Massey University | \$109,500 | 36 |
| 2013 | Kaupapa Māori evaluation of health literacy appropriate CVD intervention | Teah Carlson | Massey University | \$109,500 | 36 |
| 2013 | Taku aroha ki ngā tai e ngunguru e ra: Transforming the Māori health cancer workforce | Monica Koia | Massey University | \$110,050 | 36 |
| 2012 | Ngaitai well-being indicators: Measuring iwi health outcomes | Jodi Porter | Massey University | \$110,050 | 36 |
| 2008 | Parenting patterns of Māori women who have experienced domestic violence trauma | Alayne Hall | AUT University | \$113,050 | 52 |
| 2008 | Māori Whanau participation in mental health service delivery | Louise Ihimaera | Massey University | \$114,497 | 24 |
| 2006 | Older Māori and medication: management, regulation, and facilitation | Bevan Clayton-Smith | Massey University | \$120,519 | 24 |
| 2009 | Whanau Māori & mental health: Snapshots of strengths, resilience & recovery | Mere Balzer | Te Runanga o Kirikiriroa Charitable Trust | \$132,483 | 18 |
| 2010 | EGFR testing for Māori patients with non-small-cell lung cancer | Lesley Batten | Massey University | \$143,868 | 12 |
| 2008 | Monitoring sexually transmitted infections among Māori in the Bay of Plenty | Clive Aspin | University of Waikato | \$144,267 | 12 |
| 2009 | Developing Sleep Services that meet the needs of Māori: A feasibility study | Sarah Jane Paine | Massey University | \$145,561 | 12 |
| 2008 | Whānau Ora cardiovascular risk assessment and management - a feasibility study | Tania Riddell | University of Auckland | \$146,002 | 12 |
| 2012 | Feasibility of an exercise programme to reduce smoking during pregnancy among Māori | Ralph Maddison | University of Auckland | \$149,985 | 12 |

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|------|---|----------------------|--|-----------|----|
| 2010 | Mental health and substance abuse disorders among Rangatahi Māori offenders | Tai Kake | Victoria University | \$149,999 | 12 |
| 2011 | Haua Mana Māori | Leigh Hale | University of Otago | \$151,790 | 12 |
| 2006 | Cognitive behavioural therapy for depression with Māori tangata whaiora | Simon Bennett | Massey University | \$191,858 | 39 |
| 2006 | Partnership: refocusing successful interventions for Māori deaf/hearing impaired children | Kirsten Smiler | Victoria Link Limited | \$196,923 | 36 |
| 2008 | Measuring Whanau - Research methods to capture whanau realities | Fiona Cram | Katoa Ltd | \$200,000 | 12 |
| 2007 | A best practice package: early intervention for whanau violence | Erana Cooper | University of Auckland | \$229,575 | 37 |
| 2011 | Rangatahi Sexual and Reproductive Health Research | Lynne Russell (Pere) | Victoria University | \$244,360 | 24 |
| 2010 | Mauri Ora - Growing healthy tamariki, whanau, and hapu in Tuhoe communities | Haromi Williams | Tuhoe Education Authority Charitable Trust | \$247,743 | 21 |
| 2008 | Parental attitudes to HPV vaccinations: a survey of Māori and non-Māori | Beverley Lawton | University of Otago | \$249,538 | 12 |
| 2011 | Māori health literacy and communication in palliative care: Kaumatua-led models | Rangimahora Reddy | Rauawaawa Kaumatua Charitable Trust | \$249,998 | 12 |
| 2013 | Whanau Pakari: A multi-disciplinary intervention for children with weight issues | Yvonne Anderson | University of Auckland | \$250,000 | 48 |
| 2007 | Quality of public hospital care for Māori and NZ Europeans in Christchurch, NZ | Juliet Rumball-Smith | University of Otago | \$250,311 | 61 |
| 2006 | Hauora practice led frameworks for health-related new technologies | Jessica Hutchings | Massey University | \$256,063 | 36 |
| 2009 | Oral health research priorities for Māori | Bridget Robson | University of Otago | \$257,124 | 13 |
| 2007 | He mokopuna, he taonga: Health and well-being of grandparents raising mokopuna | Cherryl Smith | Te Atawhai o Te Ao | \$265,045 | 44 |
| 2010 | Māori priorities for life stage research: Hapu Ora | Helen Moewaka-Barnes | Massey University | \$270,000 | 19 |
| 2008 | Research priorities identified by Māori with disabilities and their whanau | Adelaide Collins | Māori Development Research Centre | \$270,000 | 14 |

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|------|--|-------------------------------|--|-----------|----|
| 2006 | Health, cultural and social experience of Māori affected by chemical related illness | Cherryl Smith | Te Runanga o Ngati Apa | \$275,625 | 36 |
| 2011 | Palliative care, health literacy, Māori communities and health services | Jacque Kidd | Auckland Uni Services Ltd & University of Auckland | \$290,002 | 12 |
| 2008 | The socioeconomic factors associated with food security and physical activity for Māori | Charles Waldegrave | The Family Centre | \$291,107 | 19 |
| 2011 | Nga ara hou: New pathways toward Whānau Ora for incarcerated Māori women | Lily George | Massey University | \$293,948 | 36 |
| 2011 | Mauri Tangata: Re-Positioning Māori resistance and well-being in Sexual and Reproductive Health Policy and Service Provision | Mera Penehira | University of Waikato | \$296,297 | 36 |
| 2011 | Oranga niho me nga tangata whaiora | John Broughton | University of Otago | \$303,540 | 12 |
| 2010 | Tangata-centered Huntington's disease research: Partnership between Indigenous community and biomedical science | Melanie Cheung | University of Waikato | \$305,780 | 36 |
| 2007 | Nursing and Māori patient outcomes | Denise Wilson | Massey University | \$311,620 | 15 |
| 2009 | Whakaoranga Whanau: Whanau Resilience | Mason Durie | Massey University | \$313,000 | 24 |
| 2008 | Moe tike, moe pai: Advancing sleep health in Aotearoa/New Zealand | Te Hereripine Pain Sarah-Jane | Massey University | \$321,740 | 41 |
| 2010 | Tomo mai, Responsive Child and Adolescent Mental Health Services (CAMHS) for Māori Rangatahi | Kahu McClintock | Te Rau Matatini | \$322,034 | 36 |
| 2012 | Ka puāwa ngā kōhungahunga turi: The early development of Māori deaf children | Kirsten Smiler | Victoria University | \$330,734 | 36 |
| 2012 | Huarahi rongoa ka a ngai tatou: Māori views on rongoa Māori and primary health | Glenis Mark | Whakauae Research Service | \$333,273 | 36 |
| 2012 | Huarahi rongā ki a ngai tātou: Māori views o rongā (traditional medicine and practices) | Glenis Mark | Whakauae Research Service | \$333,273 | 36 |
| 2011 | Nga Pou Wahine: A kaupapa wahine intervention addressing gambling misuse | Laurie Morrison | AUT University | \$334,761 | 38 |
| 2012 | The best exercise for Māori | Isaac Warbrick | Massey University | \$335,538 | 36 |

| | Men | | | | |
|------|--|--------------------------|--|-----------|----|
| 2012 | Exploring the practical applications of Matakite (unusual perception) understandings in health provision | Ronald Ngata | University of Waikato | \$339,407 | 36 |
| 2010 | Kia Ngawari: Investigating Palliative Care of Māori and their whanau | Tess Moeke-Maxwell | University of Waikato | \$341,433 | 36 |
| 2009 | Facilitating whanau resilience through Māori primary healthcare intervention | Heather Gifford | Whakauae Research Services (Te Maru o Ruahine Trust) | \$349,734 | 24 |
| 2008 | Te Tomokanga: a model for facilitating bicultural health policy and programme development | Annabel Ahuriri-Driscoll | Inst. Of Environmental Science & Research Ltd | \$350,000 | 18 |
| 2013 | Te Maramatanga: How education positively affects Māori health over time | Reremoana Theodore | University of Otago | \$354,512 | 36 |
| 2013 | Establishing Māori-focused standards for neuropsychological measures | Margaret Dudley | AUT University | \$375,234 | 36 |
| 2010 | Health research and services: Localising the interface between Mātauranga Māori and Science | William Edwards | Massey University | \$388,626 | 40 |
| 2007 | Growing up kapo Māori: Whanau, identity, cultural well-being and health | Nancy Higgins | Donald Beasley Institute | \$389,589 | 24 |
| 2007 | Kei ruka kei raro: Māori health experiences and perspectives | Emma Wyeth | University of Otago | \$400,774 | 58 |
| 2006 | Health measurement and knowledge translation for improved Māori health outcomes | Catherine Waetford | AUT University | \$417,189 | 18 |
| 2009 | Growing up kapo Māori: Accessing paediatric ophthalmology services | Nancy Higgins | Ngati Kapo O Aotearoa Inc. | \$501,216 | 24 |
| 2008 | Interventional study on bronchiectasis in indigenous children | Catherine Byrnes | University of Auckland | \$555,895 | 30 |
| 2009 | Māori and Cancer - the Role of Primary Care | Lis Ellison-Loschmann | Massey University | \$574,465 | 36 |
| 2008 | Enhancing food security and physical activity for Māori, Pacific, and low-income whanau/families | Cliona Ni Mhurchu | Auckland Uni Services Ltd | \$599,000 | 24 |
| 2010 | Racism as a health determinant: implications for Māori health and inequalities | Ricci Harris | University of Otago | \$600,032 | 36 |

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|------|--|-----------------------|---|-------------|----|
| 2007 | Pukapuka Hauora: Parents' knowledge of preventing and treating their child's asthmas | Bernadette Jones | University of Otago | \$624,415 | 24 |
| 2007 | He kakano: Māori views and experiences of fertility, reproduction, and ART | Paul Reynolds | Te Atawhai o Te Ao | \$656,062 | 36 |
| 2013 | Māori health identities: Affecting and driving health | Helen Moewaka Barnes | Massey University | \$666,299 | 36 |
| 2008 | Nga Tohu o te Ora: traditional Māori wellness outcome measures | Maui Hudson | Inst. Of Environmental Science & Research Ltd | \$699,370 | 36 |
| 2007 | Determining the contaminant health risk of kai moana, kai roto, and kai awa | Ngaire Phillips | National Institute of Water and Atmosphere Research | \$705,786 | 36 |
| 2008 | Wahine Hauora - Inequalities in uterine cancer: exploring the pre-diagnosis gap | Beverley Lawton | University of Otago | \$707,474 | 30 |
| 2012 | Best Health for Māori: Te Hoe Nuku Roa - Housing, Hazards and Health | Chris Cunningham | Massey University | \$786,852 | 36 |
| 2011 | Culturally appropriate end of life care for Māori | Maureen Holdaway | Massey University | \$803,763 | 36 |
| 2008 | Stomach Cancer in Māori | Lis Ellison-Loschmann | Massey University | \$951,381 | 60 |
| 2011 | Can Better Surveillance Prevent Liver Cancer and Death in Māori with Chronic HBV | Professor Edward Gane | Auckland District Health Board | \$964,393 | 30 |
| 2011 | Supporting the Traditional Rongoa Practice in Contemporary Healthcare Settings | Amohia Boulton | Te Maruo Ruahine Trust & Whakauae Research For Māori Health and Development | \$1,023,301 | 36 |
| 2011 | Marae Food Gardens: Health and Well-being through the Urban Marae in Tamaki Makaurau | Rhys Jones | University of Auckland | \$1,165,597 | 36 |
| 2009 | Wahine Hauora: reducing barriers to care for pregnant mums and their whanau | Beverley Lawton | University of Otago | \$1,179,945 | 48 |
| 2013 | Pakeketanga: Living and dying in advanced age | Merryn Gott | University of Auckland | \$1,191,255 | 36 |
| 2012 | Diabetes - The Impact of Maternal Care Disparities on Māori Mothers and Infants | Beverley Lawton | University of Otago | \$1,192,365 | 36 |
| 2013 | He kura: Asthmas support for Māori tamariki at school | Bernadette Jones | University of Otago | \$1,199,064 | 36 |

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|------|--|----------------------------|--|-------------|----|
| 2010 | Addressing barriers to care for young pregnant Māori women and their infants | Beverly Lawton | University of Otago | \$1,199,936 | 36 |
| 2013 | Preventable Māori mortality | Andrew Sporle | University of Auckland | \$1,199,945 | 36 |
| 2006 | The Māori community heart study | Suzanne Pitama | University of Otago | \$1,919,504 | 60 |
| 2007 | Programme Extension: Te Pumanawa Hauora | Mason Durie | Massey University | \$2,345,384 | 36 |
| 2009 | He Kainga Oranga/Community Healthy Housing Intervention Research Programme | Philippa Howden-Chapman | University of Otago | \$2,966,584 | 36 |
| 2012 | He Kainga Oranga/Community Housing and Health Intervention Research Programme | Philippa Howden-Chapman | University of Otago | \$3,749,138 | 36 |
| 2011 | He Kokonga Whare: Māori Intergenerational Trauma and Healing | Paul Reynolds | Independent Māori Institute for Environment and Health: Te Atawhai o te Ao | \$4,728,200 | 60 |
| 2013 | A joint Auckland and Waitemata District Health Board Pacific Demographic and Health Status Report | Zarah Allport | University of Auckland | \$5,000 | 2 |
| 2012 | Cook Island Adolescent perception and behaviour of alcohol use in Auckland | Tupuna Mataio | University of Auckland | \$5,000 | 3 |
| 2013 | A review of community development initiatives for the prevention of self-harm behaviour amongst Pacific youth in New Zealand | Synthia Dash | University of Auckland | \$5,000 | 2 |
| 2012 | The effects on breast cancer in Pacific women and cancer survival rates in regions with most Pacific Island residents | Sara Samuela | University of Otago | \$5,000 | 3 |
| 2013 | A literature review on the health profile of Tuvaluans living in New Zealand | Saneta Manoa | University of Auckland | \$5,000 | 2 |
| 2012 | Health promotion and Pacific Peoples | Rochelle Newport | University of Otago | \$5,000 | 3 |
| 2013 | Pacific health models: Do they fit? | Mayor Mataio | University of Auckland | \$5,000 | 2 |
| 2013 | Barriers to Pacific women breastfeeding in the Waitemata District Health Board region | Manusui Henaua Esther Latu | University of Auckland | \$5,000 | 2 |
| 2013 | The role of culture in Pacific suicide prevention | Luarell King | University of Otago | \$5,000 | 2 |

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|------|---|--------------------------|--------------------------|-----------|----|
| 2013 | Vaevae manava and food security in Tongan communities: A way forward | Litiuingi Ahio | AUT University | \$5,000 | 2 |
| 2013 | Literature review of nutritional issues amongst pregnant Pacific women in New Zealand from ages 15-40 years | Heimata Herman | University of Auckland | \$5,000 | 2 |
| 2013 | Stepping Forward: A needs analysis addressing gaps in knowledge in regards to family violence amongst Pacific people in New Zealand - a literature review | Fakavamoeatu Lutui | University of Auckland | \$5,000 | 2 |
| 2013 | Stepping Forward: A needs analysis addressing gaps in knowledge in regards to family violence amongst Pacific people in New Zealand - a literature review | Fakavamoeatu Lutui | University of Auckland | \$5,000 | 2 |
| 2012 | Identifying risk factors associated with Pacific suicide in New Zealand | Eliza Puna | University of Auckland | \$5,000 | 3 |
| 2013 | Exploring mental health and suicide amongst Cook Islanders: A review of the literature | Eliza Puna | University of Auckland | \$5,000 | 10 |
| 2013 | Pacific smoking cessation services: Will they be enough to help us research Smokefree 2025 goal | Athena Tapu | AUT University | \$5,000 | 2 |
| 2012 | The Canterbury Earthquake: Impact of Pacific Health Provision | Ashalya Noa | University of Canterbury | \$5,000 | 3 |
| 2013 | Depression amongst Tongan (New Zealand born) | Afu Taufa | University of Auckland | \$5,000 | 2 |
| 2012 | Going Local: Impact of sustainable development policies on health in Rarotonga | Rochelle Newport | University of Auckland | \$18,253 | 12 |
| 2012 | Diabetes: Impact on work, income, and finances for Samoan families | Jacqueline Schmidt-Busby | University of Auckland | \$18,253 | 12 |
| 2006 | Samoans and Disability Study | Nite Fuamatu | Massey University | \$101,550 | 36 |
| 2013 | Substance use amongst Samoan youth in New Zealand | Helen Tanielu | University of Auckland | \$105,896 | 36 |
| 2013 | Promoting health literacy to improve health outcomes for Samoan people | Tuaupua Tauheetia-Su'a | Victoria University | \$110,555 | 36 |
| 2012 | Pacific Men's Health and Well-being; The Case of Niue and the Cook Islands | Vili Nosa | University of Auckland | \$150,000 | 36 |

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|------|---|---------------------------|--|-------------|----|
| 2012 | Suicide prevention for Pacific youth in New Zealand: Pacific Community Solutions | Jemaima Tiatia | Auckland Uni Services Ltd | \$289,437 | 20 |
| 2008 | Exploring Samoan women's attitudes towards antenatal and midwifery care | Ausaga Faaselele Tanuvasa | Victoria University | \$303,331 | 36 |
| 2013 | Arterial function, vitamin D and cardiovascular disease in Pacific peoples | John Sluyter | University of Auckland | \$387,195 | 48 |
| 2007 | Strengthening Career Pathways: A Pacific Health Programme of Research | Billie Harbidge | Auckland Uni Services Ltd/University of Auckland | \$570,000 | 29 |
| 2012 | A lifestyle intervention model to address obesity and type 2 diabetes in Pacific | Ofa Dewes | Auckland Uni Services Ltd | \$594,434 | 24 |
| 2010 | Pacific Islands Families Study: Hearing Status of 11-year-olds (PIF:HS) | Philip Schluter | AUT University | \$732,717 | 24 |
| 2011 | Pacific Health Outcomes: Trends, barriers and navigating ways forward | Margaret Southwick | Pacific Perspectives Ltd | \$897,303 | 16 |
| 2008 | Transnationalism in Pacific health through the lens of TB | Judith Littlejohn | University of Auckland | \$1,411,510 | 36 |
| 2010 | New Zealand law on the sterilisations of intellectually disabled girls and women | Amelda Schrenk | University of Waikato | \$5,000 | 3 |
| 2006 | Examination of the outcomes of resettlement of residents from Kimberly Centre: Phase Two | Anne Bray | Donald Beasley Institute | \$540,033 | 24 |
| 2006 | Evaluation of Intersectorial Disability Needs Assessment and Service Coordination Trials: 3-month extension | Anne Bray | Donald Beasley Institute | \$54,248 | 3 |
| 2006 | In search of the molecular basis of mental retardation | Armaz Aschrafi | Massey University | \$138,350 | 36 |
| 2009 | Communication intervention for adults with intellectual disability | Jeff Sigafos | Victoria University | \$150,000 | 12 |
| 2007 | Working in intellectual disability services: Staff retention and turnover | Nancy Higgins | Donald Beasley Institute | \$1,137,610 | 36 |
| 2009 | Reducing inequalities in the Primary Health Sector | Lynda Hare-Rangitauira | Western Bay of Plenty PHO | \$4,000 | 2 |
| 2013 | Cultural perspectives on hearing and hearing aids among Māori and Pacific People | Alehandrea Manuel | University of Auckland | \$5,000 | 2 |

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|------|---|-----------------------|---------------------------|-------------|----|
| 2012 | Racism and its link with body size | Rhiannon Jones | University of Otago | \$5,000 | 3 |
| 2013 | Acceptability and access to primary care: The reception process | Patricia Neuwelt | University of Auckland | \$148,730 | 30 |
| 2010 | Can we reduce Māori and Pacific School children's hospitalisations to Pakeha rates | Diana Lennon | University of Auckland | \$149,883 | 12 |
| 2009 | Studying eye diseases of Māori, Pacific, and the elderly using animal models | Monica Acosta | University of Auckland | \$150,000 | 36 |
| 2009 | What motivates Māori, Pacific and Low SEC users of tobacco to stop smoking? | Marewa Glover | Auckland Uni Services Ltd | \$217,000 | 12 |
| 2010 | Ethnic and socioeconomic differences in pandemic influenza infection in New Zealand | Michael Baker | University of Otago | \$229,323 | 12 |
| 2012 | Translating best practice to reduce equity gaps in immunisation | Nikki Turner | University of Auckland | \$444,809 | 24 |
| 2009 | Inequalities in cervical cancer survival in New Zealand | Lis Ellison-Loschmann | Massey University | \$665,198 | 36 |
| 2007 | Equity in prescription medicines use | Pauline Norris | University of Otago | \$911,503 | 36 |
| 2006 | Cancer trends: Ethnic and socio-economic trends in cancer incidence and survival | Tony Blakely | University of Otago | \$924,356 | 36 |
| 2010 | Whiti Te Ra: Bronchiolitis Disparities among Māori and Pacific children | Tristram Ingham | University of Otago | \$1,146,720 | 36 |
| 2011 | Whiti Te Ra: The Contribution of Housing Conditions to Bronchiolitis Disparities | Tristram Ingham | University of Otago | \$1,157,725 | 36 |
| 2008 | Programme Extension: Health Inequalities Research Programme (HIRP) | Tony Blakely | University of Otago | \$4,310,406 | 36 |

Appendix A-1: Trial Registry Data

Trial Registry Data across the various trial databases comes in different formats, and each trial document has a long trial record. I do not provide a list here of the trials included as once each electronic search engine provided results based on the search strategies described in the chapter, trial registrations were printed and kept as paper records.

I then hand-searched these paper records for statistical descriptions, prospective/retrospective registration and study results/publication descriptions. This searching was repeated multiple times by the author, but not double-checked by a second, given that definitions were clear (i.e. prospective or retrospective inclusion is a line within the trial record and is in no way ambiguous).

Where study results or publications were listed, these were also searched electronically and then printed and attached to the paper registration record. I searched study results and papers for references to demographics and ethnicity data.

Appendix A-2: Health and Disability Ethics Committee Data

New Zealand Health and Disability Ethics Committee provide their annual reports including a list of all reviewed applications on their website.

Methodology

I converted tables of applications in Annual reports' (in PDF/Word format) into Excel. These were then searched using multiple methods:

- 4) Electronic search using "Find" option in Excel searching for terminology related to Māori (Māori, Māori, whenua, kaupapa, whanau, Whānau Ora, nga*, whan*, whak*, *ori, tanga*), Pasifika (Pacific*, Pasifik*, Samoa*, Tonga*, Fiji*, Cook*, Niue*, Kiri*) and Learning Disability (intellectual, learning, Down*, Prada*, fetal*, disability) groups. These provided lists that were then scrutinised for those that pertained to our groups (i.e. some results with *ori or fetal* were not related our case groups, but these were then excluded). A fourth group was created that included those projects related to equity or that involved two of our groups or that included studies that relate to rheumatic fever which has been a particular health issue for Māori and Pasifika children and adults. These terms included: equity, disparity, rheum*, equality, determinants. This was completed by the primary investigator.
- 5) Additionally, manual checking (i.e. checking in each item in the list) was completed by the primary investigator and an external checker (medically trained). Filtering of titles was thrice-checked by the author on three separate occasions each multiple days apart, and by the external checker (medically trained). The principle of charity was used between checkers and searches, insofar as the largest list was used as the final list.
- 6) All titles that were an acronym rather than a title such as "SPRINT Trial" or that were considered ambiguous in the larger list were searched online to check the nature of the study before being included or excluded.

A full dataset (without analysis) has been posted openly for future use by others in the spirit of collaboration and collegiality. It is available from www.figshare.com

Tumilty, Emma (2016): New Zealand Health and Disability Ethics Applications 2005-2013. figshare.

<https://dx.doi.org/10.6084/m9.figshare.3206299.v1>

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| | Māori |
| | Pasifika |
| | Learning Disability |
| | Equity or Multiple case groups |

| Project Key | Short title | Co-ordinating Investigator | Study status |
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| 12/CEN/6 | Could local 'Aunties' facilitate better Māori pregnancy outcomes? | Dr. Marewa Glover | Approve |
| 13/NTB/15 | Intergenerational Communication Practices and Themes within Whanau Māori | Dr. Stephanie Palmer | Approve |
| 13/NTB/4 | Thyrotoxicosis in Māori | Dr. Jade Tamatea | Approve |
| 13/CEN/138 | Te Waiata a Hinetitama | Dr Debra Tepora Emery | Approve |
| 13/STH/187 | Filaggrin mutations in atopic dermatitis in Māori -Revised | Professor Peter Hull | Provisionally approve |
| 12/CEN/18 | Whanau-Ora – whanau-centred engagement and provision | Mrs. Te Moana Campbell-Knowles | Approve |
| 12/CEN/32 | Te Kete Tuatea | Ms Kirikowhai Mikaere | Approve |
| 12/CEN/88 | Optimal antenatal care for Māori woman | Ms. Marnie Reinfelds | Approve |
| 12/NTA/62 | The Māori and Assessment Of Renal Impairment (MĀORI) Study | Dr. Curtis Walker | Approve |
| 12/NTB/32 | Incentives to stop smoking among pregnant Māori women | Dr. Marewa Glover | Approve |
| 12/NTB/5 | Diabetes: The impact of maternal care disparities on Māori mothers | Prof Peter Larsen | Approve |
| NTX/12/05/047 | Ngā Waiata O Tāne Whakapiripiri: music, mental health, and healing in a Māori context. PIS/Cons V#2, 30/04/12 | Lauren E Sweetman | Approved |
| NTX/12/EXP/084 | Palliative care, health literacy, Māori communities and health services | Dr. Sue Crengle | Approved |
| NTX/12/EXP/116 | Korero Mai E Te Whanau – Whanau stories of engagement, innovation and integration. PIS/Cons V#2, 31/05/12 | Ms. Moana Eruera | Approved |
| NTY/12/04/021 | Oranga Niho Nga Tangata Whaiora | Associate Professor John Broughton | Approved |
| NTY/12/04/027 | The Hua Oranga: A Māori measure of mental health | Ms. Kahu McClintock | Approved |

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| | outcome service application | | |
| NTY/12/05/033 | HRC 11/793 He Kokonga Whare: Māori intergenerational trauma and healing | Dr. Paul Reynolds | Approved |
| NTY/12/06/052 | Māori experiences of bipolar affective disorder and pathways to care | Associate Professor Linda Nikora | Approved |
| NTY/12/EXP/007 | Change in patient scores following arthroplasty surgery: are there any differences between Māori and non-Māori? A registry-based cohort study. | Neal Singleton | Approved |
| MEC/12/03/031 | Mouri Whakapapa: Repositioning Māori resistance and well-being in sexual and reproductive health policy and service provision | Ms. Mera Penehira | Approved |
| MEC/12/EXP/038 | Health literacy: and the prevention and early detection of gout; prevention and treatment of skin infections in Māori children, and the screening and management of gestational diabetes | Ms. Susan Reid | Approved |
| MEC/12/EXP/050 | Palliative care, health literacy, Māori communities, and health services | Dr. Jacquie Kidd | Approved |
| MEC/12/EXP/066 | The Wahakura: A qualitative study of the flax bassinet as a safe infant sleeping environment for Māori | Dr. Sally Abel | Approved |
| URA/12/03/007 | Whaia Te Waimarino: The experiences of Māori who may use Psycho-Oncology Services | Dr. John Waldon | Approved |
| NTY/12/06/054 | Aunty Whakahaere Hapunga Initiative (AWHI): Could local 'aunties' facilitate better Māori pregnancy outcomes? | Dr. Marewa Glover | Closed |
| CEN/11/03/014 | Culturally Appropriate End of Life Care for Māori | Dr. Maureen Holdaway | Approved |
| CEN/11/11/059 | Whakatirotirohia nga korero a te Māori mau atu ki te whakatakotoranga whakaaro petipeti - Exploring Māori input decision-making on gambling | Dr. Nicole Coupe | Approved |
| MEC/11/EXP/079 | Māori women's experiences of healthcare in the pregnancy, birth and postpartum periods. | Maria Baker | Approved |
| MEC/11/EXP/084 | The perspectives of speech language therapists on working in communication disorders with Māori clients | Ms. Carolin Jentsch | Approved |
| MEC/11/EXP/099 | Palliative Care, Health Literacy, Māori Communities and | Dr. Sue Crengle | Approved |

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|----------------|--|--------------------------|----------|
| | Healthcare Services | | |
| MEC/11/EXP/129 | What Are The Challenges Faced by Māori Rural Health Nurses in Accessing Knowledge To Support Their Practice? | Ms. Gina Chaffey-Aupouri | Approved |
| MEC/11/EXP/132 | Trends in Genital Wart National Sentinel Surveillance Data for Māori and Non-Māori Following The Introduction of Quadrivalent Human Papilloma Virus Vaccination in New Zealand | Dr. Kerry Sexton | Approved |
| NTX/11/04/022 | Nutritional well-being of Māori living to advanced age: kai ora me to noho a te kaumatua Māori: PIS/Cons V# 27/4/11 | Mr. Eruera Maxted | Approved |
| NTX/11/05/034 | Kaumatua Well-being study: Supporting whanau aspirations of Whānau Ora: PIS/Cons V#2, 26/05/11 | Mr. John Waldon | Approved |
| NTX/11/09/082 | The evaluation of anatomical and biomechanical parameters of the feet in Māori with diabetes: a feasibility study: PIS/Con V#2, 21/09/11 | Professor Keith Rome | Approved |
| NTX/11/EXP/197 | Reducing and preventing violence in tamariki Māori | Dr. Stacey Byers | Approved |
| NTX/11/EXP/207 | Te kete o wananga: What are the beliefs, intentions, needs, and capabilities of Māori participation in lifestyle programmes to improve metabolic health from a rural community? PIS/Cons V#2, 25/11/11 | Dr. Geoff Kira | Approved |
| NTX/11/EXP/208 | Reducing and preventing violence in taitamariki Māori intimate partner relationships in the context of their whanau, hapu and iwi. PIS/Cons v#1, 3/8/2011 | Ms. Terry Dobbs | Approved |
| NTX/11/EXP/261 | Exploring the end of life experiences of Māori and non-Māori living to advanced old age in Aotearoa, New Zealand: a study to identify research priorities and methods | Professor Merryn Gott | Approved |
| NTX/11/EXP/308 | WERO: Whanau End smoking Regional Whānau Ora Challenge | Dr. Marewa Glover | Approved |
| NTY/11/05/057 | Tangata-centred Huntington's disease research: partnership between Māori whanau and biomedical scientists. | Dr. Melanie Cheung | Approved |
| NTY/11/06/067 | Why do Māori Women in Taupo Have a Low Cervical | Dr. Helen Patricia Loan | Approved |

| | Screening Rate? | | |
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| NTY/11/08/085 | Māori Health Literacy and Communication in Palliative Care: Kaumatua-led Models. | Mrs. Rangimahora Moko Reddy | Approved |
| NTY/11/EXP/054 | Negotiating Māori Kaumatua 'Space' in Ageing Healthcare in Aotearoa New Zealand: Ka tae au ki taku Kaumatuatanga ma wai au e tiaki? (Who will look after me when I grow old?) | Ms. Marie Were | Approved |
| URB/11/07/021 | Te Hoe Nuku Roa: Best Health for Māori: Nelson Marlborough District Health Board Study | Professor Chris Cunningham | Approved |
| MEC/11/03/024 | Impacts of Gambling for Māori Families and Communities: A Strengths-Based Approach to Achieving Whānau Ora | Ms. Mere Balzer | Approved |
| NTX/11/09/086 | Ko tōu Manawa, ko tōku Manawa ka ora: Pain and suffering through Māori Eyes. PIS/Cons V#2, 13/09/2011 | Ms. Marara Rogers-Koroheke | Approved |
| NTX/11/EXP/116 | Exploring mental health service users' sensory experiences during participation in Kapa haka: PIS/Cons V#4 | Ms. Tania Hollands | Approved |
| CEN/11/11/057 | Tipping Points: The Relationship between Māori Youth Workforce Participation and Mental Health | Professor Linda Smith | Approved Subject to Conditions |
| NTY/11/11/107 | A 12 week, Kaupapa Māori, comprehensive cardiac risk reduction programme that specialises in exercise and Māori appropriate lifestyle modification education | Ms. Anna Rolleston | Approved Subject to Conditions |
| LRS/11/12/059 | Māori Child Maltreatment: A Way Forward: He Ara Whakamua | Ms. Helen Harte | Deferred |
| CEN/11/EXP/075 | Stocktake and Profile of Māori Healthcare Workers in Hawke's Bay | Professor R.N Marshall | Ethical approval not required |
| MEC/11/EXP/065 (a) | Evaluating the process within the Whānau Ora System for the National Hauora Coalition | Mr. Antony Raymont | Ethical approval not required |
| NTY/11/EXP/041 | Comparison of complications following lower limb arthroplasty between Māori and non-Māori. | Mr. Dawson Muir | Ethical approval not required |
| CEN/11/EXP/026 | Evaluation of Whanau Auahi Kore Project | Dr. Heather Gifford | Ethical approval not required |
| MEC/10/001/EXP | He Kura Aro Huangō: How are primary schools responding to the needs of Māori children with Asthma? | Bernadette Jones | Approved |
| MEC/10/01/011 | Māori deaf children and their whānau: A study of the nature | Kirsten Smiler | Approved |

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| | and impacts of early intervention | | |
| MEC/10/026/EXP | Developing Mahi Oranga - a Māori-specific measure of occupational well-being | Ms. Lisa Stewart | Approved |
| MEC/10/05/042 | Te Tomo mai, Responsive Child and Adolescent Mental Health Services (CAMHS) for Māori Rangatahi | Ms. Kahu McClintock | Approved |
| MEC/10/050/EXP | Racism as a health determinant: implications for Māori health and inequalities | Dr. Ricci Harris | Approved |
| MEC/10/060/EXP | Te whakapunanga me te whakaita i ngā tāngata whaiora Māori - Towards understanding seclusion and restraint on Māori | Dr. Melissa McLeod | Approved |
| MEC/10/10/106 | Ngā Tohu o te Ora: Traditional Māori Wellness Outcome Measures – Stage two of MEC/08/08/098 | Mr. Maui Hudson | Approved |
| CEN/10/09/041 | Central Corneal Thickness in a Māori Population in Hawke's Bay | Dr. Alex Buller | Approved Subject to Conditions |
| CEN/10/02/10 | The Type, Grade, Stage at Diagnosis, and Survival Rates in Endometrial Cancers in new Zealand Māori and non-Māori population. | Dr. Dushyant Maharaj | Approved |
| CEN/10/03/11 | Māori Perspectives on Hospice Care | Ms. Elizabeth Taylor | Approved |
| CEN/10/05/018 | Within the Current Primary Healthcare System How Easy is It for Registered Nurses Employed by Māori Healthcare Providers to Work in a Holistic Way with People with Type 2 Diabetes | Ms. Liz Day | Approved |
| CEN/10/07/024 | The Effect of An Acute Bout of Exercise on Smoking Withdrawal Symptoms (craving) in Māori | Dr. James Faulkner | Approved |
| CEN/10/09/036 | Wahine Hauora : Reducing Barriers to Care for Pregnant Māori Women 20 and their Infants | Dr. Beverley Lawton | Approved |
| CEN/10/09/040 | A Feasibility Study of EGFR Testing for Māori Patients with Non-Small-Cell Lung Cancer (HRC Ref ID: 10/675) | Lesley Batten | Approved |
| CEN/10/EXP/01 | A Needs Assessment to Identify if Specific Kai Preparation and Cooking Skills is a barrier to Healthy Eating for Adult Māori with Diabetes or at Risk of Diabetes, Principally Enrolled in Valley PHO and A resident in | Ms. Tammy Kaiwai | Approved |

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| | Wainuiomata | | |
| CEN/10/EXP/04 | Use of Public and Private Health Services by Māori and Non-Māori women: An audit of uterine biopsy laboratory results | Dr. Beverley Lawton | Approved |
| CEN/10/EXP/05 | Facilitating Whanau Resilience Through Māori Primary Health Intervention | Dr. Alexander Sasse | Approved |
| MEC/10/072/EXP | He Kakano: Māori views and experiences of fertility, reproduction, and ART - a review of epidemiological and statistical data. | Dr. Donna Cormack | Approved |
| MEC/10/082/EXP | Well Child/ Tamariki Ora Nursing: Who are the Māori Health Provider Well Child/ Tamariki Ora registered nurses and what are their experiences in delivering a Well Child/ Tamariki Ora program to Tamariki Māori and their Whanau? | Ms. Haley Petkovich | Approved |
| NTX/10/07/063 | He Kakano ahau i ruia mai i Rangiatea: engaging Māori in child and adolescent mental health services: PIS/Cons V#2, 3/08/10 | Ms. Pikihuia Pomare | Approved |
| NTY/10/06/056 | Critical Success Factors in Kaupapa Māori AOD residential treatment: Māori Youth Perspectives. | Dr. Ria Schroder | Approved |
| NTY/10/06/059 | VerifyNow Assessment of Māori Platelet Inhibition Relative to European New Zealanders. (VAMPIRE). | Dr. Gerard Devlin | Approved |
| NTY/10/EXP/052 | An examination of research carried out by the Mental Health Foundation on the subject of the over representation of Māori people in mental health services. | Mr. Abraham Matonga | Approved |
| NTY/10/EXP/095 | Toiora: Conceptualisation and measurement for iwi and Māori communities. | Ms. Jodi Porter | Approved |
| URA/10/11/074 | A community-based participatory approach to diabetes education for Christchurch Māori | Ms. Alison Farmer | Approved |
| URA/10/EXP/041 | What is the cost? Estimating the economic costs of Māori: Non-Māori child health inequities in Aotearoa. A scoping study. | Dr. Papaarangi Reid | Approved |
| URB/10/03/014 | Hauora Māori day Review and Evaluation Project | Mr. Cameron Lacey | Approved |

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| NTY/10/04/034 | He whakamarama rua I te wairangi o te hinengaro: At the interface – A bicultural understanding of psychoses. | Mr. Jhanitra Gavala | Approved |
| MEC/10/088/EXP | A feasibility study of EGFR testing for Māori patients with non-small-cell lung cancer | Mr. Christopher Drury | Approved Subject to Conditions |
| NTX/10/11/117 | Oral health promotion services for young Māori pregnant women in the Whangaroa Health Services region | Professor Jeffrey T.F. Watts | Approved Subject to Conditions |
| NTX/10/12/129 | The secret to happiness - narratives from Māori elders in the Bay of Plenty | Ms. Marama McDonald | Approved Subject to Conditions |
| NTY/10/12/101 | The experiences of Māori with aphasia and their whanau. | Ms. Karen McLellan | Approved Subject to Conditions |
| URB/10/11/047 | Tupu Ake: Developing a kaupapa Māori definition of resiliency for rangatahi in Taranaki | Ms. Bry Kopu | Approved Subject to Conditions |
| NTY/10/10/081 | Rites of Passage: Strengthening the capacity of Māori communities to support whanau aspirations for Whānau Ora. | Mere Balzer | Ethical approval not required |
| NTY/09/03/027 | Oranga Tāne Māori. | Mr. Wayne Johnstone | Approved |
| CEN/09/05/030 | A Kaupapa Māori qualitative investigatory study into the origins of domestic violence within the whanau of Taranaki | Dr. Janice Wenn | Approved |
| CEN/09/09/068 | Wahine Hauora: Reducing Barriers to care for Pregnant Mums and their Whanau | Dr Beverley Lawton | Approved |
| CEN/09/11/085 | Māori Adaptation of an Ultra-Brief Intervention for Common Mental Health Syndromes in Primary Care | Fiona Mathieson | Approved |
| CEN/09/32/EXP | Identifying pathways that support Māori access of Psycho- Oncology services within MidCentral DHB region | Julie Beckett | Approved |
| CEN/09/55/EXP | Health Professionals Experience Delivering Asthma Services to Māori Children | Bernadette Jones | Approved |
| LRS/09/10/044 | Perspectives on the ethical and practical issues of prenatal alcohol use screening for indigenous females: Māori and Native American Indian | Ms. C Angelina Mattheiss | Approved |
| NTX/09/161/EXP | The acceptability of cystisine by Māori people that smoke | Dr. Marewa Glover | Approved |
| NTY/09/01/003 | A pilot study to test the effectiveness of a Computerised CBT resource for Māori adolescents experiencing mild to moderate depressive disorder. | Matthew Shepherd | Approved |

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| NTY/09/02/009 | An Evaluation of the Rangatahi Māori Sexual and Reproductive Health Strategy for Hamilton: The “Rangatahi Realising Potential” Project. | Ms. Naina Watene | Approved |
| NTY/09/05/045 | Acceptance of a computer-based heart imagery programme in the exploration of beliefs about heart failure and adherence to symptom management among Māori | Ms. Eva Rose Morunga | Approved |
| NTY/09/08/069 | Improving Access for Māori to Palliative Care Services in Te Tai Tokerau/Northland. | Ms. Liane Penney | Approved |
| NTY/09/09/091 | A randomised controlled trial of a family-centred tobacco control program about environmental tobacco smoke (ETS) to reduce respiratory illness in Māori infants. | Dr. Natalie Walker | Approved |
| NTY/09/10/104 | Kia Ngawari: Investigating Palliative Care of Māori and their Whanau. | Dr. Tess Moeke-Maxwell | Approved |
| NTY/09/59/EXP | The 'Potential Benefit' of Māori Models of Health/Practice in Forensic Psychiatry Inpatient Settings. "What is the level of knowledge and experience of Māori Models of health/practice in acute Forensic Psychiatric inpatient setting of Ward 33 of the Henry Rongomau Bennett Centre, Waikato? | Mr. Taipu Moana | Approved |
| URA/09/10/071 | Exploring the experiences of Māori patients and whanau living with chronic kidney disease (CKD) within the CDHB | Tania Huria | Approved |
| NTY/09/09/093 | “Te Kaponga” – Whanau Māori and Mental Health: Snapshots of Strengths, Resiliency and Recovery. | Mere Balzer | Approved Subject to Conditions |
| NTY/09/11/110 | Evaluation of breastfeeding support services for Māori whanau in Te Tai Tokerau. | Ms. Amber Logan-Riley | Approved Subject to Conditions |
| NTY/09/10/106 | Mauri Ora – growing healthy tamariki (children), whanau (families) and hapu (extended family groups) in Tuhoe communities. | Ms Haromi Williams | Approved Subject to Conditions |
| NTY/09/12/121 | Resilient Whanau: Well-being through innovation and traditional practice (WHA 08/01). | Ms. Tania Broughton | Deferred |
| CEN/08/06/026 | Supporting whanau as carers – a project to determine the support needs for Māori caring for loved ones dying at home | Ms. Dianne Keip | Approved |

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| | from cancer in the Hawke's Bay. | | |
| CEN/08/09/049 | The experience of urban Māori women and perceived delay in accessing women's healthcare in Aotearoa New Zealand: an exploratory study. | Beverley Parton | Approved |
| CEN/08/11/058 | Identification and description of the barriers and facilitators for Māori in maintaining healthy lifestyle changes using a Kaupapa Māori research framework. | Christine Kerr | Approved |
| MEC08/03/031 | Research priorities by Māori with disabilities and their whanau | Dr. Adelaide Collins | Approved |
| MEC/08/09/102 | Stomach cancer in Māori | Dr Lis Ellison-Loschmann | Approved |
| NTX/08/03/017 | Engagement pathways for Māori in mental health services at Auckland District Health Board: PIS/Cons V#2, 25/03/08 | Mr. Tom Ruakere | Approved |
| NTX/08/97/EXP | Monitoring sexually-transmitted infections among Māori in the Bay of Plenty | Dr. Clive Aspin | Approved |
| NTX/08/98/EXP | Impact on Māori clients and their family/whanau who have end stage renal failure and receive haemodialysis, and who live in rural areas of Northland: PIS/Cons V#2, 7/10/08 | Ms. Shih Li-Chin | Approved |
| NTY/08/02/012 | Characteristics of non-alcohol/drug users, particularly non-drinking (or non-problem-drinking and non-smoking) Māori youth/taiohi (under age 18) | Ms. Keri Thompson | Approved |
| NTY/08/05/048 | An investigation into the lung cancer management pathways for Māori in Northland | Ms. Amber Riley | Approved |
| NTY/08/05/050 | The impact of oranga niho on quality of life of rangatahi Māori aged between 16 years and 18 years who reside within the Waikato rohe of Tainui | Assoc Prof John Broughton | Approved |
| NTY/08/20/EXP | Kaupapa Māori advanced nurse practitioner (KMAN) service patient survey | Ms. Amber Logan-Riley | Approved |
| URA/08/08/053 | Te Pounamu: a study to explore the acceptability of a Māori explanatory model of mental well-being for rangatahi and their whanau in a Kaupapa Māori mental health | Alicia Graham | Approved |

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| | setting | | |
| URA/08/12/EXP | The quality of public hospital care for Māori and New Zealand Europeans in Christchurch, New Zealand | Dr. Juliet Rumball-Smith | Approved |
| URB/08/08/034 | Te Hoe NukuRoa: best health for Māori pilot study | Prof Chris Cunningham | Approved |
| NTX/08/09/084 | Te Tomokanga: a model for facilitating bicultural health policy and programme development: PIS/Cons V#2, 8/10/08 | Ms. Annabel Ahuriri-Driscoll | Approved |
| CEN/08/09/044 | Wahine hauora – inequalities in uterine cancer: exploring the pre-diagnosis gap. | Dr. Beverley Lawton | Approved |
| LRS/08/08/036 | Whakawhirinakitanga Ahua: exploring an iwi model of health service delivery | Carol Ann Fernandez | Approved |
| MEC/08/04/048 | He Kakano: Māori views and experiences of fertility, reproduction, and ART | Dr. Paul Reynolds | Approved |
| MEC/08/09/098 | Ngā Tohu o te Ora: traditional Māori wellness outcome measures | Maui Hudson | Approved |
| NTX/08/11/113 | Māori whanau experiences of neonatal intensive care services | Dr. Jenny Lee | Approved subject to conditions |
| NTY/08/11/106 | Whanau talk: how whanau construct diabetes | Ms. Te Maramatanga Alexandrian Hohaia | Approved subject to conditions |
| MEC/08/04/041 | Does cross-sectoral collaboration hold the key to Māori achieving their environmental goals? Using mahinga kai as the vehicle for exploring opportunities | Dr. Gail Tipa | Ethical approval not required |
| MEC/08/04/040 | Clinical characteristics of multiple sclerosis in Māori in New Zealand | Dr. Jennifer Somerfield | Suspended |
| MEC/07/02/028 | He Puawaitanga mo te Mana o te Whanau: Mental healthcare 'responsiveness' to Māori | Louise Ihimaera | Approved |
| MEC/07/04/050 | Health measurement and knowledge translation for improved Māori health outcomes. | Ms. Liane Penney | Approved |
| MEC/07/08/110 | Growing up Kapo Māori: whanau, identity, cultural well-being and health. | Dr. Nancy Higgins | Approved |
| NTX/07/07/075 | Barriers and enablers for Māori experiencing the colorectal cancer pathway from diagnosis to treatment through the Waikato Cancer | Ms. Kay Berryman | Approved |

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| | Services, Waikato Hospital: PIS/Cons V#2, 5/09/07. | | |
| NTY/07/06/061 | A diabetes-related lower limb pathology control demonstration intervention for Māori. | Ms. Liane Penney | Approved |
| NTY/07/07/072 | A pilot study of the impact of oranga niho on quality of life of rangatahi Māori. | Assoc Prof John Broughton | Approved |
| CEN/07/03/015 | Health, cultural and social experiences of Māori affected by chemical-related illness. | Dr. Cheryl Smith | Approved |
| NTX/07/11/115 | Survey of SIDS-related infant care practices in Māori families. | Dr. David Tipene-Leach | Approved subject to conditions |
| CEN/07/07/048 | Pukapuka Hauora: Māori parents' experiences managing a child with asthma. | Bernadette Jones | Approved |
| LRS/07/04/007 | The principles of Māori directed practice and development. The development of a tikanga Māori informed community development evaluation framework. | Mr. Anaru Eketone | Approved |
| CEN/06/02/006 | Older Māori and medication management, regulation and facilitation: characteristics, influences, indicators and attitudes of medication taking practice and behaviour in older Māori | Bevan Clayton-Smith | Approved |
| CEN/06/02/009 | Cognitive behavioural therapy (CBT) in Aotearoa: CBT for depression with Māori tangata whaiora | Dr. Simon Bennett | Approved |
| CEN/06/06/058 | A community-based health needs assessment of the oral health needs of Māori mothers enrolled with a Wellington-based Māori health provider | Ms. Charrissa Makowharemahihi | Approved |
| CEN/06/10/085 | A cultural approach to music therapy in New Zealand: a Māori perspective | Dennis Kahui | Approved |
| LRS/06/02/002 | Improving Māori health and well-being through kaitiakitanga: undertaking research that: <ul style="list-style-type: none"> defines cultural based experiences in the environment that can be used as a preventative intervention to enhance Māori health and well-being develops tools to assess the effect of different types of | Dr. Gail Tipa | Approved |

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| | <p>cultural based experiences in the environment on Māori health and well-being</p> <ul style="list-style-type: none"> develops a framework for applying the tool and collecting data about health outcomes for Māori resulting from application of such an intervention. | | |
| MEC/06/01/008 | Māori women's access to the national cervical screening pathway and Breastscreen Aotearoa screening pathways | Ms. Nicole Coupe | Approved |
| MEC/06/02/010 | Te Tomokanga, acceptable child/ adolescent mental health services for New Zealand Māori | Kahu McClintock | Approved |
| MEC/06/03/026 | The Māori community heart study | Suzanne Pitama | Approved |
| MEC/06/10/113 | A formative investigation of the impacts of gambling, including problem gambling, on Māori communities, whanau/hapu/iwi: a national Māori collaborative approach | Naina Watene | Approved |
| MEC/06/10/125 | Organisational pre-requisites to fund, implement, and sustain a Māori health promotion model in a primary care setting | Dr. Heather Gifford | Approved |
| NTX/06/17/CPD | The burden of renal disease in Māori with diabetes in South Auckland. | Dr. Mark Marshall | Approved |
| NTY/06/08/072 | Evaluation of Manaaki Manawa: a Kaupapa Māori cardiac rehabilitation programme | Ms. Wendy Henwood | Approved |
| NTY/06/11/115 | Community-based medical education: benefits and drawbacks from students, PGY 1 HOs (house officers), teaching GPs, practice staff and Māori and non- Māori patients | Dr. Tana Fishman | Approved |
| MEC/06/03/019 | The role of resiliency in responding to blood-borne viral and sexually transmitted infections in indigenous communities | Dr. Clive Aspin | Approved |
| CEN/06/05/035 | The experiences of a group of rangatahi Māori with psychosis during the Tuakiri o te Tangata programme | Ms Menetta TeAonui | Approved subject to conditions |
| MEC/06/07/069 | Upper gastrointestinal cancer in Māori and non-Māori | Dr. Lis Ellison-Loschmann | Approved subject to conditions |

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| NTY/06/12/130 | He Kete Korero: Māori health researcher and provider views on Kaupapa Māori and validation frameworks | Dr. Leonie Pihama | Approved subject to conditions |
| NTY/06/11/123 | Does cardiovascular rehabilitation improve the quality of life for Māori? | Ms. Helen Wihongi | Approved subject to conditions |
| MEC/06/10/130 | Health measurement and knowledge translation for improved Māori health outcomes | Dr. Robyn Manuel | Deferred |
| NTY/06/04/027 | Outcome evaluation of the centre for continuing education's iwi and Māori community initiatives project of the Frankton/Dinsdale Rauawaawa Trust | Ms. Andrea Elliot-Hohepa | Ethical approval not required |
| CEN/05/05/027 | Ngā Mokai Whānau Ora – Pilot Study | Ms. Monique Mackenzie | Approved |
| CEN/05/09/070 | Reliability of diagnoses of schizophrenia in Māori and non-Māori pilot study | Dr. Tai Kake | Approved |
| LRS/05/02/001 | Inheritance of type 2 diabetes in the Parata Whanau | Miss Emma Wyeth | Approved |
| MEC/05/03/036 | Raranga Whatumanawa: Research services on mental injury in survivors of sexual abuse: diagnosis and rehabilitation guidelines | Cheryl Wooley | Approved |
| MEC/05/06/072 | Identifying barriers to car driver licensing among Māori | Dr. Dorothy Begg | Approved |
| MEC/05/11/156 | Cognition and Psychopathology in Māori diagnosed with Schizophrenia: follow-up study | Dr. Anna Bashford | Approved |
| MEC/05/12/174 | Rakaipaaka Health and Ancestry Study | Dr. Rod A Lea | Approved |
| NTX/05/05/048 | Depression and Māori: experiences regarding antidepressant medication: a qualitative study: PIS/Cons V#2, 19/5/05 | Associate Professor Bruce Arroll | Approved |
| NTY/05/02/009 | A proposal for Foreign Studies Fellowship: a Brown University – University of Auckland co-operative pilot investigation of the traditional/western medicine interface in contraceptive health in young Māori women; summer studentship | Professor Colin Mantell | Approved |
| NTY/05/03/011 | The best of both worlds? An exploration of the relationship between kaupapa Māori and participatory action research methodologies in supporting Māori community development | Margareth Broodkoorn | Approved |

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| NTY/05/08/055 | A diabetes-related lower limb pathology control demonstration intervention for Māori | Associate Professor Mihi Ratima | Approved |
| NTY/05/10/077 | Ko taku iwi tuaroa tena – key factors in decision-making about immunisation among Māori | Ms. Stephanie Palmer | Approved |
| NTY/05/12/100 | To improve our understanding of tangata whaiora Māori and whanau needs from mental health inpatient services when acutely unwell. This project aims to identify factors that contribute to better outcomes for Māori when admitted to Te Whetu Tawera (TWT), Auckland City Adult Inpatient Mental Health, Auckland District Health Board (ADHB). | Ms. Julie Maria Wharewera- Mika | Approved |
| URA/05/10/122 | Marlborough Māori experience in accessing mental health services via primary healthcare: an exploratory study | Lorraine Eade | Approved |
| URA/05/11/145 | A profile of Māori engaged with opiate substitution therapy in Christchurch | Mr. Paul Robertson | Approved |
| URA/05/11/147 | Māori consumers perspectives on genetic research | Suzanne Pitama | Approved |
| URA/05/11/149 | The design, implementation, and evaluation of a heart disease and diabetes education programme for Māori | Josephine (Jo) Mary Elizabeth Janssen | Approved |
| URB/05/08/102 | Tissue bank: investigation into possible biological reasons for the discrepancy in cancer survival of Māori vs non-Māori in New Zealand | Dr. Gabi Dachs | Approved |
| URB/05/10/136 | Resilient indigenous health workforce networks: constructing an international framework | Mr. Paul Robertson | Approved subject to conditions |
| NTX/05/03/023 | Māori cardiac and stroke rehabilitation study | Ms. Helen Wihongi | Completed |
| CEN/05/02/007 | Nga Mokai Whānau Ora | Mr. Denis O'Reilly | Deferred |
| MEC/05/09/118 | (Retrospective review) Māori and assisted human reproduction: an exploratory study | Dr. Marewa Glover | Deferred |
| URA/05/08/088 | Māori and physical activity in Marlborough: part 2 of the research project carried out for Maata Waka ki Wairau Inc. | Ms. Melissa Love | Ethical approval not required |
| CEN/05/10/072 | Rakaipaaka Health and Ancestry Study | Ms. Helena Barwick | Transferred to M/C committee |
| 13/CEN/51 | Promoting health literacy on cardiovascular diseases (CVD) | Mrs. Tua Tauetia-Su'a | Approve |

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| | to improve health outcomes for Samoan people | | |
| 13/STH/75 | TALANOA Samoa | Dr. Vili Nosa | Approve |
| 13/NTA/12 | PIF:CYP | Professor Janis Paterson | Approve |
| 12/CEN/73 | Pilot Study: Metabolic Growth and Development of Pacific Children | Dr. Edward Saafi | Approve |
| NTX/12/06/053 | Gout and its impact-improving pacific outcomes | Professor Bruce Arroll | Approved |
| NTX/12/EXP/092 | Malaeola – Pacific family violence prevention – evaluation | Catherine Malama Poutasi | Approved |
| NTY/12/EXP/009 | The perceived barriers to following dietary advice in Pacific Island women with diabetes in pregnancy, in the Waikato District Health Board region | Dr. Alexandra Chisholm | Approved |
| CEN/11/03/011 | Validation of the WHO Alcohol Smoking Substance Involvement Screening Test (ASSIT) in Pacific Peoples in New Zealand | Dr. David Newcombe | Approved |
| CEN/11/EXP/005 | Pacific Peoples and Their Stories of Gout | Associate Professor Annemarie Jutel | Approved |
| MEC/11/02/018 | Pacific mental health services: Improving service responsiveness to meet the needs of Pacific populations. | Ms. Nandika Currey | Approved |
| MEC/11/EXP/062 | Primary Care for Pacific People - A Pacific and Health Systems Approach | Dr. Timothy Kenealy | Approved |
| NTX/11/02/006 | A pilot study: Pacific peoples' awareness and understanding of rheumatic fever: PIS/Cons V#2, 15/03/11 | Ms. Nancy Naea | Approved |
| NTY/11/03/031 | Gapatiaga i le maliu: examining customs and cultural practices that support Samoan men and their aiga through bereavement. | Mr Byron Malaela Sotiata Seiuli | Approved |
| NTY/11/06/066 | The experience of depression in the Tokelauan culture | Dr. Iain Loan | Approved |
| NTY/11/EXP/061 | Online Mental Health Information: A Pacific Perspective | Ms. Bernadette Peni | Approved |
| CEN/10/EXP/27 | Exploring if Samoan men make any lifestyle changes following cardiovascular risk assessment (CVRA) | Ms. Tuaupua Tauetia Su'a | Approved |
| LRS/10/11/059 | Infertility in Samoa and its relationship to chlamydial infection | Professor Philip C Hill | Approved Subject to Conditions |
| NTX/10/12/124 | Suicidal behaviours and ideation amongst Samoan people: the journey towards | Ms. Jemaima Tiatia | Approved Subject to Conditions |

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| | prevention | | |
| NTX/10/EXP/058 | The epidemiology of rheumatic fever and its complications in Samoa | Professor Diana Lennon | Approved subject to conditions |
| CEN/10/EXP/17 | HEHA Community Action Project: A Case Study of how HEHA was Implemented Among Pacific Communities in the Hutt Valley | Ms. Milli Burnette | Approved |
| MEC/10/055/EXP | Developing a Pacific mental health intervention: What is therapeutic? | Dr. Karlo Mila-Schaaf | Approved |
| NTX/10/10/100 | A prospective randomised controlled, open two-group, one-year feasibility trial of personal trainer facilitated individually tailored gym based structured resistance exercise programme, in comparison to usual care for Pacific adults diagnosed with type 2 diabetes mellitus | Associate Professor Mathew Parsons | Approved |
| URB/10/10/037 | Pacific people and non-financial factors influencing access to mainstream general practice services | Dr. Lynley Cook | Approved |
| NTY/10/11/092 | Pacific Islands Families Study: Hearing Status of 11-year-olds (PIF: HS) | Dr. Janis Paterson | Approved Subject to Conditions |
| CEN/09/10/076 | Community reintegration of Male Pacific Prisoners with Mental Health Issues : A Public Health Perspective | Mr. Sione Feki | Approved |
| NTY/09/09/083 | Quality Of Life Amongst Pacific People Living With Type 2 Diabetes Mellitus In New Zealand. | Ms. Claire O'Brien | Approved Subject to Conditions |
| NTX/09/13/EXP | Evaluation of the Enea Ola Pacific Community HEHA Project: PIS/Cons V#1 30/1/09 | Dr. Janet Clinton | Re-confirmed |
| MEC/08/07/076 | Transnationals in Pacific health through the lens of tuberculosis | Dr. Judith Littleton | Approved |
| MEC/08/61/EXP | Consumers with chronic conditions and chronic conditions and care: perspective of Pacific older people | Dr. Nicolette Sheridan | Approved |
| NTX/08/04/034 | A profile of traditional Pacific tattooing in New Zealand | Dr. Leti Lima | Approved |
| NTX/08/09/087 | Qualitative study of older Pacific informal caregivers of a child or young person with a chronic illness or disability: PIS/Cons V#4, 15/10/08 | Dr. Siale 'Alo Foliaki | Approved |

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| NTX/08/16/EXP | Adherence to medication: data analysis of two Pacific general practices | Dr. John Kennelly | Approved |
| NTX/08/17/EXP | Adherence to medication in a Pacific general practice: qualitative review and nurse-led intervention | Dr. Kuinileti Chang Wai | Approved |
| NTX/08/119/EXP | Length of stay of Pacific people with urosepsis | Ms. Gretchen Thomas | Approved |
| NTY/08/04/027 | Factors that support abstinence or responsible alcohol consumption amongst Pacific youth: a qualitative investigation | Dr. Tamasailau Suaalii-Sauni | Approved |
| NTY/08/04/035 | Pacific Islands families study: oral health (PIF:OH) | Assoc Prof Theresa Madden | Approved |
| NTY/08/04/037 | Process mapping with families of Pacific mental health consumers in a community mental healthcare setting | Dr. Tamasailau Suaalii-Sauni | Approved |
| CEN/08/05/025 | How do Samoan people with type 2 diabetes mellitus who need insulin for good glycaemic control, come to terms with their therapy? A qualitative exploratory descriptive study. | Ms. Sera Tapu-Ta'ala | Approved |
| MEC/08/09/103 | Exploring Samoan women's attitudes towards antenatal and midwifery care | Dr. Ausaga Faaselele Tanuvasa | Approved |
| NTX/08/05/044 | Validation of the Edinburgh postnatal depression scale as a screening tool for postnatal depression in Samoan and Tongan women: PIS/Cons V#3, 17/06/08 | Dr. Alec J Ekeroma | Approved |
| NTY/08/29/EXP | An innovative approach to the treatment of subcutaneous panniculitis-like T-cell lymphoma in Polynesian patients with cyclosporine achieves excellent outcomes in comparison to those treated at the Mayo clinic | Dr. Jovina Goh | Approved |
| NTX/08/09/088 | An evaluation of a pictorial childhood asthma medication plans for supporting asthma self-management in Pacific families | Mr. John Kristiansen | Approved subject to conditions |
| NTY/08/12/119 | The core Pacific Islands families study: towards adolescence (PIF: TA) | Dr. Janis Paterson | Approved Subject to Conditions |
| NTY/08/12/118 | Pacific Island families study: nutrition, body size and physical activity of 9-year-old children (PIF:NBS-2) | Dr. Janis Paterson | Approved Subject to Conditions |
| NTX/08/78/EXP | Project to scope Pacific matua advisory capacities within | Dr. Tamasailau Suaalii-Sauni | Ethical approval not required |

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| | WDHB | | |
| CEN/07/06/039 | Skin and wound management in the homes of Pacific children hospitalised with skin infection. | Elaine Ete-Rasch | Approved |
| NTX/07/05/031 | Use of the Case-finding and Help Assessment Tool (CHAT) to assess mental health and violence issues in Pacific populations in Auckland: Questionnaire and PIS/Cons V#2, 24/05/07: Cons for students V#1 24/5/07. | Dr. Felicity Goodyear-Smith | Approved |
| NTX/07/05/050 | Health of Pacific children: environmental and nutritional determinants (Healthy End): PIS/Cons V#3, 17/07/07. | Ms. Shamshad Karatela | Approved |
| NTX/07/28/EXP | Evaluation of the Pacific Islands Heartbeat's health promoting churches health promotion programme. | Dr. Janet Clinton | Approved |
| NTX/07/32/EXP | Evaluation of the Auckland Pacific community project: PIS/Cons V 23/03/07. | Dr. Janet Clinton | Approved |
| NTX/07/76/EXP | Pacific Island community support workers role in mental health services (ADHB). | Siosinita Alofi | Approved |
| NTY/07/05/048 | An exploratory study of factors that influence the retention of Pacific health professionals working in Pacific community health providers and primary health organisations in New Zealand. | Ms. Catherine Poutasi | Approved |
| NTY/07/22/EXP | Review of the setup and rationale for the 'Malaga a le Pasifika' service delivery pathway. | Dr. Tamasailau Suaalii-Sauni | Approved |
| NTY/07/87/EXP | A review of Pacific cultural formulation tools utilised by WDHB for cultural assessment work alongside DSMIV cultural assessment statements – 'Matalafi Project' Phase Two. | Dr. Tamasailau Suaalii-Sauni | Approved |
| NTY/07/23/EXP | Audit of the 'Matalafi Matrix' cultural formulation tool in Tupu and Malaga services – phase one. | Dr. Tamasailau Suaalii-Sauni | Approved |
| CEN/07/08/054 | The SPIRIT study: South Pacific Islanders resist diabetes with intense resistance training: a randomised controlled trial. | William Sukala | Approved subject to conditions |
| MEC/07/11/161 | Development of a provider self- evaluation tool for Pacific alcohol and other drug (AOD) | Dr. Tamasailau Suaalii-Sauni | Approved subject to conditions |

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| | services. | | |
| NTY/07/07/085 | How do attitudes, beliefs, and perceptions of Tongan asthma patients in Auckland influence access to primary healthcare? | Ms. Tenisia Hager | Approved |
| CEN/06/17/CPD | Pacific youth health perspectives | Ana Fonua | Approved |
| NTY/06/02/006 | Samoans and disabilities study | Mr. Nite Imakulata Fuamatu | Approved |
| NTY/06/11/121 | Pacific smoking cessation: exploring issues to increase the quit rate of Pacific smokers in New Zealand | Ms. Josephine Samuelu | Approved |
| URA/06/02/016 | Evaluation of pilot Pacific community project | Chris Mene | Approved |
| LRS/06/09/034 | Monitoring antibiotic resistance in Samoa | Ms. Pauline Norris | Approved subject to conditions |
| NTY/06/11/117 | Cook Island community leaders talk about their community's determinants of health | Mr. John Natua | Approved subject to conditions |
| NTY/06/10/096 | Exploring Pacific attitudes to food, food consumption, weight loss, and weight management | Mr. Kenneth Aiolupotea | Deferred |
| NTX/06/03/021 | Dimensions of the nasolacrimal duct by computed tomography in European and Polynesian peoples: PIS/Cons. | Dr. Austin McCormick | Approved |
| MEC/05/05/061 | The development of a self-assessment tool for use by Pacific providers | Dr. Gail Robinson | Approved |
| NTX/05/04/032 | Process evaluation of a framework for services to assess a range of Pacific service models of care within the Pacific alcohol and other drugs (AOD) sector: PIS/Cons V#2, 26/4/05 | Dr. Gail Robinson | Approved |
| NTX/05/05/044 | Why Pacific patients do not attend ('DNA') outpatient clinics in the Counties Manukau District Health Board ('CMDHB') area: PIS/Cons V#5, 11/5/05 | Ms. Yvonne Timaloa | Approved |
| NTX/05/09/122 | Fijian Indian patients' understanding on diabetes; how they self-manage and their views on a culturally tailored educational intervention: PIS/Cons V#4, 7/11/05 | Ms. Faieza Ali | Approved |
| NTX/05/12/159 | Pacific Islands families: nutrition and body size of six-year-old Pacific children (PIF:NBS): PIS/Cons V#2, | Dr. Janis Paterson | Approved |

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| | 15/12/05: Amend 18/1/07 | | |
| NTX/05/03/016 | An observational study of the impact of long-acting risperidone microspheres in Māori and Pacific people with schizophrenia and related psychotic disorders: ADHB PIS/Cons V#4, 26/9/05: Wai/C-M DHB IS/Cons V.5, 27/1/06 | Dr. Wayne Miles | Approved |
| CEN/05/12/097 | Effects of 'back migration' on atopic markers and asthma symptoms in Tokelauans: a pilot study | Dr. Robert Siebers | Approved subject to conditions |
| MEC/05/10/127 | Learning communities. Searching for 'Pacific" solutions: a community-based intervention project to minimise harm from alcohol misuse | Ms. Margaret Southwick | Approved subject to conditions |
| 13/CEN/45 | Executive Functioning, Social Cognition and Adaptive Behaviour in Children with Fetal Alcohol Spectrum Disorders (FASD) | Ms. Andi Crawford | Approve |
| 13/NTA/74 | Music therapy to support the well-being of young people with intellectual disability | Dr. Daphne J. Rickson | Approve |
| 13/NTB/34 | Advance Care Planning and Intellectual Disability | Ms. S Brandford | Approve |
| 13/NTB/85 | A screening study to identify adult and adolescent individuals with Down Syndrome for eligibility to participate in a future Drug Treatment Research Study. | Professor Ed Mitchell | Approve |
| 13/STH/94 | Cervical and Breast Screening for Women with Intellectual Disability | Dr. Brigit Mirfin-Veitch | Approve |
| 12/STH/45 | Relationship education and intellectual disability | Ms. Cate Shields | Approve |
| URA/12/06/022 | Developing a legal system responsive to the needs to people with intellectual disability | Dr. Brigit Mirfin-Veitch | Approved |
| MEC/11/EXP/127 | The Mental Healthcare of People With a Dual Disability of Mental Illness and Intellectual Disability: A Comparative Study of the Mental Health Inpatient Experience of People with Dual Disability, Carers, and Nurses | Mrs. Chris Taua | Approved |

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| NTX/11/EXP/152 | A comparison of the differences with fitness to stand trial between mentally disordered and intellectually disabled defendants within the New Zealand Criminal Justice System | Dr. Joseph Allan Sakdalan | Approved |
| NTX/11/EXP/272 | Audit of children with Down Syndrome and sleep disordered breathing - use and acceptability of CPAP | Ms. Amy Doherty | Approved |
| URA/11/02/004 | Aging with an intellectual disability in New Zealand: Experiences, perspectives, and future planning for individuals living with family/whanau | Ms. Henrietta Trip | Approved |
| URA/11/08/045 | Prevention of falls for adults with intellectual disability (PROFAID) | Dr. Leigh Hale | Approved |
| URB/11/EXP/035 | Local impact of antenatal screening for Down Syndrome and other conditions on diagnosis and outcomes in a Fetal Medicine Centre | Dr. Rosemary Reid | Approved |
| CEN/11/02/04 | Pilot Study to Assess Nocturnal Sleep Duration in Children with Prader-Willi Syndrome and Normal Controls, and relationship to Daytime Activity | Dr. Shiree Gibbs | Approved |
| CEN/11/EXP/090 | A better understanding of the deaths of people with intellectual disability. | Dr. Stuart Todd | Ethical approval not required |
| MEC/11/EXP/031 | An audit of New Zealand's intellectual disability specialty in-patients units: focusing on antipsychotic medication use | Ms. Sarah Moana Skipper | Ethical approval not required |
| NTY/11/EXP/022 | 10-year trends in Down Syndrome diagnosis in Auckland | Dr. Karena de Souza | Ethical approval not required |
| MEC/10/086/EXP | CCS Disability Action: Article 19 Project | Mr Paul Milner | Approved Subject to Conditions |
| MEC/10/030/EXP | The Incidence of Down Syndrome in NZ Pacific Births Born in the Auckland Region | Professor Peter Stone | Approved |
| NTX/10/04/029 | Constructing the lives of 'care recipients' under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: a discourse analysis: PIS/Cons V#4, 24/05/10 | Ms. Amanda Smith | Approved |
| NTY/10/EXP/071 | Improved Health Outcomes for Ageing People with Intellectual Disability Pilot. | Dr John Parsons | Ethical approval not required |
| LRS/09/10/040 | Assessment of central GABA-B function in subjects with Down syndrome and normal controls | Professor Paul Glue | Approved |

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| LRS/09/11/052 | Assessment of cognitive functioning in children with Down Syndrome | Dr Thelma (Tess) Patterson | Approved |
| NTY/09/06/048 | Acquisition of periodontopathic bacteria in children with Down syndrome | Mrs Karthika Balaji | Approved |
| URA/09/04/029 | Living with Diabetes and intellectual disability: Self-management practices | Dr. Lisa Whitehead | Approved |
| URA/09/06/040 | The use of oral health services by adults with Intellectual disability who required a general anaesthetic for dental treatment over a five-year period in Christchurch, and the perceptions of their guardians and support people relating to their oral healthcare. A mixed methods study. | Victoria McKelvey | Approved |
| MEC/08/10/118 | Access to ACC for people with pre-existing disabilities (physical, blind/ vision impaired and intellectual) | Sally Duckworth | Approved |
| NTX/08/10/093 | Body composition in children and young persons with Down syndrome: comparison of DEXA, bioelectrical impedance analysis, and anthropometry: PIS/Cons V#2, 11/08 | Dr. Sarah Loveday | Approved |
| NTY/08/24/EXP | Suitability of actuarial and structured professional judgment risk assessment measures for the regional forensic intellectual disability service of the Waikato DHB | Mr. Chris Floyd | Approved |
| URA/08/06/EXP | Prenatal detection rate and outcome of Downs Syndrome pregnancies in Canterbury 1991-2007 | Dr. Nigel Anderson | Approved |
| CEN/07/07/050 | Exploration of nurses' experiences of using a pre-admission pack for people with intellectual disabilities in the Day of Surgery Department of Palmerston North Hospital. | Dina Cole | Ethical approval not required |
| NTY/07/40/EXP | Five-year trends in Down Syndrome diagnosis in Auckland. | Dr. Yvonne Lake | Ethical approval not required |
| LRS/07/11/042 | Transforming notions of disability – a qualitative evaluation of the joint IHC/CCS “Our stories” community education project. | Dr. Nancy Higgins | Approved |
| LRS/07/06/EXP | Prevalence of chronic conditions causing developmental disability in children in the province of Otago and the assessment of their service provisions. | Muhammed Mujeeb Bin Haji Mohd Taib | Approved |

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| MEC/07/05/070 | Incidence of and risk factors for falls in adults with intellectual disability: a pilot study. | Dr. Leigh Hale | Approved |
| MEC/07/50/EXP | Working in intellectual disability services. Phase I: staff retention and turnover. | Dr. Nancy Higgins | Approved |
| NTY/07/06/063 | Pilot testing new measures of a) quality of care and b) quality of life for people with intellectual and physical impairment and c) attitudes to disability. | Prof Kathryn McPherson | Approved |
| LRS/07/05/021 | A case study on the use of the levonorgestrel intrauterine device (Mirena) in an adolescent with an intellectual disability. | Dr. Helen Paterson | Completed |
| CEN/06/06/044 | The lived experience of supporting a family member with an intellectual disability who is dying in a community setting: an interpretive analysis of family member's accounts | Ms. Susan Marlow | Approved |
| LRS/06/02/001 | Preventing falls in people with intellectual disability: an innovative clinical placement combining theory, practice and research | Dr. Leigh Hale | Approved |
| NTX/06/09/114 | Core affect and its role in the maintenance of subjective well-being of people with intellectual disability: PIS/Cons V#1, 18/09/06. | Ms. Kathleen Jane Martindale | Approved |
| URA/06/07/045 | Responding to the mental health needs of people with an intellectual disability: a pilot education programme for nurses | Dr. Caroline Mohr | Approved |
| URB/06/08/058 | Exploring counseling for clients with a mild intellectual disability from multiple perspectives | Ms. Marilyn Raffensperger | Approved |
| CEN/06/07/072 | Analysing inter-agency activity – a case study examining the relationship between a health and education state sector that provides services for children with special needs | Carlene Receveur | Ethical approval not required |
| URB/05/05/059 | Impact of the use of the functional health assessment tool (TFHAT) by direct-care staff on the interface between people with an intellectual disability and their general practitioner | Ms. Henrietta Trip | Approved |

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| MEC/05/12/164 | Peer abuse in group homes for adults with intellectual disabilities | Dr. Anne Bray | Approved subject to conditions |
| 13/CEN/79 | The composition of breast milk according to different ethnicities of individuals living in New Zealand | Dr. Christine Butts | Approve |
| 13/NTA/185 | Innate Immune Defects in Māori and Pacifica Children with Bronchiectasis | Dr. Annaliese Blincoe | Approve |
| 13/NTB/36 | Cultural Adaptation of the QPS Battery and GICS | Ms. Karen Hayman | Approve |
| 13/CEN/202 | Transforming & Healing Whānau Violence in Hauraki | Dr. Stephanie Palmer | Approve |
| 13/CEN/55 | Breast cancer tumour profiles and disparities | Dr Lis Ellison-Loschmann | Approve |
| 13/STH/57 | Genetic background of susceptibility to Rheumatic Fever | Professor Diana Lennon | Approve |
| 13/STH/189 | The Familial Rheumatic Heart Disease Study | Dr. Nigel Wilson | Approve |
| 12/NTA/91 | Impact of a promotional DVD on bowel screening uptake for Māori and Pacific | Dr. Peter Sandiford | Approve |
| 12/NTB/22 | A whanau approach to health and well-being | Dr. Anna Rolleston | Approve |
| 12/NTA/9 | TAK875 in Asia Pacific Subjects with Type 2 Diabetes | Dr. John Baker | Approve |
| NTY/12/02/017 | The management of metastatic prostate cancer in high health needs ethnic groups | Professor Ross Lawrenson | Approved |
| MEC/12/EXP/046 | National retrospective audit of perinatal outcomes including Caesarean section, NICU admission, readmission and mortality in relation to ethnicity, rural, urban and provider factors | Dr. Beverley Lawton | Approved |
| URB/12/EXP/020 | Normal range of exophthalmometric values and interobserver variations across various ethnic and age groups | Dr. Kathleeya n Stang-Veldhouse | Approved |
| NTY/12/06/050 | Incredible years specialist service – an evaluation of the efficacy of adding a manualised enhancement service to improve outcomes for high-risk families/ whanau attending the incredible years parent programme | Ms. Dianne Lees | Approved |
| MEC/12/EXP/003 | Examination of the experiences of older people with dementia and their family/whanau/caregivers and staff during admission to an acute hospital unit | Dr. Kay de Vries | Approved |

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| NTX/12/EXP/017 | Ethnic differences in creatinine generation in South Auckland peritoneal dialysis patients | Ms. Tina Sun | Approved |
| NTX/12/EXP/034 | To examine the prevalence of HLA DQ2/DQ8 positivity among different ethnicities particularly Asian extracts from HLA DQ2/DQ8 tissue typing | Dr. John Hsiang | Approved |
| NTY/12/EXP/022 | How can the costs of providing care for family and whanau within a palliative care context be appropriately captured for research purposes? | Professor Merryn Gott | Ethical approval not required |
| NTY/12/EXP/005 | A retrospective observational study on growth discordancy in dichorionic twins stratified by ethnicity | Dr. Unmandani Devashana Gupta | Ethical approval not required |
| CEN/11/EXP/022 | Healthcare provider's perspective of the effect of stigma and cultural values on reporting an incident of exposure to patient's blood and body fluid in NZ" | Mr. Moazzam Zaidi | Approved |
| CEN/11/EXP/024 | Teaching the Generalisable Skills of Cultural Competency: A New Educational Intervention in NZ | Ms. Katy Thomas | Approved |
| MEC/11/02/016 | Determining whether the paraplegin haplotype which is thought to be causing hereditary spastic paraplegia in a New Zealand is of Māori or European Origin | Dr. Richard Roxburgh | Approved |
| MEC/11/EXP/094 | The Impact of Ethnicity on Maternal Serum Markers for Aneuploidy Screening in Māori and Pacific Islanders | Dr. Richard Mackay | Approved |
| MEC/11/EXP/125 | Questionnaire Study: "Whanau opinion on tamariki involvement in research" | Dr. Catherine Byrnes | Approved |
| NTX/11/EXP/062 | Improving support for families/whanau of clients post stroke (phase two): longitudinal study of experiences of family/whanau members | Dr. Dianne Roy | Approved |
| NTX/11/EXP/117 | Family/Whanau involvement in goal setting and rehabilitation outcomes: PIS/Cons V#1, 7/06/11 | Ms. Jamie Taylor | Approved |
| NTX/11/EXP/204 | Indexing integration of health and social services for young children in Tairāwhiti 2: Surveying parents and whanau | Professor Tony Dowell | Approved |
| NTX/11/EXP/225 | Incidence of melanoma in Māori and Pacific Island population in the Counties | Tien Ming Lim | Approved |

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| | Manukau District Health Board area in Auckland, New Zealand | | |
| NTX/11/EXP/252 | Evaluation of 'Tomorrow's Clinical Leaders' - a leadership training programme for Māori nurses and midwives | Julian King | Approved |
| NTX/11/EXP/315 | Growing Our Own: Using a sector partnership model to build the Māori and Pacific Health workforce in Aotearoa New Zealand | Jenna Clarke | Approved |
| NTY/11/08/084 | Articulating cultural practice within a New Zealand nursing context | Ms. Christine Baker | Approved |
| NTY/11/EXP/053 | "The usefulness of a cultural framework to guide treatment for people with Methamphetamine Problems - Clinical Perspectives" | Ms. Peti Murray | Approved |
| CEN/11/09/054 | Whanau Pakari : A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity | Dr. Yvonne Anderson | Approved |
| MEC/11/EXP/022 | What do family / whanau of people with mental health and addiction issues think about smoke-free mental health and addiction services?: A qualitative descriptive study | Ms. Rebecca Missen | Approved |
| MEC/11/EXP/061 | Research Question: How is decision-making by whanau altered when the birth plan is repeat caesarean section? | Dr. Patricia Boyd | Approved |
| NTX/11/EXP/143 | Managing cultural diversity in CMDHB a key driver for effective service delivery | Rachna Sudhakar | Approved |
| NTX/11/EXP/033 | Surveys to evaluate the effectiveness of a change in the pain management protocol for Intramuscular Penicillin injections for children, adolescents and young adults with rheumatic fever | Ms. Kathryn Russell | Approved |
| NTX/11/12/113 | Evaluation of an Innovative Sleep Intervention for The Prevention of Sudden Unexpected Death in Infancy in a cohort of Māori and Pacific Infants in South Auckland New Zealand | Dr. Adrian Trenholme | Approved Subject to Conditions |
| NTX/11/EXP/301 | "It's not just about heart failure": optimising the Primary Healthcare (Practice Nurse) role as a Navigator in supporting patients with multiple long-term conditions and their family/whanau | Ms. Susan Waterworth | Ethical approval not required |

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| CEN/10/EXP/32 | Analysing discourse in intercultural health settings: constructing identities in meetings | Ms. Mariana Virginia Lazzaro Salazar | Approved |
| NTX/10/03/020 | Evaluation of Waitemata DHB child disability service project for culturally and linguistically diverse (CALD) families: | Dr. Amanda Wheeler | Approved |
| LRS/10/07/029 | Association of ethnicity and levator ani muscle elasticity with avulsion injury following vaginal delivery | Dr. Vivien Wong | Approved |
| MEC/10/008/EXP | Implementing the Rheumatic Fever Guidelines: Identifying the challenges and crossing the theory/practice divide | Ms. Michelle Hooker | Approved |
| NTX/10/EXP/009 | Acute predict: evaluation of differences in incidence & method of revascularisation by ethnicity in patients with acute coronary syndromes | Dr. Andrew Martin | Approved |
| NTX/10/EXP/038 | Epidemiology of pharyngeal group A streptococcus in acute rheumatic fever household contacts in Auckland, 2008-2009 | Dr. Brigid O'Brien | Approved |
| NTX/10/EXP/100 | The epidemiology of rheumatic fever and its complications in Auckland | Professor Diana Lennon | Approved |
| NTX/10/EXP/133 | Development of an ethnicity data audit tool for primary healthcare; PIS/Cons V#2, 5/8/10 | Dr. Dale Bramley | Approved |
| NTY/10/02/013 | A cross-sectional observational study of the timing and pattern of emergence of permanent teeth in children of different ethnic origin between the ages of 5 and 13 years. | Dr. Sathananthan Kanagaratnam | Approved |
| NTY/10/10/078 | The adult legacy of Acute Rheumatic Fever; Rheumatic Heart Disease and its complications in the Eastern Bay of Plenty 2000 - 2009. | Dr. John Malcolm | Approved |
| NTY/10/EXP/090 | Abdominal aortic aneurysm survival trends and ethnicity data in Waikato Hospital | Ms. Simone Oldham | Approved |
| NTY/10/03/018 | Congenital Hypothyroidism Screening - Are we preserving Intellectual Function? | Dr. Paul Hofman | Approved Subject to Conditions |
| MEC/10/093/EXP | Compliance with CPAP in obstructive sleep apnoea: effects of ethnicity and socioeconomic status - A NZ Wide Study | Dr. Angela Campbell | Approved Subject to Conditions |

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| NTY/10/EXP/004 | A descriptive observational study to determine if there are any differences in ethnicity of individuals presenting to Auckland City Hospital late after stroke (greater than 24 hours after symptom onset) in comparison to individuals presenting to hospital early after stroke (less than 24 hours after symptom onset) during 2009. | Ms. Anna McRae | Ethical approval not required |
| NTX/10/09/097 | Can we reduce Māori and Pacific School Children's hospitalisations to Pakeha rates? PIS/Cons V#2, 20/10/10 | Professor Diana Lennon | Approved |
| NTX/10/EXP/067 | Screening for kidney disease amongst family/whanau of people with stage 4 or 5 advanced kidney disease | Dr. John Collins | Approved |
| NTX/10/EXP/071 | Improving support for families/whanau of clients post CVA/stroke: a longitudinal study | Dr. Dianne Roy | Approved |
| NTY/10/04/040 | Patients' and their whanau/families' perspectives of hospital care on one hospital ward in one District Health Board. | Dr. Elizabeth Finn | Approved |
| NTY/10/EXP/025 | Understanding the perceptions of Māori and Pacific Island parents towards childhood immunisations. | Mr. Liesje Donkin | Approved |
| NTY/10/EXP/093 | Evaluation of the WDHB CALD cross-cultural competency training programme. | Associate Professor Robyn Dixon | Approved |
| NTY/10/EXP/045 | Complications related to Obesity in THJR and TKJR in Māori and Pacific Island population at Counties Manukau DHB between June 1999 and June 2005. | Dr. Simon Kim | Approved Subject to Conditions |
| URA/10/EXP/068 | Examining ethnic differences in psychiatric inpatient care in Māori and non-Māori patients diagnosed with Schizophrenia | Ms. Karen Keelan | Ethics approval not required |
| NTX/09/145/E XP | International standardisation of echocardiographic diagnosis of rheumatic heart disease | Dr. Nigel Wilson | Approved |
| NTX/09/152/E XP | The epidemiology of rheumatic heart disease and its sequelae in Tairāwhiti | Ms. Rebecca Moore | Approved |
| NTX/09/178/E XP | Analysis of ethnic variation of breast size in correlation to BMI in Auckland | Mr. David Moss | Approved |
| NTX/09/179/E XP | The impact of ethnicity and body mass index on adverse | Dr. Ngaire Anderson | Approved |

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| | pregnancy outcomes | | |
| NTX/09/75/EXP | Transposition of the Great Arteries: Incidence and Ethnicity | Dr. Tom Gentles | Approved |
| NTX/09/84/EXP | Ethnic differences in the duration of untreated psychosis and referral patterns in patients presenting to an early psychosis intervention team | Dr. Ian Soosay | Approved |
| CEN/09/11/091 | The Effect of Ethnicity, Socioeconomic Status, Health Literacy and Self- Efficacy on Compliance to Continuous Positive Airway Pressure Therapy for Obstructive Sleep Apnoea | Jessie Bakker | Approved |
| NTY/09/10/099 | Cross-cultural communication with patients in the hospital setting. | Dr. Jeremy Rossaak | Approved Subject to Conditions |
| NTY/09/113/EXP | Epidemiology of Rheumatic Heart Disease in New Zealand children and Young adults 1994- 2008. | Dr. Rachael Webb | Approved Subject to Conditions |
| NTY/09/90/EXP | Morbidity of New Zealand Children admitted to the Paediatric Cardiology Unit with Acute Rheumatic Fever or Rheumatic Heart Disease over a 2 year period. | Dr. Nigel Wilson | Approved Subject to Conditions |
| NTX/09/156/EXP | A 10-year review of outcomes for surgical treatment of development dysplasia of hips between patients of European origin and Māori/Pacific Islanders in Starship Hospital | Mr. Haemish Crawford | Approved |
| NTX/09/10/095 | Task one: exploring the voices of parents and whanau, increasing our understanding of families' experiences by listening to families involved in paediatrics palliative care | Ms. Erin Gaab | Approved |
| NTY/09/06/055 | Understanding barriers to accessing immunisation for whanau/families who are referred to the Outreach Immunisation Service as being overdue for immunisation. | Dr. Nikki Turner | Approved |
| URB/09/02/001 | START Evaluation – Is Involving caregiver and family/whanau an effective treatment strategy to reduce sexual abuse symptomology and what evidence exists of dissociative symptomology amongst START clients | Mr. Simon Pankhurst | Approved |

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| NTX/09/08/077 | Whanau/Family and Health Professionals' Perspectives on Paediatric end-of-life care planning at Starship Children's health: PIS/Cons V#2, 06/09/2009 | Ms. Jess Jamieson | Approved |
| MEC/08/01/004 | Investigation of biological factors in colon tumours from cancer patients self-identified as Māori, Pacific Islander, and New Zealand European in New Zealand | Assoc Prof John Koea | Approved |
| MEC/8/04/051 | The socioeconomic factors associated with food security and physical activity for Māori and Pacific people | Mr. Charles Waldegrave | Approved |
| NTX/08/94/EXP | Clinical presentation of nasopharyngeal carcinoma: is there a fundamental biological difference in the pattern of presentation between Asians and Pacific Islanders (including Māori)? | Mr. Louis Lao | Approved |
| CEN/08/06/EXP | An exploratory study investigating the acquisition of 'cultural competence' at the organisational level to enable delivery of culturally safe services in the mental health sector. | Miss Naomi Aporo | Approved |
| NTX/08/120/EXP | Improving the quality of ethnicity data in primary care | Ms. Miriam Bennett | Approved |
| NTY/08/21/EXP | The influence of cultural background on health beliefs and condition management in individuals with diabetes | Ms. Danielle Vignati | Approved |
| MEC/07/38/EXP | Family/whanau views on psychiatric diagnoses and classification. | Prof Graham Mellsop | Approved |
| NTY/07/07/086 | A best practice package: early intervention for whanau violence (Phase I). | Erana Cooper | Approved |
| NTX/07/12/127 | Exploring the culture of safety in the influence of nursing leadership in the contemporary healthcare organisation in New Zealand (pilot study): PIS/Cons V#4, 1/08. | Ms. Deborah Rowe | Approved |
| URA/07/04/030 | An exploration of the relationship between culture and fatigue for people living with chronic obstructive pulmonary disease. | Ruth Haynes | Approved |

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| CEN/07/04/020 | Characterisation of plaque development in Māori, Pacific, and NZ European children with high caries and without caries by analysing the microbiota of plaque microcosm biofilms grown in a laboratory-based artificial mouth plaque culture system from saliva obtained from these children. | Dr. Christopher Sissons | Approved subject to conditions |
| NTX/07/06/053 | A randomised trial of adjunction intensive psychological, dietary and cultural management versus standard guidelines based care to maximise weight loss among high-risk subjects with type 2 diabetes mellitus and morbid obesity treated with bariatric surgery. Protocol V#1, 25/05/07: Protocol/amendment V#2 23/11/07 + Questionnaires: Prot. Synopsis V#3, 11/01/08: PIS/Cons V#4, 11/01/08. | Dr. Brandon Orr-Walker | Approved |
| CEN/07/24/EXP | The cultural, age and injury demographics of clients using the Back Institute (TBI) at each of their Wellington clinics and how did the clients find out about TBI services. | Alec Beresford | Completed |
| MEC/07/01/011 | Acute rheumatic fever and household crowding in New Zealand. | Richard Jaie | Approved |
| NTY/07/52/EXP | Outcomes of valve surgery for rheumatic heart disease in children: 1990–2005. Phase one: retrospective review. | Dr. Rachel Webb | Approved |
| NTX/06/24/CPD | Nutrition labels: understanding and use by ethnicity and income in New Zealand: PIS V#2, 13/12/06, Survey V#3, 20/12/06. | Dr. Cliona Ni Mhurchu | Approved |
| NTY/06/03/017 | Prevalence of neuroleptic-induced movement disorders in psychotic patients within Northland DHB: ethnic variation | Hossam Mahmoud | Approved |
| URB/06/10/078 | Tissue bank: Is there a molecular link between cancer and metabolic syndrome to explain ethnic disparities in cancer survival in New Zealand | Dr. Gabi Dachs | Approved |
| MEC/06/01/007 | Determinants of inequalities in breast cancer survival | Dr Mona Jeffreys | Deferred |
| LRS/06/09/033 | A New Zealand experience of men in a bi-cultural therapeutic community | Karl Meyer | Approved |

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| NTY/06/05/032 | Individualised growth assessment in different ethnic groups: an observational ultrasound study of fetal growth | Dr. GK Parry | Approved |
| MEC/06/06/063 | Whakanui Orana: using the New Zealand Disability Strategy as a framework for strategic policy development for US indigenous peoples with disabilities | Ms. Adrienne Wiley | Approved |
| NTY/06/12/140 | Ethnic women's experience of traumatic birth and PTSD following childbirth | Ms. Nimisha Waller | Approved subject to conditions |
| MEC/05/03/039 | Improving stroke recovery for Māori, Pacific people, and their whanau | Dr. Matire Harwood | Approved |
| NTX/05/02/010 | An intervention for changing symptom perceptions of European and Māori women with angina or a heart attack: | Ms. Cheryl Campbell | Approved |
| MEC/05/06/069 | Differential colon cancer survival by ethnicity in New Zealand | Diana Sarfati | Approved |
| MEC/05/07/082 | SoFIE-PRIMARY CARE: structure of primary care, quality and health outcomes | Prof Peter Crampton | Approved |
| MEC/05/07/085 | Unequal Treatment – the role of health services | Bridget Robson | Approved |
| NTX/05/11/141 | The influence of demographic factors, injury severity and fatigue on post-traumatic brain injury employment outcome in a New Zealand population: PIS/Cons V#2, 11/1/06 | Mr. Timothy Forbes Dyer | Approved |
| CEN/05/03/CPD | Assessing response to the free heart check campaign in Māori and Pacific men over 35: what are the barriers to care? | Adnan Bilgrami | Completed |
| NTY/05/10/079 | Public health and integration of first nations at the time of indigenous reconciliation: an impossible enterprise? Investigator: Dominique Rouviere | Ms. Dominique Rouviere | Ethical approval not required |
| NTX/05/07/081 | An evaluation of four community service organisations in Tai Tokerau (Northland) New Zealand: PIS/Cons V#2, 21/7/05 | Ms. Tina Darkins | Approved |
| NTX/05/10/129 | The EASAP study: evaluation of asthma in a South Auckland population. Diagnosing asthma accurately and assessing severity in a South Auckland population of asthmatics – do a range of investigations previously validated in | Associate Professor Jeffrey Garrett | Approved |

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| | research environment have clinical relevance and lead in turn to better management? PIS/Cons V#2, 18/10/05 | | |
| NTX/05/10/140 | Accommodation needs and preferences for consumers/tangata whai ora of mental health services: PIS/Cons V 1, 26/10/05 | Associate Professor Mike O'Brien | Approved |
| NTY/05/11/083 | Bridging the gap: multicultural music therapy in long-term care (LTC) | Ms. Esther Leauanae | Approved |
| MEC/05/03/031 | Rheumatic fever monitoring in New Zealand | Dr. Diana Lennon | Approved subject to conditions |

Appendix A-3: Guidelines Data

| Citation: | Breakdown: |
|--|---|
| Associate Minister of Health. 2006. The New Zealand Suicide Prevention Strategy 2006–2016. Wellington: Ministry of Health | 51 references in total 7 Māori 7 Pasifika 2 Both |
| Māori | |
| <ol style="list-style-type: none"> 1. Coupe NM. 2005. Whakamomori: Māori Suicide Prevention. PhD Thesis, Massey University, Palmerston North. 2. Durie M. 1998. Whaiora: Māori Health Development. Auckland: Oxford University Press. 3. Hirini P, Collings S. 2005. Whakamomori: He whakaaro, he korero noa: A collection of contemporary views on Māori and suicide. Wellington: Ministry of Health. 4. Lawson-Te Aho K. 1998. Kia Piki te Ora o te Taitamariki: A review of the evidence. Wellington: Te Puni Kōkiri. 5. Minister of Health, Associate Minister of Health. 2002. He Korowai Oranga: The Māori Health Strategy. Wellington: Ministry of Health. 6. Ministry of Health. 2002a. Te Puawaitanga: Māori Mental Health National Strategic Framework. Wellington: Ministry of Health. 7. Williams H. (1971). A Dictionary of Māori Language. Wellington: Government Printer. | |
| Pasifika | |
| <ol style="list-style-type: none"> 1. Finau SA. 1982. Social Anthropology: The Tongan family: Relevance to health. New Zealand Medical Journal 95: 880–3. 2. Finau SA. 1994. The value of Pacific children: Perspectives for a way forward. Pacific Health Dialog 1(2): 52–62. 3. Gray A. 2001. The Definition and Measurement of Ethnicity: A Pacific perspective. Wellington: Statistics New Zealand. 4. Ministry of Health. 1997. Making a Pacific Difference: Strategic initiatives for the health of Pacific people in New Zealand. Wellington: Ministry of Health. 5. Ministry of Pacific Island Affairs. 1999. Pacific Vision Strategy Pacific Directions. A Report to Government on a possible pathway for achieving Pacific peoples' aspirations. Wellington: Ministry of Pacific Island Affairs. 6. Tiatia, J, Coggan, C. 2001. Young Pacifican suicide attempts: a review of emergency department medical records. Pacific Health Dialog 8(1): 124–8. 7. Tiatia, J. 2003. Reasons to live: NZ-born Samoan young people's responses to suicidal behaviours. PhD Thesis, The University of Auckland, Auckland. | |
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| <ol style="list-style-type: none"> 1. Statistics New Zealand. 2006. 2001 Census of Population and Dwelling – Cultural diversity tables: Cultural Table 8. http://www.stats.govt.nz/census/cultural-diversity-tables.htm. Date of download 17th March 2006. 2. Ajwani S, Blakely T, Robson B, et al., 2003. Decades of Disparity: Ethnic mortality trends in New Zealand, 1980–1999. Wellington: Ministry of Health and Otago University. | |

| Citation: | Breakdown: |
|---|---|
| Ministry of Health. 2015. Suicide Prevention Toolkit for District Health Boards. Wellington: Ministry of Health. | 51 references in total 3 Māori 1 Pasifika 3 Both |
| Māori | |
| <ol style="list-style-type: none"> 1. Ihimaera L, MacDonald P. 2009. Te Whakauruora. Restoration of health: Māori suicide prevention resource. Wellington: Ministry of Health. URL: http://www.matatini.co.nz/sites/default/files/Te%20Whakauruora.pdf. Accessed February 2015. | |

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| <p>2. Lawson TA. 1998. A Review of Evidence: a background document to support Kia Piki te Ora o te Taitamariki. Wellington: Te Puni Kokiri. URL: http://www.moh.govt.nz/notebook/nbbooks.nsf/0/DBB94E84AEB5E3554C25665E00094EC3/\$file/Lawson%20-%20Te%20Aho%201998.pdf. Accessed February 2015.</p> <p>3. Ministry of Health. 2014. He Korowai Oranga: Māori Health Strategy 2014. Wellington: Ministry of Health. URL: http://www.health.govt.nz/system/files/documents/publications/guide-to-he-korowai-oranga-Māori-health-strategy-jun14.pdf. Accessed February 2015.</p> |
| <p>Pasifika</p> <p>1. Ministry of Health. 2008. Pacific Cultural Competencies: A Literature Review. Wellington: Ministry of Health. URL: http://www.health.govt.nz/system/files/documents/publications/pacific-cultural-competencies-may08-2.pdf. Accessed February 2015.</p> |
| <p>Both</p> <p>1. Te Pou o Te Whakaaro Nui. The National Centre of Mental Health Research, Information and Workforce Development. 2010. Evaluation of the NZGG Self-Harm and Suicide Prevention Collaborative. Wellington: Te Pou o Te Whakaaro Nui. The National Centre of Mental Health Research, Information and Workforce Development. URL: http://www.tepou.co.nz/library/tepou/evaluation-of-the-nzgg-self-harm-and-suicide-prevention-collaborative. Accessed February 2015.</p> <p>2. Te Pou o Te Whakaaro Nui. The National Centre of Mental Health Research, Information and Workforce Development. 2012. Updated evidence and guidance supporting suicide prevention activity in New Zealand schools 2003–2012. Wellington: Te Pou o Te Whakaaro Nui. The National Centre of Mental Health Research, Information and Workforce Development. URL: http://www.tepou.co.nz/library/tepou/updated-evidence-and-guidance-supporting-suicide-prevention-activity-in-new-zealand-schools-2003---2012. Accessed February 2015.</p> <p>3. Waitemata District Health Board and Counties Manukau District Health Board. 2010. Toolkit for Staff Working in a Culturally and Linguistically Diverse Health Environment. Auckland: Waitemata District Health Board and Counties Manukau District Health Board. URL: http://www.caldresources.org.nz/info/info/CALD-Toolkit_WDHB.pdf. Accessed February 2015.</p> |

| Citation: | Breakdown: |
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| Stroke Foundation of New Zealand and New Zealand Guidelines Group. Clinical Guidelines for Stroke Management 2010. Wellington: Stroke Foundation of New Zealand; 2010. | 1107 references in total 18 Māori 10 Pasifika 17 Both |
| Māori | |
| <p>1. Corbett A, Francis K, Chapman Y, et al.,(2006). The experience of whanau caring for members disabled from the effects of a cerebrovascular accident. Contemporary Nurse, 22(2), 255–263.</p> <p>2. Cormack D, Harris R. (2009). Issues in monitoring Māori health and ethnic disparities: An update. Wellington, New Zealand: Te Rōpu Rangahau Hauora a Eru Pōmare.</p> <p>3. Durie M. (2001). Mauri ora: The dynamics of Māori health. Auckland, New Zealand: Oxford University Press.</p> <p>4. Harwood M. (2005). Stroke recovery for Māori and their whanau. A paper presented at New Zealand Rehabilitation Association Conference, Auckland 18 November 2005.</p> <p>5. Jansen P, Bacal K, Crengle S. (2009). He ritenga whakaaro: Māori experiences of health services. Auckland, New Zealand: Proclaim Solutions Group.</p> <p>6. Jansen P. (1999). Incorporating Māori values into guidelines. Presentation at the New</p> | |

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| <p>Zealand Guidelines Conference, Wellington. URL http://www.nzgg.org.nz/download/files/jansen_presentation.pdf Jarvis M, Wardle J. (1999).</p> <ol style="list-style-type: none"> 7. King M, Smith A, Gracey M. (2009). Indigenous health part 2: The underlying causes of the health gap. <i>Lancet</i>, 374(9683), 76–85. 8. Ministry of Health. (2002). He Korowai Oranga. Wellington, New Zealand: Ministry of Health. 9. Ministry of Health. (2007). He Pa Harakeke: Māori Health Workforce Profile. Wellington, New Zealand: Ministry of Health. 10. Ministry of Health. (2010). Kōrero mārama: Health literacy and Māori. Wellington, New Zealand: Ministry of Health. 11. Moewaka Barnes H, Tunks M. (1996). Māori me te ikura roro: Māori and stroke. In: Baskett JJ (ed). <i>Life after stroke: New Zealand guidelines for best practice in rehabilitation after stroke</i>. Stroke Foundation New Zealand Inc. Auckland, New Zealand: Adis International. 12. Ratima MM, Durie MH, Allan GR, et al.,(1995). He anga whakamana: A framework for the delivery of disability support services for Māori. A report to the Core Services Committee. Wellington, New Zealand: National Advisory Committee on Core Health and Disability Support Services. 13. Riddell T, Jackson R, Wells S, et al.,(2007). Assessing Māori/non-Māori differences in cardiovascular disease risk and risk management in routine primary care practice using we based clinical decision support (PREDICT CVD-2). <i>NZMJ</i> 120 (1261). 14. Riddell T. (2003). Cardiovascular health of Māori. In Evidence-based best practice guideline. The assessment and management of cardiovascular risk. Wellington, New Zealand: New Zealand Guidelines Group. 15. Robson B, Harris R (eds). (2007). <i>Hauora: Māori Standards of Health IV. A study of the years 2000–2005</i>. Wellington, New Zealand: Te Rōpu Rangahau Hauora a Eru Pōmare. 16. Robson B. (2004). Economic determinants of Māori health and disparities: a review for Te Rōpu Tohutohu i te Hauora Tūmatanui. Wellington, New Zealand: Te Rōpu Rangahau Hauora a Eru Pōmare, University of Otago. 17. Smith L. (1999). <i>Decolonizing methodologies</i>. Dunedin, New Zealand: Zed Books Ltd London and University of Otago. 18. Whānau Ora Taskforce. (2010) Whānau Ora: Report of the Taskforce on Whanau-Centred Initiatives. Retrieved from: http://www.tpk.govt.nz/_documents/whanau-ora-taskforce-report.pdf |
| <p>Pasifika</p> <ol style="list-style-type: none"> 1. Blakely T, Richardson K, Young J, et al.,(2009). Does mortality vary between Pacific groups? Estimating Samoan, Cook Island Māori, Tongan and Niuean mortality rates using hierarchical Bayesian modeling, Official Statistics Research Series, 5. Retrieved from: http://www.statisphere.govt.nz/official-statistics-research.aspx 2. Callister P, Didham R. (2008). Emerging demographic and socioeconomic features of the Pacific population in New Zealand. In A Bisley (ed), <i>Pacific Interactions: Pasifika in New Zealand – New Zealand in Pasifika</i> (pp.13–40). Wellington, New Zealand: Institute of Policy Studies, Victoria University of Wellington. 3. Minister of Health and Minister of Pacific Island Affairs. (2010). “Ala Mo”ui: Pathways to Pacific health and well-being 2010–2014. Wellington, New Zealand: Ministry of Health. 4. Ministry of Health and Ministry of Pacific Island Affairs. (2004). <i>Tupu ola moui: Pacific health chartbook 2004</i>. Wellington, New Zealand: Ministry of Health. 5. Ministry of Health. (2008a). <i>Improving Quality of Care for Pacific Peoples</i>. Wellington, New Zealand: Ministry of Health. 6. Ministry of Health. (2008b). <i>Pacific cultural competencies: A literature review</i>. Wellington, New Zealand: Ministry of Health. 7. Statistics New Zealand. (2007). <i>QuickStats about Pacific peoples</i>. Wellington, New Zealand: Statistics New Zealand. 8. Tait R. (2008). An outcomes framework for Pacific people in New Zealand. Report for the Ministry of Pacific Island Affairs. Retrieved from: http://www.mpia.govt.nz/resources/pdfs/newspublications/Framework%20report%20-%20final.pdf 9. Tiatia J. (2008). <i>Pacific cultural competencies: A literature review</i>. Wellington, New Zealand: Ministry of Health. 10. Ulugia-Veukiso A, Perese L, Samu KS, et al.,(2009). <i>Workforce development: A study of</i> |

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| Both | |
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| | |
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| <ol style="list-style-type: none"> 1. Durie M. 2001. <i>Mauriora: The dynamics of Māori health</i>. Auckland: Oxford University Press. 2. McCreanor T, Nairn R. 2002. Tauivi general practitioners talk about Māori health: interpretative repertoires. <i>New Zealand Medical Journal</i> 115(1167): U272. 3. Ministry of Health. 2002. <i>He Korowai Oranga: The Māori Health Strategy</i>. Wellington: Ministry of Health. 4. Ratima E, Waetford C, Wikaire E. 2006. Cultural competence of physiotherapists: reducing inequalities in health between Māori and non-Māori. <i>New Zealand Journal of Physiotherapy</i> 34(3): 153–9. | |
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|---|---|
| New Zealand Guidelines Group. 2003. <i>Assessment and management of cardiovascular risk</i> . Wellington: New Zealand Guidelines Group | 705 references in total 6 Māori 2 Pasifika 11 Both |
| Māori | |
| <ol style="list-style-type: none"> 1. Ministry of Health, He Korowai Oranga: Māori Health Strategy. 2002, Ministry of Health: Wellington. 2. Nixon G, Coronary artery surgery and the Māori. <i>N Z Med J</i>, 1986. 99(800): 290. 3. Pomare E, Keefe-Ormsby V, Ormsby C, et al., Hauora: Māori Standards of Health III. A study of the years 1970-1991. 1995, Te Ropu Rangahau Hauora a Eru Pomare: Wellington. 4. Westbrooke I, Baxter J, and Hogan J, Are Māori under-served for cardiac interventions? <i>N Z Med J</i>, 2001. 114(1143): 484-7. 5. Curtis E, <i>The Colour of Your Heart</i>. An analysis of ethnic disparities in invasive cardiovascular procedure use between Māori and non-Māori in New Zealand. Masters of Public Health dissertation. 2002, University of Otago: Wellington. 6. Foliaki S and Pearce N, Changing pattern of ill health for indigenous people. <i>BMJ</i>, 2003. 327(7412): 406-7. | |
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Appendix B: Ethics approval and Māori Consultation - Survey



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
Te Komiti Rakahau ki Kai Tahu

Tuesday, 21 October 2014.

Dr Simon Walker,
Bioethics Centre - Division of Health Sciences,
DUNEDIN.

Tēnā Koe Dr Simon Walker,

Ethics Committee Members Views regarding Justice and Research Practices

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 21 October 2014 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of interest and importance.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee suggests dissemination of the research findings to Health and Disabilities Ethics Committees and to organisational ethics committees such as the University of Otago Human Ethics and Human Ethics Health Committees regarding this study.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kaiti Huirapa Rūnaka ki Poketeraki
Te Rūnanga o Moeraki

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
Te Komiti Rakahau ki Kai Tahu

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 21 October 2014 to 21 April 2016.

Nāhaku noa, nā



PR NTRCC

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otāgo
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

*Te Rūnanga o Ōtākou Incorporated
Kāi Huirapa Rūnaka ki Paketeraki
Te Rūnanga o Moeraki*



14/195

Academic Services
Manager, Academic Committee, Mr Gary Witte

21 November 2014

Dr S Walker
Bioethics Centre
Dept. of Medical and Surgical Sciences
Dunedin School of Medicine

Dear Dr Walker,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled **"Ethics Committee Members' Views on Justice Requirements and Potential Future Research Practices"**.

As a result of that consideration, the current status of your proposal is:- **Approved**

For your future reference, the Ethics Committee's reference code for this project is:- **14/195**.

The comments and views expressed by the Ethics Committee concerning your proposal are as follows:-

While approving the application, the Committee would be grateful if you would respond to the following:

The Committee would be grateful if you could specify how the survey data will be stored in "cloud storage" (page 7 data storage and security). The University has a policy around cloud storage which is outlined on the ITS website at <http://www.otago.ac.nz/its/about/publications/otago030292.html>. ITS offers a range of secure data storage options, including "Syncplicity Sync and Share" (which is a secure form of drop box managed by the University), to appropriately safeguard your research data.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Gary Witte". The signature is written in a cursive style with some loops and flourishes.

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor J McMillan Director and Professor of Bioethics Bioethics Centre

Appendix B-1: Survey questions

(The questions provided below come from a pdf created by the electronic survey platform, this PDF includes awkward page breaks that do not reflect how the survey was viewed by participants online.)

Welcome to My Survey

We invite you to complete this survey as a member of an accredited Ethics Committee in Aotearoa New Zealand. We are asking participants to provide their views on two interrelated topics:

- 1) The principle of justice in ethics review
- 2) The ethical review of certain research practices which may foster greater outcomes in relation to justice.

All the information in this survey is entirely anonymous. The only question related to personal information is one related to your ethnicity based on Maori consultation process. As with other questions it is entirely voluntary. All information collected using this question will be dealt with sensitively in the reporting, i.e. if small numbers respond in individual categories this will be taken into consideration when reporting all categories.

We appreciate your time and consideration in completing this survey. Information collected will be published as part of a PhD thesis and may also be published in academic journals or presented at academic meetings. We will also provide all ethics committees in Aotearoa New Zealand with a report of the findings. However, should you wish to receive an individual report of the survey results, there will be an option at the end of the survey to submit your email address. This information is collected separately from your results and cannot be linked to them in anyway. The report will be emailed by the student to all those who provide their email addresses using the blindcopy function in Outlook and then the email will subsequently be deleted both from the "Sent" folder and the "Deleted Folder".

Information collected via SurveyMonkey will be downloaded and then subsequently deleted from SurveyMonkey. The downloaded material will be kept on the student researcher's password protected computer. Secondary aggregated files will be shared between the student researcher and supervisors electronically via a password-protected cloud account. None of these files include identifiable information.

By completing this survey, we infer your consent. You may leave any questions blank that you wish to and discontinue the survey at any time. Withdrawal of your submitted answers, once the survey has begun is however not possible, given the anonymity of responses.

We thank you again for providing your time and expertise in exploring these issues. Should you have any questions, please contact:

| | | |
|---|---|---|
| Emma Tumilty McMillan PhD Candidate Bioethics Centre University of Otago emma.tumilty@postgrad.otago.ac.nz john.mcmillan@otago.ac.nz | Dr Simon Walker PhD Supervisor Bioethics Centre University of Otago simon.walker@otago.ac.nz | Assoc. Prof. John PhD Supervisor Bioethics Centre University of Otago |
|---|---|---|

1. Are you a member of an HRC accredited ethics committee in Aotearoa New Zealand

Yes

No

2. Which ethnic group do you belong to? Tick all that apply:

New Zealand European

Maori

Pacific Peoples

European

Asian

Other (please specify)

Section 1: Justice

This first section deals with your understanding and views of justice when reviewing ethical applications. The National Ethics Advisory Committee Guidelines for Intervention/Observational Studies define justice as:

Justice

1.1 Justice requires that, within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. Accordingly, investigators must:

(a) avoid imposing on particular groups an unfair burden of participation in intervention studies (eg, vulnerable members of a community should not bear disproportionate burdens of studies from which other members of the community are intended to benefit)

(b) design studies so that the inclusion and exclusion conditions for participants are fair. (See also the criteria in 'Inclusion and exclusion of participants', paragraphs 5.26–5.27.)

1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities.

1.3 The Treaty of Waitangi is the founding document of New Zealand. The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable, should be incorporated into all health research proposals (HRC 2005b). The principles can be explained as follows:

• partnership: working together with iwi, hapū, whānau and Māori communities to ensure Māori individual and collective rights are respected and protected in order to achieve health gain

- **participation: involving Māori in the design, governance, management, implementation and analysis of research, particularly research involving Māori**
- **protection: actively protecting Māori individual and collective rights, and Māori data, cultural concepts, norms, practices and language in the research process.**

1.4 There should be due recognition of Māori as the tāngata whenua and indigenous people of Aotearoa New Zealand.

1.5 Any potential cultural and ethical issues pertaining to Māori must be addressed through appropriate engagement with Māori, which may include discussions with appropriate representatives of specific whānau, hapū and iwi as determined by the scope and method of the study.

1.6 Comprehensive, high-quality Māori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whānau, hapū and iwi to be involved in meeting these priorities.

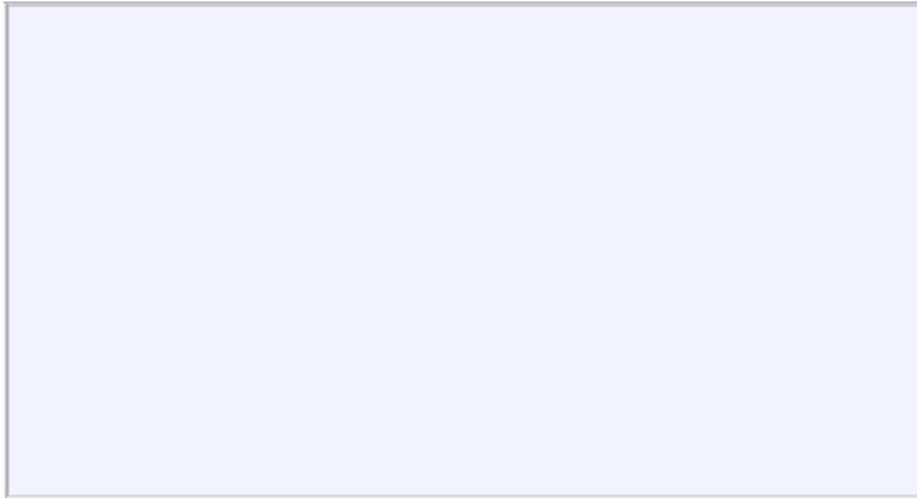
Justice

3. Do you agree with these statements:

| | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment |
|---|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:



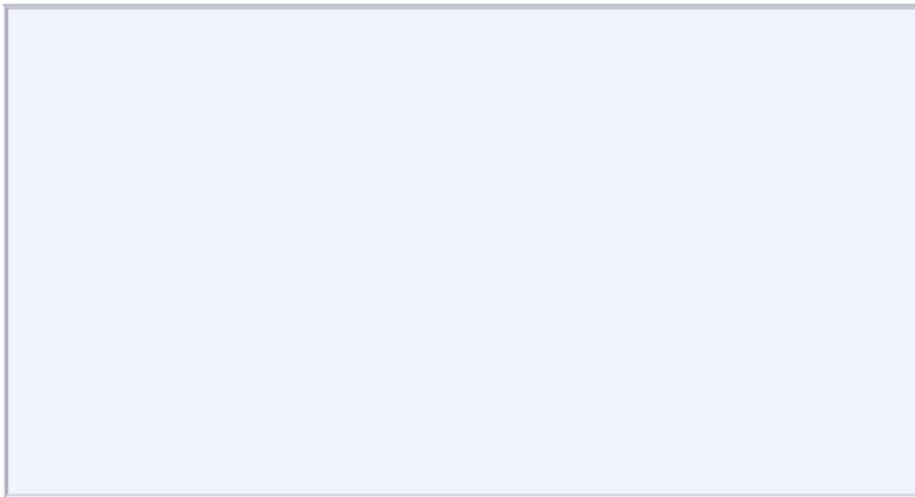
Justice

4. How often do you receive applications that address these statements in their initial submission:

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl.discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:



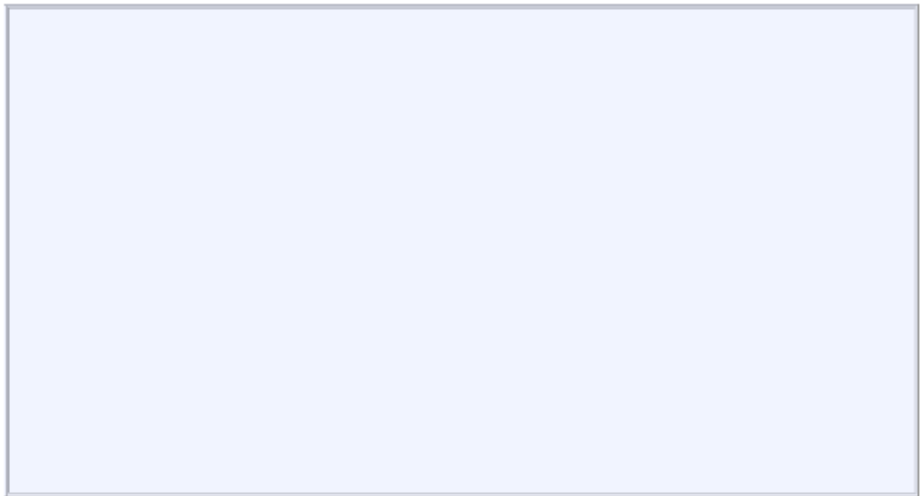
Justice

5. How often does your committee make recommendations to applicants in relation to these statements:

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:



Justice

6. How often have you felt that your committee should make a recommendation in relation to the following statements, but it hasn't:

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl.discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:

7. If you felt there were instances where matters of justice were not addressed, why do you think this was the case?

Justice

8. How often has your committee made recommendations in relation to the following statements that were contested or opposed by an applicant:

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl.discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:

9. Where they were met with opposition, explain what you think the reasons for that opposition were?

10. Where they were met with opposition, how was the situation resolved?

Justice

11. How often has your committee made recommendations in relation to the following statements that were well received by applicants:

| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.1 Justice requires, that within a population, there is a fair distribution of the benefits and burdens of participation in a study and, for any participant, a balance of burdens and benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

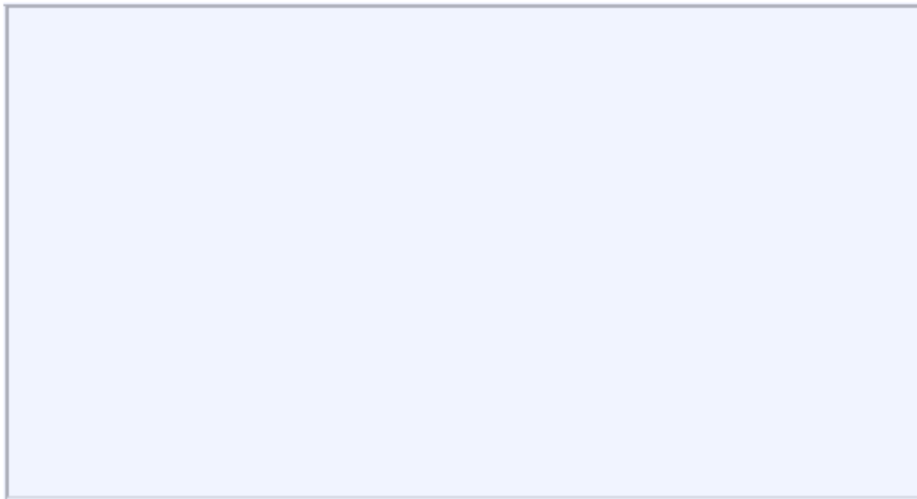
| | Very Often | Often | Sometimes | Rarely | Never | No comment |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1.2 Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.3 The principles of partnership, participation and protection implicit in the Treaty should be respected by all researchers, and, where applicable should be incorporated into all health research proposals. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.4 There should be due recognition of Maori as the tangata whenua and indigenous people of Aotearoa New Zealand. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.5 Any potential cultural/ethical issues pertaining to Maori must be addressed through appropriate engagement, which may incl. discussions with appropriate representatives of specific whanau/hapu/iwi as determined by the scope/method of the study. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 1.6 Comprehensive, high quality Maori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whanau/hapu/iwi to be involved in meeting these priorities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment, that may help us understand your answers:



12. Do you as a member of your committee ever omit recommendations in relation to justice that you would like to make? Why?

Please add any further comment that may help us to understand your answer:



Justice

13. Please describe the process by which you review an ethics application, in terms of what sections or elements you consider and in what order? Describe what you look for in each section or element.

14. Would you like to make any further comments on considerations of justice in ethical review?

Data Use in Research

In this section, we are investigating ethics committee members understanding and opinions about "open" and "big" data.

15. Please describe what you think is meant by the term "Big Data"

Data Use in Research

Big data can be defined as any large data set that could be described as complex and requires extra infrastructure to analyse (i.e. normal methods will not work due to size, etc.) Key Characteristics of Big Data are:

Volume – The quantity of data that is generated is very important in this context. It is the size of the data which determines the value and potential of the data under consideration and whether it can actually be considered as Big Data or not. The name 'Big Data' itself contains a term which is related to size and hence the characteristic.

Variety - The next aspect of Big Data is its variety. This means that the category to which Big Data belongs to is also a very essential fact that needs to be known by the data analysts. This helps the people, who are closely analyzing the data and are associated with it, to effectively use the data to their advantage and thus upholding the importance of the Big Data.

Velocity - The term 'velocity' in the context refers to the speed of generation of data or how fast the data is generated and processed to meet the demands and the challenges which lie ahead in the path of growth and development.

Variability - This is a factor which can be a problem for those who analyse the data. This refers to the inconsistency which can be shown by the data at times, thus hampering the process of being able to handle and manage the data effectively.

Complexity - Data management can become a very complex process, especially when large volumes of data come from multiple sources. These data need to be linked, connected and correlated in order to be able to grasp the information that is supposed to be conveyed by these data. This situation, is therefore, termed as the 'complexity' of Big Data.

(http://en.wikipedia.org/wiki/Big_data)

For our purposes, Big Data refers to datasets that either represent a huge collection of information from within the health system or are a combination of information sources from across the health sector and/or other government or research sectors.

16. How much do you agree with the following statements about "Big Data" initiatives:

| | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment |
|---|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| The expanded use of health/government data for research purposes is critical to addressing health issues in the 21st century. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The expanded use of health/government data for research purposes can aide in addressing issues of health inequity. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The expanded use of health/government data for research purposes carries a high risk. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Oversight of the use of health/government data can safeguard against risk and ensure proper use. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Strongly Disagree Disagree Neither Disagree Nor Agree Agree Strongly Agree No comment

Ethics Committees are best placed to provide oversight for use of health/government data.

Please add any further comment that may help us to understand your answer:

17. Please describe what you think is meant by the term "Open Data"

Data Use in Research

According to the Open Data Handbook (www.opendatahandbook.org): "Open data is data that can be freely used, reused and redistributed by anyone - subject only, at most, to the requirement to attribute and sharealike."

It is important to note here, that the data referred to is "non-personal" data, so data that doesn't allow the identification of specific individuals. For our purposes, we largely mean data sets derived from research projects.

18. How much do you agree with the following statements about "Open Data" initiatives:

| | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree | No comment |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| The compulsory sharing of research data is critical to addressing health issues in the 21st century. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The compulsory sharing of research data can aide in addressing issues of health inequity. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The compulsory sharing of research data carries a high risk. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Oversight of the sharing of research data can safeguard against risk and ensure proper use. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ethics Committees are best placed to provide oversight for the sharing of research data. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please add any further comment that may help us to understand your answer:

19. Would you like to make any further comment on this section on data?

Engagement

In this section, we are investigating ethics committee members understanding and opinions about engagement with participants and their communities.

20. Please describe what you think is meant by the term "stakeholder engagement" in research, including who stakeholders might be and what engagement might entail?

21. Please describe what you think is meant by the term "collaborative partnerships" in research, including who are the "partners" in these relationships and what the activities such partnerships might entail.

22. Closer relationships with communities/groups that are the target of research is recommended. Do you feel that these relationships present challenges for researchers and their participants


- Yes
 No
 No comment

23. If yes, please describe the challenges you think arise:

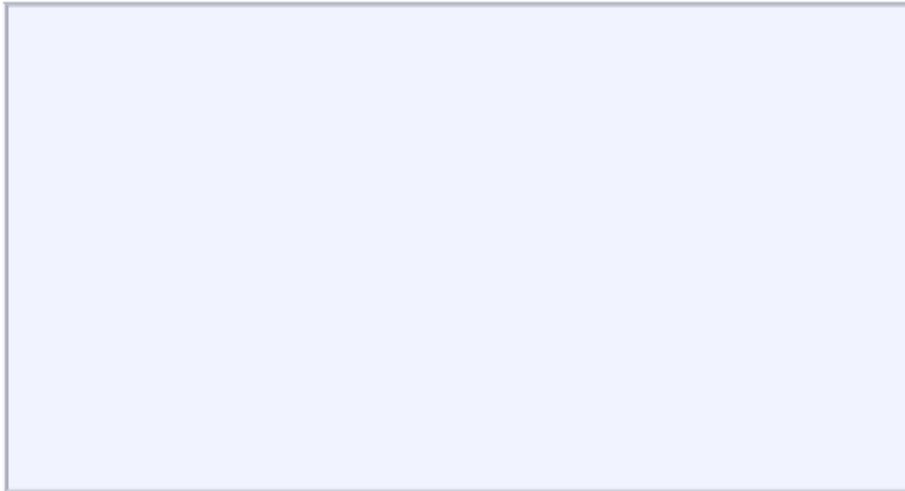
24. If no, please explain why not:

25. Do you think the challenges that arise from closer relationships in research can be managed effectively by a researcher?

Strongly Disagree Disagree Neither Disagree Nor Agree Agree Strongly Agree



Please add anything further, that may help us to understand your answer:



26. Do you as a member of your committee ever omit recommendations in relation to engagement that you would like to make? Why?

Please add any further comment that may help us to understand your answer:

27. Would you like to make any further comments on this section?

Final Comments

28. Would you like to make any final comment on the issues raised in this survey as a whole?

Report of Findings

We will be sending a report of the findings of this survey to each ethics committee across the country regardless of their participation in the survey. This work forms part of a PhD that will be available in the Otago University library and may be published in academic journals.

29. Should you wish to have a report sent you directly, please add your email address below. This is collected separate from your answers and will be deleted once a report is sent. It will not be used to identify you in anyway.

Appendix C: Māori consultation and Ethics Approval - Ethnography

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
Te Komiti Rakahau ki Kai Tahu

Tuesday, 18 November 2014.

Dr Simon Walker,
Bioethics Centre - Division of Health Sciences,
DUNEDIN.

Tēnā Koe Dr Simon Walker,

An institutional ethnography for researchers undertaking research with/for disadvantaged populations

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 18 November 2014 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

The Ministry of Health website <http://www.health.govt.nz/publications> contains a list of Māori health publications. The Committee recommends you review the Māori health publications on this website, eg. Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status 2002-2006 and Tatau Kahukura: Māori Health Chart Book 2010. Another Publication, Hauora: Māori Standards of Health IV (2000-2005), has its own website, <http://www.hauora.maori.nz/>. These publications provide information on a range of Māori health issues.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kaiti Huirapa Rūmaka ki Puketeraki
Te Rūnanga o Moeraki

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KAI TAHU

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 18 November 2014 to 18 May 2016.

Nāhaku noa, nā



MR

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otāgo
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

*Te Rūnanga o Ōtākou Incorporated
Kāi Huirapa Rūnaka ki Poketeraki
Te Rūnanga o Moeraki*



14/194

Academic Services
Manager, Academic Committees, Mr Gary Witte

9 December 2014

Dr S Walker
Bioethics Centre
Dept. of Medical and Surgical Sciences
Dunedin School of Medicine

Dear Dr Walker,

I am again writing to you concerning your proposal entitled "An institutional ethnography for researchers undertaking research with/for disadvantaged populations", Ethics Committee reference number 14/194.

Thank you for your letter received on 8 December 2014 which responded to the Committee. Thank you for providing evidence that consultation with Ngai Tahu Research Consultation Committee has been initiated. Thank you for advising that the email invitation has been amended in response to the Committee's letter. Please provide a copy of the updated documentation to attach to the record of your application.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor J McMillan Director and Professor of Bioethics Bioethics Centre

Appendix C-1: Institutional Ethnography - Methods

An institutional ethnographic method collects information from informants, texts, and experiences in the field and brings these together to understand the “ruling relations” guiding actions of varying people translocally through textual and discursive media (Campbell et al., 2006; Smith, 2005).

In using this institutional ethnographic method, I interviewed 11 participants (see sampling below), gathered texts from universities, ethics committees, the Performance Based Research Fund²³⁹ website, and research funders (see list below) and took field notes (2014-2016). Field notes reflected my experiences in research administration, research governance and research practice at the University of Otago and Otago Polytechnic campuses.

Ethics and Māori Consultation

I completed the University of Otago Ngāi Tahu Research Committee process for Māori consultation. The committee responded and gave approval (Appendix C) with a comment regarding the collection of ethnicity data and reporting back findings, which I agreed to positively. The Otago University Ethics Committee (Human) approved the project (Appendix C).

Sample

I used purposive and snowball sampling in this project. People who undertook health research with groups who identified as Māori, Pasifika, LGBTQ, or who worked with groups who had learning disabilities, mental health issues, youth health issues, drug and alcohol addiction, or researchers working on the social determinants of health and who met one or more criteria for seniority were invited to take part by email and the email included a request to pass this on to other suitable researchers. Seniority was defined as:

- Position in university of Senior Research Fellow/Senior Lecturer or higher
- Evidence of multiple grant success, including one from the main funder or equivalent
- Publication record
- 10+years practical experience
- Role as “research expert” on government or NGO committee

²³⁹ A research evaluation exercise in New Zealand tied to funding, similar to the Research Excellence Framework (REF) in the United Kingdom and the Excellence in Research for Australia (ERA), in Australia. All three measure research performance against metrics (largely to do with publications, citations and research funding) and distribute government funding based on scores.

This selection of inclusion criteria meant that informants were experienced researchers working with marginalised populations who had had some success. The reasoning for this being, that success would equal, firstly more exposure to and involvement with the various entities that are involved in the health research system with ongoing relationships created through funding contracts and producing outputs related to those contracts. Secondly, a degree of savviness about how to navigate that system, i.e. an awareness of what is needed to get results. Thirdly, a length of time in which they may have seen changes occur within the system. This exclusion of more novice researchers misses views of how engaging with the system as an early career researcher for marginalised groups may further explicate the ruling relations in this context and further work in this area is needed. Thirteen researchers responded eleven of whom were interviewed (the two not interviewed, were due to time and one self-identifying an unsuitability). As can be seen from the table below (Table 17), these participants were researchers who worked with Māori, Pasifika, youth, mental health and addictions, and people with learning disabilities. Participants who worked with LGBTQ or who investigated the social determinants of health did not respond to invitations to participate.²⁴⁰

| Category | Total |
|--|--------------|
| Research Area: | 13 |
| Māori | (4) |
| Pasifika | (1) |
| Learning Disabilities | (4) |
| Youth Research | (3) |
| Mental Health | (1) |
| LGBTQ | (0) |
| Social Determinants | (0) |
| Ethnicity: | 11 |
| NZE | (5) |
| Māori | (4) |
| Pasifika | (1) |
| European | (0) |
| Asian | (0) |
| Other | (0) |
| Experience: | 11 |
| 0-9 years | (1) |
| 10 + years | (10) |
| Organisation: | 11 |
| University | (8) |
| Other (private/3 rd sector) | (3) |

²⁴⁰ It is of note, that New Zealand is an extremely small research community. For some of these groups there are only a handful of researchers who met the criteria and so this may have been perceived as a confidentiality risk in taking part.

| | |
|-------------|------|
| Sex: | 11 |
| Female | (10) |
| Male | (1) |

Table 17 - Sampling Summary

Those interviewed were overwhelmingly women. The majority worked at a university and had more than ten years' experience. Those who did not work for a university worked either within a charitable organisation or were self-employed contractors working for NGOs and government bodies. Seven were in permanent positions (both full and part-time) and four worked in fixed-term or contract-based roles (both full- and part-time). The participants identified in some cases as researchers for more than one marginalised group (i.e. youth and mental health or Māori & Youth), which reflects the intersectionality of disadvantage.

Texts

In addition to talking to researchers who work with marginalised groups, I utilised the following websites and texts:

- 1) Health Research Council New Zealand
 - a. Website (www.hrc.govt.nz)
 - b. Statement of Intent (2010-2013)
 - c. Investment Signals
 - d. Annual Reports (2006-2013)
 - e. HRC Strategic Plan (2008-2013)
- 2) National Ethics Advisory Committee
 - a. Website (www.neac.govt.nz)
 - b. Māori Research Ethics (2012)
 - c. Streamlined Guidelines for Interventional and Observational Studies (2012)
- 3) Health and Disability Ethics Committee
 - a. Website (<http://ethics.health.govt.nz/>)
 - b. Standard Operating Procedures
 - c. Parliamentary review and submissions
- 4) University websites and documentation (with health research activity)
 - a. Otago University (www.otago.ac.nz)
 - b. Auckland University (www.auckland.ac.nz)
 - c. Waikato University (www.waikato.ac.nz)
 - d. Victoria University (www.victoria.ac.nz)
 - e. Massey University (www.massey.ac.nz)
 - f. Auckland University of Technology (www.aut.ac.nz)

- 5) Government Ministry and Offices' websites and documentation
- a. Tertiary Education Commission – Performance-Based Research Funding
<http://www.tec.govt.nz/Funding/Fund-finder/Performance-Based-Research-Fund-PBRF-/>
 - b. Ministry of Health (www.moh.govt.nz)
 - c. Ministry of Social Development (www.msd.govt.nz)
 - d. Office for Disability Issues (www.odi.govt.nz)
 - e. Accident Compensation Corporation (Government-owned) (www.acc.co.nz)
 - f. PHARMAC (www.pharmac.govt.nz)
 - g. National Health Committee archive via Ministry of Health
(<https://www.health.govt.nz/about-ministry/ministry-health-websites/national-health-committee>)

Experiences and Perspective

I identify as a Pakeha, female migrant who has gained New Zealand citizenship. I am a developing intersectional feminist with broad professional and personal interests in social justice and activism. Before my PhD enrollment and then during my studies, I had employment in various health research administration (research administrator), governance (ethics committee member and Vice-Chair), and assistance (research assistant and assistant research fellow) roles across Otago University and Otago Polytechnic in Dunedin. I took field notes of my attendance at various seminars, funding roadshows, workshops and interactions with research governance structures. I also wrote reflections on how my professional experience has informed and guided my research and determined my perspective in reviewing transcripts and documentation, to be able to utilise this within the analysis. My point of view naturally sides with that of the participants, given my experiences within the health research system.

Analysis

To begin the analysis, I read interview transcripts alongside interview notes written immediately after each interview reflecting on the conversation. These notes had also been added to after I transcribed each interview, providing another point in time to consider nuance and meaning. I sought descriptions of informants' experiences of practice in interviews that were rich enough to be used to analyse the conditions in which they occurred. I then searched these experiences or entry points to the problematic for similarities and differences between participants. From here, I scrutinised these groupings of experiences alongside relevant institutional texts, which led back to transcripts for further experiences and back to the texts (as a reflexive process). This back and forth is the

two-level process of the institutional ethnography; the first level being the accessing of experience, the second being the examination of that experience beyond the personal within the context of the institutional environment (Campbell, 2002). I discussed the categorisation and analysis for coherence with supervisors. From the relationship between the categories of experience to the conditions in which they were created based on the interviews, texts, personal experience, fieldwork, and literature, I formulated a theory of ruling relations within the framework Dorothy Smith created (Campbell et al., 2006; Smith, 2005).