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Models of Indigenous community-controlled health care in Chile

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Abstract

For Indigenous peoples, community-controlled health services are a key means by which communities exert control in the planning, development and delivery of primary health care services and represent an avenue to ensure that health policy and services reflect Indigenous values and an understanding of their health needs. Sustainable implementation of community-controlled health services is strongly dependent on the existence of supportive policy, as well as a health system that is open, flexible and able to respond to external input. However, assessments of participatory health initiatives frequently examine the features of the initiative or program with minimal consideration of how the wider policy environment affects participatory processes.

The current study examines the influence of local and distant factors on the effectiveness of Indigenous community-controlled health centres as participatory mechanisms, including interactions between international and domestic legislation and policy. Additionally, the research explored the applicability of lessons learned from countries' experiences in Indigenous community participation in health to other international contexts.

Case studies were undertaken with two Mapuche community-controlled health centres in Chile in order to gain perspective on the day-to-day workings and decision-making processes of the health centres. Interviews were also conducted with Ministry of Health personnel to provide a comprehensive picture of Indigenous health policy and stakeholders' perspectives. Evidence from international experiences was then used to contextualise the Chilean findings and provide some guidance for strengthening Indigenous community participation in health both in Chile and internationally.

Mapuche health administrators cited the existence of a wider system that was extremely resistant to external influence and 'blind' to Mapuche health as a key barrier to their work. As a result, Mapuche health centres were highly restricted in terms of their capacity to respond to local priorities and needs, even as staff considered the centres as potential vehicles for increased Mapuche political power within the health system. One of the primary aims of Indigenous community control, increased autonomy and self-determination, was thereby curtailed.

Overall, the evidence indicates that international legislation alone carries little weight in facilitating consultation or engagement with Indigenous communities; however, these instruments can provide guidance to countries for the alignment of domestic policy with established principles. Such alignment both enables countries to adopt international

agreements and subsequently facilitates implementation of the relevant principles and obligations.

The research makes the case for approaches to Indigenous health policy that are undertaken with an eye towards building cohesion between legislation and policy across all levels to support engagement with Indigenous peoples. In conjunction with stronger political representation, incorporating the principles of reciprocal accountability into contractual agreements between the State and Indigenous health centres could support a shift towards relationships that are more equitable, provide greater stability for Indigenous health centres and facilitate increased latitude to respond to their communities' needs appropriately. Analysis of Indigenous health policy, programs and services that takes a holistic perspective of the international, national and community-level factors impacting implementation would support decision-making in this area.

Declaration

This is to certify that:

i. The thesis comprises only my original work towards the PhD except where indicated in the Preface,

ii. Due acknowledgement has been made in the text to all other material used, and

iii. The thesis is fewer than 100,000 words in length.

Angeline Ferdinand
5 April 2020

Preface

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Acronyms

ACCHOs:	Aboriginal community-controlled health organisations
AHLOs:	Aboriginal health liaison officers
AHS:	Aboriginal Health Services
AI/AN:	American Indian and Alaska Native
AIDA:	Aboriginal Indigenous Doctors' Association
ATSIC:	Aboriginal and Torres Strait Islander Commission
BC:	British Columbia
BFIHC:	Boroa Filulawen Intercultural Health Centre
COAG:	Council of Australian Governments
CONADI:	Corporación Nacional de Desarrollo Indígena, or National Corporation of Indigenous Development
CQI:	Continuous quality improvement
DoH:	Department of Health
DS Nº 40:	Supreme Decree 40
DS Nº 66:	Supreme Decree 66
ECOSOC:	Economic and Social Council
FII:	Fundación Instituto Indígena, or Indigenous Institute Foundation
FNHA:	First Nations Health Authority
FONASA:	Fondo Nacional de Salud, or National Health Fund
GDP (PPP):	Gross domestic product at purchasing power parity
GES:	Garantías Explícitas en Salud, or Explicit Health Guarantees Program
HRC:	Human Rights Council
HDI:	Human Development Index
ICAP:	Improving Care for Aboriginal and Torres Strait Islander Patients
ICHP:	Improving the Culture of Hospitals Project

IDB:	International Development Bank
ICESCR:	1966 International Covenant on Economic, Social and Cultural Rights
INDH:	Instituto de Derechos Humanos, or Human Rights Institute
INIHPP:	International Network of Indigenous Health Promotion Professionals
IHS:	Indian Health Service
IIAHN:	International Indigenous Academic Health Network
ILO 107:	International Labour Organisation Convention Number 107, Indigenous and Tribal Populations Convention
ILO 169:	International Labour Organisation Convention Number 169, Indigenous and Tribal Peoples Convention
IMF:	International Monetary Fund
IPHC:	Improving the Pathways to Hospital Care
LIME:	Leaders in Indigenous Medical Education
MINSAL:	Ministerio de Salud, or Ministry of Health
MJA:	Medical Journal of Australia
NACCHO:	National Aboriginal Community Controlled Health Organisation
NHMRC:	National Health and Medical Research Council
OECD:	Organisation for Economic Co-operation and Development
ORIC:	Office of the Registrar of Indigenous Corporations
PAHO:	Pan American Health Organisation
PROMAP:	Programa de Salud Mapuche, or Mapuche Health Program
RCH:	Royal Children's Hospital
SENAME:	Servicio Nacional de Menores, or National Young Peoples' Service
SEREMI:	Secretarías Regionales Ministeriales, or Regional Secretaries of the Ministry
SSAS:	Servicio de Salud Araucanía Sur, or Health Service of South Araucanía
TO:	Territorial Organisation
VACCHO:	Victorian Aboriginal Community Controlled Health Organisation

VAHS:	Victorian Aboriginal Health Service
UDHR:	1948 Universal Declaration of Human Rights
UHC:	Universal health coverage
UNICEF:	United Nations Children's Fund
UPR:	Universal Periodic Review
USD:	United States Dollar
WCIP:	World Council of Indigenous Peoples
WHO:	World Health Organization

Glossary of Mapudungun terms

Che: Person, people, human being

Kejuwün: Reciprocity

Kimche: Elder/wise person

Kume felen: Being well

Kume mongen: Living well

Lawen: Medicinal plants

Lawenche: Herbalist

Lawentuchefe: Herbalist

Lof: Mapuche community

Longko: Head of the *lof*

Machi: Shaman or healer in the Mapuche community. He or she leads the *machitún*.

Machitún: A ritual peformed to treat a sick person by imploring the gods and making use of medicinal plants

Mapu: Land; region; nation

Mapu kütran: Illnesses caused by transgression against natural laws; spiritual illnesses

Nguillatún: Special ritual carried out to praise, ask or beg the deities to maintain or restore the wellbeing and equilibrium of the people who live on the land

Ngütamchefe: Traditional bonesetter

Ñiempin: Person who is in charge of the ngillatún ritual along with the longko

Püñeñelchefe: Traditional midwife

Ragiñelwe: Intermediary, mediator

Re kütran: Illnesses that have a biological (not spiritual) origin

Ruka: Traditional Mapuche building or house

Trawun: Meeting

Tuwun: Ancestry; place of origin

Werken:	Messenger
We Tripantü:	Mapuche new year (winter solstice)
Winka:	Non-Mapuche, Chilean. Literally: thief. Generally perjorative
Yam:	Respect for all elements of life, nature and natural energies

Chapter 1. Introduction

For Indigenous peoples, community participation in health represents the ability to ensure that health policy and services, including priority-setting, planning, resource allocation and program implementation incorporate their values and an understanding of their health needs. As such, community participation is viewed as a way to improve access, utilisation and effectiveness of health services as well as a form of social justice and a step towards recalibrating inequitable health systems. Community-controlled Indigenous health services are central to the process of community participation in health. They are a key means by which communities exert control in the planning, development and delivery of primary health care services and represent an avenue for providing input into how the broader health care system functions.

Sustainable implementation of community-controlled health services is strongly dependent on the existence of supportive policy and legislation, as well as a health system that is open, flexible and able to respond to input from communities. In the case of Indigenous health, community participation is supported by international conventions such as the United Nations Declaration on the Rights of Indigenous Peoples (UN DRIP)[1] and the International Labour Organisation's Convention No. 169: Indigenous and Tribal Peoples Convention (ILO 169).[2] However, assessments of participatory health initiatives frequently have quite a narrow focus, examining the features of the initiative or program with minimal consideration of how the wider policy environment affects the shape and effectiveness of participatory processes. Where local, jurisdictional or national policy is taken into account, this does not normally extend to the connection between domestic and international policy.

Chile is one of 23 countries that have ratified both ILO 169 and the UN DRIP, and is therefore obliged to engage in consultation with its Indigenous peoples regarding policy, development and legislative matters that concern them.[1,2] Among Chile's largest Indigenous group, the Mapuche, communities have taken an increasingly active role in developing and administering health services over the past 30 years. Two of the oldest and most well-established community-controlled health centres are Makewe Hospital and Boroa Filulawen Intercultural Health Centre (BFIHC).[3-6]

This thesis utilises Makewe Hospital and BFIHC as case studies to examine the interplay between international and domestic legislation and policy and how the resulting environment influences the effectiveness of Indigenous community-controlled health centres as

participatory mechanisms. Therefore, the thesis represents a unique contribution to the literature in that the Indigenous health centres are examined in a holistic manner, incorporating relationships between the centres and their communities, as well as interactions between the centres and the broader health system and the impact of international and national policy on their functioning.

The thesis outline is as follows:

In Chapter 2, the literature review, the main themes of the thesis are introduced. This begins with an overview of Indigenous peoples and health, including Indigenous conceptualisations and determinants of health; international instruments that have been developed to protect Indigenous health and traditional Indigenous healing systems; as well as how traditional Indigenous and biomedical systems interact. A discussion of community participation in health and how it has been utilised by Indigenous communities follows. Subsequently, these concepts are explored within the context of Mapuche communities in Chile. The chapter closes with an examination of global trends in international Indigenous health policy.

Chapter 3 reviews the methodology of the research as well as relevant ethical considerations. The research has been undertaken in three parts: 1) Literature review, scoping and case study selection; 2) Case studies, including key informant interviews, observation and patient interviews; and 3) Reporting and dissemination. Key informant interviews were undertaken with staff members from the Ministry of Health (MINSAL), and staff from the two case study sites, Makewe Hospital and Boroa Filulawen Intercultural Health Centre. Observation included attendance at community and organisational meetings, as well as informal conversations and attendance at ceremonies. Interviews were also conducted with Makewe Hospital outpatients.

The ethical considerations relevant to the research included an understanding of the often contentious history between academia and Indigenous peoples that continues today, and how the effects of Indigenous communities' experience with academia manifests as distrust and reluctance to engage with research. At this point, the ethical approach taken to guide the research is outlined.

Chapter 4 is the first of four chapters that present the research results. As the central theme of the thesis is community participation, it is necessary to have an explicit discussion of what is meant by the term 'community.' In this chapter, different understandings of Mapuche communities are explored—the State definition of Mapuche communities, which relies on

rigid, bureaucratic and geographic boundaries; the perception of MINSAL staff, relating to interpersonal relationships; and constructions of community by Mapuche people themselves, which integrate an understanding of traditional social structures and traditional authorities, but are also complicated by the fact that Mapuche communities are diverse and changeable.

Following this, Chapter 5 reviews the policy and legislative environment within which Indigenous community participation operates in Chile. The backdrop of conflict between State forces and Mapuche communities stemming from the history and continuing legacy of dispossession and discrimination is a constant pressure on all policy and decision-making processes in relation to Indigenous health. Chilean policy regarding Indigenous community participation in health is described here, along with a discussion on how different actors view Indigenous community participation, its aims and its possible benefits. Policy is examined from the level of international agreements that outline governmental obligations to consult with Indigenous communities on matters that concern them to national legislation and regional-level interactions that impact on the day-to-day operations of the two health centres.

Chapters 6 and 7 are concerned primarily with the relationships between the health centres and other entities. These relationships form the means by which the health centres are recognised as relevant actors in policy formulation and practices that affect Mapuche health. Chapter 6 therefore introduces the governance structures that form the basis of the centres' interactions with the State and the wider health system, and which also have an influence on the internal organisation of the centres. This chapter also describes the centres' organisational ties with other Mapuche health centres and non-governmental agencies.

In Chapter 7, the focus shifts from the centres' formal organisational relationships to the relationships they maintain with their communities. These relationships are understood to be bidirectional, encompassing the influence of the communities on the health centres and their operations as well as the way the health centres engage with wider community life. The roles of the centres in maintaining and strengthening traditional knowledges and social structures are explored in this chapter.

As the last of the results chapters, Chapter 8 focuses on Makewe Hospital patient perspectives regarding their experiences of receiving health care. This chapter is concerned with the question of patient choice in selecting health care services, how patients perceive the utility and importance of Mapuche hospital administration and how they feel about the care provided at Makewe Hospital.

The discussion section of the thesis is then presented in the following two chapters, both of which integrate the Chilean situation as presented in the results chapters with the international context of Indigenous health policy and participation in health. Chapter 9 consolidates the findings in Chapters 5-8 and places them alongside the experiences of other countries in order to develop a number of ways Chilean policy and practice could be strengthened to better support Indigenous community participation in health and fulfil Chile's obligations under international law.

Chapter 10 then extends the consideration of various countries' experiences as presented in Chapter 9 to discuss implications for international policy and practice in Indigenous community participation in health. This chapter consists of three main sections: the first reviews cross-country transfer of Indigenous policy, utilising Australia's ratification of an international convention on Indigenous rights as a case study; the second section applies some of the lessons covered previously towards the development of policy and practice to support effective implementation of Indigenous health services as avenues for community participation; and the third section examines assessment of Indigenous community participation in light of themes raised throughout the thesis.

The final chapter, Chapter 11, consists of some concluding remarks and final reflections on possible further directions.

Chapter 2. Literature review

This chapter provides a critical review of the literature supporting the research aims and questions in four sections. The first provides a brief overview of the health of Indigenous people worldwide. This includes Indigenous conceptualisations of health as well as Indigenous health determinants and outcomes and the maintenance of traditional Indigenous health knowledge alongside biomedical systems. The next section outlines the concepts of community participation and community control in health, introduces theory around how community participation and control serve to reduce health inequity, examines the utilisation of these concepts in relation to Indigenous health and presents international and national policies that serve to shape participatory processes. The following section focuses on Mapuche (Indigenous) health and health care in Chile and examines the role of community participation within an intercultural health framework. The fourth and final section examines the issue of policy exchange across countries in relation to Indigenous participation in health, and presents a framework that enables prospective consideration of the likelihood of successful policy transference.

2.1 Indigenous peoples and health

There is no one definition of Indigenous peoples, who may also be called tribal peoples, First Nations, Aboriginal, or minority peoples. Within the Americas and parts of the Pacific, Indigenous may be used to refer to populations and descendants of native peoples who inhabited a nation or area before European colonisation. In parts of Asia and Africa, mass displacement by European settlers did not take place; however, the experience of domination, displacement and suppression of one population by another has been central to the formation of an Indigenous identity.[7] Worldwide, the issue of defining Indigenous peoples is complex, disputed and contentious. A widely-used definition of the concept 'Indigenous' comes from José R. Martínez Cobo's 1981 *Study on the problem of discrimination against Indigenous populations*, which considers that:

> *Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their*

> *continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system.*[8]

Estimates of Indigenous people worldwide vary but are generally placed at approximately 250-350 million Indigenous people, representing more than 5,000 groups across 70 countries and about 4 to 5 percent of the world's population.[9-11] Stephens (2005) estimates more than half of Indigenous peoples to be living in China and South Asia, approximately 6 percent to be in Latin America, and a little over 1 percent to be in Australia, Canada, New Zealand and the United States combined.[10]

2.1.1 Indigenous conceptualisations of health

Indigenous peoples worldwide hold holistic views of health, incorporating ideals of familial and community ties, spirituality, relationships to land and responsibilities to the self and others.[12] Many Indigenous languages do not have a specific word for 'health.' Rather, they may have concepts that refer more holistically to ideas of 'living well.' For example, s*umak kawsay* in Quechua and s*uma qamaña* in Aymara both translate to 'living well' and incorporate an understanding of living in harmony with nature and with other people.[13,14] The Ojibway term *mno bmaadis* similarly translates to 'the good life' or 'being alive well,' and refers to a sense of balance.[12] This holistic way of thinking about health and wellbeing also extends to other, related concepts. Aboriginal Australian languages have no words that translate to 'disability,' referring instead to individuals' specific impairments: rather than labelling someone as 'deaf,' they may speak about a person not being able to hear well.[15] In 2017, 200 words were added to the Māori language in order to encapsulate concepts related to mental health, disability and addiction in ways that were coherent with how Māori people with lived experience in these areas viewed themselves and with the Māori worldview.[16] A sense of community is necessarily tied to health for many Indigenous peoples. In Australia, the National Aboriginal Community Controlled Organisation (NACCHO) makes this connection explicit in its adopted definition of health:

> *'Aboriginal health' means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing*

> *about the total well-being of their Community. It is a whole of life view and includes the cyclical concept of life-death-life.*[17]

2.1.2 Determinants of Indigenous health

Internationally, Indigenous populations are consistently reported to have poorer health outcomes, including higher mortality and morbidity, than their non-Indigenous counterparts.[7,18] Data regarding Indigenous health is highly variable; in some countries, including the United States, Australia, Canada and New Zealand, reliable information on Indigenous trends in morbidity and mortality in relation to non-Indigenous health exists.[19,20] However, in most other areas where Indigenous peoples reside, this data is not available due to the difficulty in identifying Indigenous people, collection of epidemiological data that does not allow disaggregation by ethnicity, a lack of representation of Indigenous people in the data that is collected, or a combination of these factors.[21] Despite these limitations, the available evidence overwhelmingly indicates that Indigenous peoples worldwide have higher morbidity and mortality rates than non-Indigenous people in the same community or area, including in such indicators as life expectancy, adequate child nutrition and infant and maternal mortality.[18] The factors underlying these disparities are complex but often similar across borders, including colonial dispossession, familial disruption and violations against self-determination.[10,12] Through the processes of colonisation and dispossession, many Indigenous peoples have experienced profound losses of identity, language, ties to land and territory and family and social connections.

A number of academic studies have reinforced the connection between Indigenous identity, community, culture and physical and mental health. In Australia, a study identified six main themes in the links between culture and Aboriginal and Torres Strait Islander health and wellbeing:

- Connection to Country;
- Cultural beliefs and knowledge;
- Language;
- Family, kinship and community;
- Expression and cultural continuity; and
- Self-determination and leadership.[22]

Also in Australia, the incorporation of kinship ties into the experience of being relocated to give birth in hospital helped to mediate the stress, fear and loneliness experienced by Aboriginal mothers. This was the case even as they continued to have strong negative feelings about the birthing experience.[23] The authors conclude that incorporating an understanding of kinship into hospital birthing services may support improved post-natal health outcomes.[23]

On the other side of the coin, loss or weakening of identity has been tied to higher levels of suicide risk,[24] mental illness[25] and use of alcohol and other drugs[26,27] in some Indigenous communities. Chandler and Lalonde's work in Canada demonstrates that the variation in suicide rates among First Nations youth in British Columbia are strongly associated with the extent to which their communities engaged in practices that fostered cultural continuity.[24,28] Historical trauma as a concept was developed to provide a framework for describing the effects of colonisation on American Indian behavioural health disparities without pathologising Native communities.[29] Historical trauma can be summarised with four Cs: *collective* experience of *colonial* injury with *cumulative* effects snowballing to produce *cross-generational* impacts.[30] The concept of historical trauma overlapping with intergenerational and collective trauma has also been applied to Indigenous peoples internationally.[31-33]

Social determinants, including socioeconomic status, educational attainment, adequate employment, experiences of racism and discrimination, and living conditions, have also been identified as particularly relevant to Indigenous health.[12,34] Where data is available, it demonstrates that Indigenous people tend to experience disadvantage and marginalisation across these dimensions in their respective countries. For example, the 2011 Canadian National Household Survey showed that 48.4% of Aboriginal people aged 25 to 64 had a postsecondary qualification, compared to 64.7% of the non-Aboriginal population of the same age.[35] The 2014 Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report indicates that in 2012-13, nearly one quarter (23%) of all Aboriginal and Torres Strait Islander people were living in overcrowded households, in comparison to 5% of non-Indigenous Australians.[36] Aboriginal and Torres Strait Islander people also represented 28% of the homeless population in 2011 and were 14 times as likely as non-Indigenous Australians to be homeless.[37]

Indigenous people tend to have poor access to health care services—a situation that is compounded by a lack of existing services that incorporate and are responsive to Indigenous ideas and beliefs about health. Where health care services are available, they may not be accessible due to geographical placement, financial cost, lack of language support and/or

incompatibility with health beliefs and cultural norms. In particular, Indigenous holistic conceptualisations of health may not easily be incorporated into biomedical perspectives supported by governments or mainstream service providers, and this disjuncture has been recognised as a persistent barrier to adequate Indigenous access to biomedical health care services.[38]

The pathways by which these determinants affect Indigenous health are interconnected and reinforce each other, leading to stress, maladaptive coping mechanisms, social fragmentation and an inability to access necessary services (Figure 1).

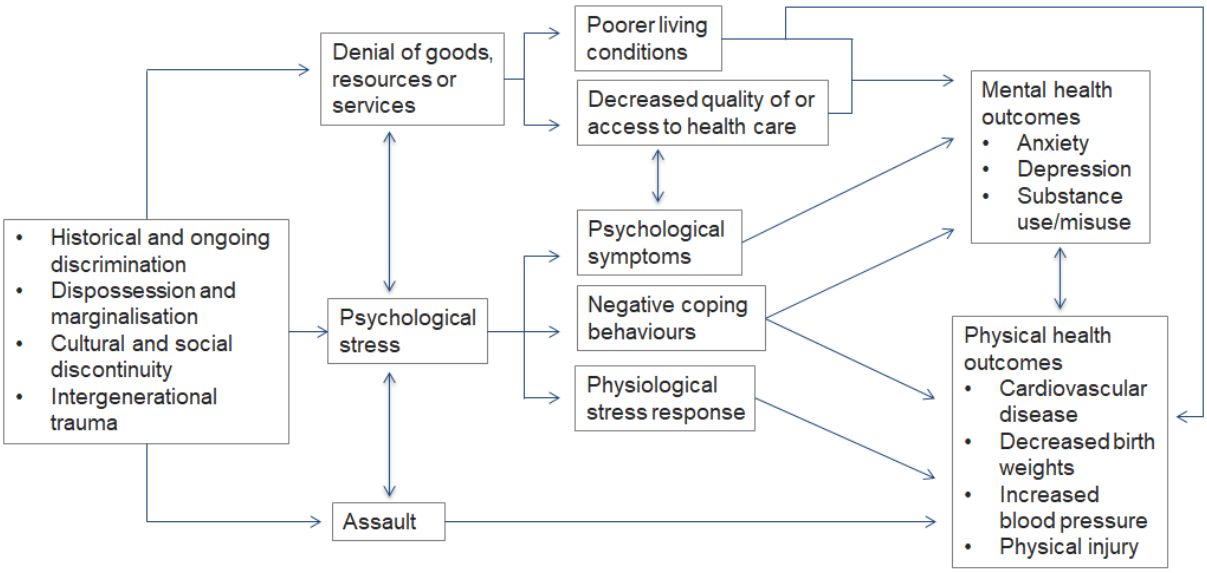

Figure 1. Potential pathways between Indigenous determinants of health and resultant health effects

2.1.3 International frameworks regarding Indigenous health

Because many of the determinants of Indigenous health and wellbeing are similar and shared across borders, there have been a number of international instruments developed with the aim of defining the roles of national governments in protecting Indigenous peoples' health. These documents have been important in the development of international minimum standards for Indigenous peoples' social, political and economic rights and governments' obligations to uphold them.

Discussions to draft the International Labour Organisation Indigenous and Tribal Populations Convention 107 (ILO 107), *Indigenous and Tribal Populations Convention*, began in 1946 within the international context of a rising concern regarding human rights in the wake of World War II.[39,40] These discussions lasted 11 years before ILO 107 was adopted in 1957.[39,40]

Article 20 of ILO 107 outlines the responsibilities of governments to provide adequate health service for Indigenous populations, and that these services should be 'based on systematic studies of the social, economic and cultural conditions of the populations concerned.'[39]

ILO 107 was groundbreaking in being the first international instrument to address the issue of Indigenous rights. However, it is also a reflection of the state of dominant thought regarding Indigenous peoples at the time, with a strong view towards assimilationism.[40] Indigenous peoples therefore advocated for the development of new international standards, which lead to the revision of ILO 107. ILO 107 continues to be legally binding for the 18 countries that have ratified it but have not ratified ILO 169, *Indigenous and Tribal Peoples Convention*.[40]

ILO 169 is the outcome of the revision and updating of ILO 107, and was adopted in 1989. Similarly to ILO 107, ILO 169 is a binding international convention for those countries that have ratified it. It obligates governments to consult with Indigenous peoples and ensure that Indigenous peoples are able to participate in decision-making processes regarding legislation, policies and programs that concern them.[2,41] Articles 6 and 7 of the Convention obligates governments to 1) consult with Indigenous peoples 'through appropriate procedures and in particular through their representative institutions,' regarding legislative and administrative issues that affect them and 2) allow Indigenous peoples to participate in 'the formulation, implementation and evaluation of plans and programs for national and regional development which may affect them directly.'[2] The issues covered by the Convention include employment and training, education, health, traditional laws and institutions and languages.[42] Specifically regarding health, Article 25 of the Convention stipulates, in part, that 'Governments shall ensure that adequate health services are made available to the peoples concerned, or shall provide them with resources to allow them to design and deliver such services under their own responsibility and control, so that they may enjoy the highest attainable standard of physical and mental health' and that 'Health services shall, to the extent possible, be community-based.'[2] ILO 169 has been ratified by 23 countries in total, with the majority in Latin America. Countries outside of Latin America which have ratified ILO 169 include Nepal, Norway and Spain.[43]

Across Latin America, ILO 169 has played a critical role in establishing the obligation of governments to consult with Indigenous peoples about those matters that concern them. ILO 169 has been an influential tool wielded by Indigenous peoples in response to inadequate prior consultation, particularly in relation to inappropriate development, such as resource extraction and construction of hydroelectric dams on or near Indigenous lands.[44]

In cases where the needs of Indigenous communities and the desires of governments or private sectors are at odds, Indigenous community participation is frequently perceived to be a threat to business and economic interests that seek to exploit Indigenous resources for their own end. Mining and forestry in particular are key drivers of both social conflict and economic stability in Latin America. This has been amply demonstrated in Chile, whose relatively stable and prosperous (albeit inequitable) economic situation is in large part due to the mining and forestry multinational corporations that conduct their business on or adjacent to Indigenous lands, often resulting in disaster for affected communities and territories.[45] For example, the installation of acres of plantations in or alongside Indigenous territories has led to persistent drought in Indigenous communities and entrenched conflict.[46] Similar issues are apparent throughout the Latin American region.[47] Because of this, Latin America is characterised by a high level of violence and armed conflict between Indigenous groups on the one hand and extractive and development companies and the State on the other with regards to private and public projects on or bordering Indigenous territories. Within this context, it is almost inevitable that an instrument that grants Indigenous communities more influence in deciding what is and is not acceptable use of their lands would be met with a high level of resistance from both the private sector and elements of the government.

In this case, the decision to ratify ILO 169 and thereby protect Indigenous rights to participation means that governments must weigh the demands of their Indigenous peoples against powerful private entities—with Indigenous rights often seen as carrying less weight. The pattern of encountering resistance to ratification, particularly from the private sector and economic interests, has been evident across many of the ratifying countries. This accounts for much of the tension and pushback experienced in the nearly 20 years' worth of attempts for Chile to ratify ILO 169. The nearly twenty years of negotiation and resistance that Chile took to ratify the Convention in 2008 is longer than the majority of other Latin American and Caribbean ratifying counties, although others also delayed ratification significantly; for example, Nicaragua ratified ILO 169 in 2010, Venezuela and Brazil in 2002 and Argentina in 2000.[43]

The complexities surrounding ILO 169 are exacerbated by the Convention's ambiguity. In order to balance the interests of Indigenous peoples and member States, as well as in recognition of the diverse and complex environments within which the Convention would be implemented, there are no specifications regarding what constitutes adequate consultation or the mechanisms for such. The establishment of regulations for consultation are therefore the responsibility of individual governments. This includes under what circumstances Indigenous

peoples' rights to consultation are triggered, who has responsibility for such consultation, who specifically has the right to be consulted with in regards to a particular issue and by what mechanisms such consultation should be conducted. Each country has approached the task in a different way, and the extent to which the principles of the Convention are enshrined in national law are variable. It is also worth noting that the participatory processes covered by ILO 169 extend only to 'consultation' with Indigenous communities. It is explicit that ILO 169 does not provide Indigenous communities the right of veto over projects or programs that affect them. Additionally, Article 6(2) stipulates that consultations must be undertaken in good faith and with the objective of obtaining consent or agreement. However, obtaining consent or agreement is not a requirement in itself.[42]

ILO 169 becomes legally binding for States upon ratification and is the only legally binding international instrument specifically concerned with the rights of Indigenous peoples. However, '[t]he question [of] whether a treaty requires legislative implementation after the treaty enters into force internationally must be distinguished from the question whether legislative approval is necessary prior to treaty ratification.'[48] Under dualist systems, no treaties have the status of law within the domestic legal system without a relevant statue being authorised by the legislature, separate from the executive act of ratifying the treaty. In contrast, monist states (including Chile) necessitate some form of legislative approval before the executive is authorised to ratify at least some types of treaties; subsequently, at least some treaties are then incorporated into domestic law without the need for further legislative act.[48] Even in cases where a treaty has formal status of domestic law without implementing legislation, legislature may be enacted in order to facilitate practical application of the law within the legal system and to ensure harmonisation with domestic law.[48] In Chile, ratified international treaties have the force of law.[44]

The United Nations Declaration on the Rights of Indigenous Peoples (UN DRIP) was adopted by the UN General Assembly in 2007, with four States voting against adoption: Australia, Canada, New Zealand and the United States.[1] All four States have since reversed their position to support the Declaration, with the United States being the last country to do so in 2010.[49] Unlike ILO 169, the UN DRIP is not legally binding. The Declaration has several articles that pertain to Indigenous health and community participation in health. It states that 'Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health.'[1] In order to fulfill this principle, the right of Indigenous peoples to both maintain their traditional health practices and access formal health services without

discrimination is affirmed in the Declaration: 'Indigenous peoples have the right to their traditional medicines and to maintain their health practices…. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.'[1] The right of Indigenous peoples to have control over matters that affect their health is also outlined, as the Declaration lays out that 'Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health…programmes affecting them and, as far as possible, to administer such programmes through their own institutions.' Under the Declaration, States have an obligation to 'consult and cooperate…with the indigenous peoples concerned…before adopting and implementing legislative or administrative measures that may affect them.'[1,50]

The principles outlined in ILO 169 and the UN DRIP are further supported by additional international instruments that do not directly mention Indigenous peoples. This includes the recognition of individuals' 'right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care and necessary social services,' under the UN Universal Declaration of Human Rights.[51]

2.1.4 Traditional healing systems, medical pluralism and intercultural health

Despite much traditional knowledge having been lost, many Indigenous peoples continue to maintain and practice traditional forms of healing. Medical pluralism, where multiple health systems are simultaneously in use within a population, is therefore a reality for many Indigenous communities that engage with both traditional and biomedical health systems.[52-55]

Individuals and communities engage in medical pluralism for a variety of reasons, shaped by historical, cultural and environmental factors. While there are many traditional Indigenous medicines to treat physical maladies, traditional Indigenous systems are frequently used to treat illnesses that manifest through spiritual or supernatural means, or that come from being 'out of balance' in some way. These illnesses are classified separately from those that are appropriate for the attention of biomedical services. Additionally, for many Indigenous people, there is not a distinct separation between body and mind, as is generally understood in Western concepts of health.[56] Individuals may therefore willingly engage with both systems, depending on the type of care required.[53,55] Wedel (2009) reports that among the Miskitu people of Nicaragua,

Indigenous medicine is used in response to illnesses with spiritual or sorcerous origins, with a strong distinction between those illnesses that belong to the traditional and biomedical realms.[55] At the same time, traditional healers demonstrated openness to the utility and validity of the biomedical model within its own framework, and some used their understanding of the biomedical model to refer patients when this type of attention was warranted.[55] Indigenous people may also engage with traditional health systems in order to maintain cultural knowledge, or as an expression or connection to culture. However, there are also situations where individuals engage with traditional health systems when their preference would be to attend biomedical services, but these are inaccessible. This lack of access might be due to cultural differences, geographic location, language barriers, or the experience or threat of experiencing discrimination. It is therefore recognised that the process of deciding which system to attend for care is complex, dynamic and nuanced.[52]

The way that medical pluralism is expressed in Indigenous communities and the relationship between traditional Indigenous health systems and biomedicine also varies. Traditional healers often show at least some openness to engage with the biomedical; however, the biomedical system is often closed to traditional Indigenous health practices at both an institutional and an individual level.[57] The relationship between the two may be characterised by mistrust and conflict.[58] On the other hand, Hoyler *et al* (2018) describe medical pluralism in Guatemala as not only the simultaneous utilisation of two health systems, but as and interconnectedness between the biomedical and traditional. Traditional services are utilised at a high rate alongside biomedical services, with the two systems not being perceived as conflicting; rather, practitioners from both systems report incorporating elements from the other.[54]

The World Health Organisation (WHO) Traditional medicine strategy 2014-2023 recommends the integration of traditional and complementary medicine into health systems and sees this as a useful strategy to achieve universal health coverage (UHC).[59] This aligns with the approach of intercultural health. Expanding slightly on the definition cited by Mignone *et al* (2007), intercultural health is presented here as a system of practices that integrate traditional or indigenous and biomedical health care, where both are considered complementary and equally valid (see Figure 2).[4] The concept of intercultural health is based in recognition of the social, cultural and economic rights of minority peoples, including the right to maintain their cultural practices and the right to appropriate health care without regard to race, ethnicity, gender or geographic location.[7,60] Within the context of Indigenous health, intercultural health practices have been used with increasing frequency worldwide, including in such diverse contexts as

North America, Uganda and Australia.[26,57] In Latin America, various models are found in Mexico, Colombia, Ecuador, Chile, Guatemala and Suriname, among others.[4,61]

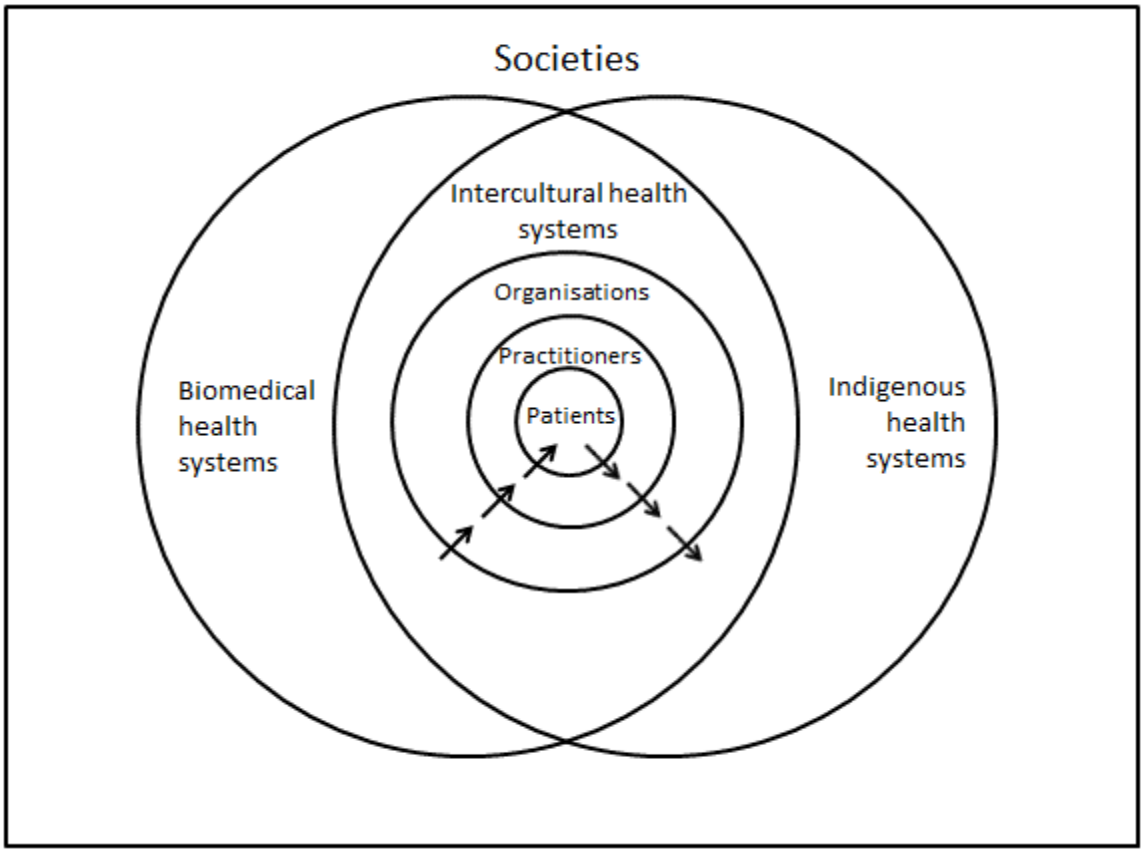

Figure 2. Framework for intercultural health care systems

However, while intercultural approaches have been supported by some governments and health systems,[58,62] there have been criticisms that the epistemological bases of traditional Indigenous health systems and biomedicine are too much in opposition to be meaningfully integrated. In contrast to the holistic approach of Indigenous health systems, biomedicine is largely hierarchical and positivistic, with a focus on illness rather than wellbeing.[58,63] Against a background of the historical and current use of biomedicine as a way of pathologising and delegitimising Indigenous knowledges,[64] some Indigenous peoples have expressed resistance to the State having control or input into traditional systems through their integration with formal health systems, seeing this as an unwelcome and inappropriate intrusion.[65] While intercultural health has been conceptualised as a way of reorienting the relationship between Indigenous peoples and formal health systems to be more equitable, there is also a concern that the approach may be co-opted or applied in a superficial way.[62] In reviewing the literature

regarding intercultural approaches, Joe *et al* (2016) highlight that a key barrier is the unwillingness of biomedical systems to engage with Indigenous traditional health systems.[66] The authors therefore conclude that most intercultural health approaches are strongly shaped by the level of flexibility and respect exhibited by the relevant biomedical system.[66]

2.2 Indigenous community participation in health

Over the past few decades, interest has grown in the decentralisation of governing across fields as diverse as education, health, and justice.[67-69] Decentralisation has been enacted through a reduction in rigid hierarchical structures, increasing partnerships with civil society and localised decision-making processes—a trend that has gone hand-in-hand with the rising discourse of community participation in health. Community participation in health has been identified as a central strategy to reduce health inequities, including those experienced by Indigenous populations, since the 1978 Alma Ata Declaration.[70] Variously called 'citizen participation,' 'community involvement,' 'social participation' and 'stakeholder participation,' the concept of community participation refers to the processes by which individuals or communities influence priority-setting, planning, resource allocation and program implementation with regards to the policies and services that affect them.

The need for community participation in health is often framed in two ways: either as a way to improve democratic processes in health, incorporate elements of social justice and enable lay and marginalised people to have power over their health (*i.e.* a democratic perspective) or as a method of increasing the effectiveness and outcomes of health systems (*i.e.* a utilitarian perspective).[71,72] The democratic perspective of community participation recognises that health systems operate within and are shaped by social, political and economic contexts which drive inequitable health outcomes. Centering the expressed needs of marginalised or vulnerable populations in ways that recognise their agency is therefore necessary to provide appropriate services and address the social and political determinants of health.[73,74] Evidence supporting the utilitarian perspective indicates that community participation at all levels of health systems and service delivery improves the responsiveness, acceptability and quality of service provision, particularly for marginalised communities.[75] Additionally, the integration of community participation may improve the cost-effectiveness of hospital services and patient outcomes in resource-limited settings.[76] Not only is the representation of communities necessary in order for health systems to respond appropriately to local contextual factors, when managed appropriately, participation enables communities to gain awareness about and utilise their own resources to address behaviours, beliefs and processes that affect their health.[77]

Figure 3 demonstrates the ways that community participation has been hypothesised to support improved health outcomes.[72,78,79]

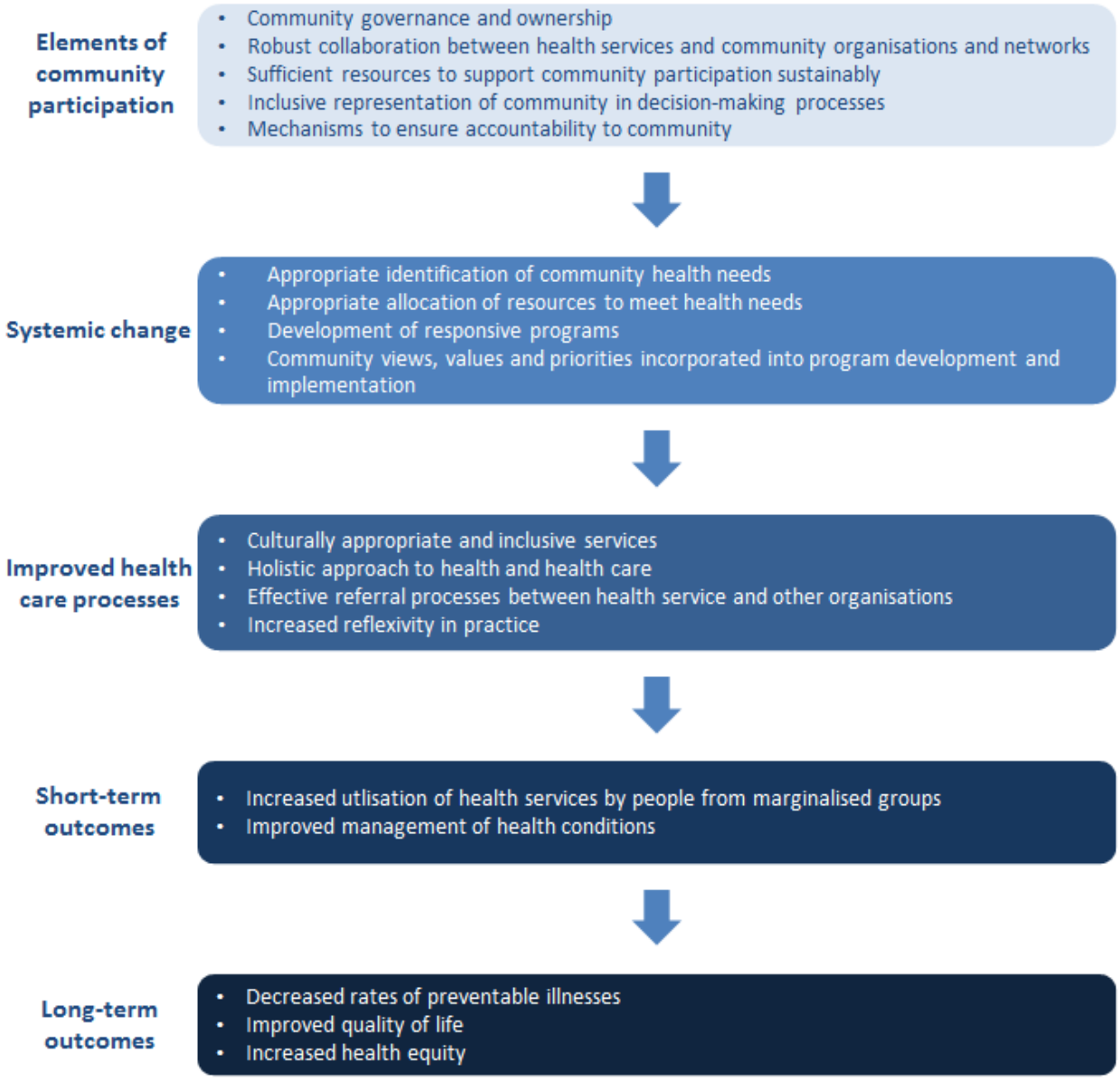

Figure 3. Program logic for community participation in health and improved health outcomes

Part of the appeal of community participation seems to be that it can represent all things to all people—depending on who is using the term and in what way, community participation in health may be seen as a tool to improve access to health care for marginalised populations; to reduce inefficiencies and increase the effectiveness of the health care system; and to produce more equitable power distributions.[72] While the wide range of hoped-for benefits associated with community participation in health has contributed to its endurance, this variation is also a

reflection of the lack of clarity around the term.[72] The meanings of both 'community' and 'participation' are contested, and understandings of the purpose of and best practice around implementation can be widely divergent—even amongst actors contributing to the same community participation initiative.

2.2.1 Conceptualising 'community'

While often used in an imprecise way, the way the term 'community' is defined has significance in providing the basis for social analysis by delineating in- and outgroups and framing social structures. Complications in defining who exactly does and does not belong to a particular community arise for a number of reasons. Given that all people are members of multiple communities, community membership must by necessity be overlapping, and boundaries may therefore be blurred. The guidelines of community membership may also shift or be redefined over time, so that people move into or out of the community—either through their own volition or on someone else's terms. These guidelines may be explicitly stated or implicit and vague.[80]

The issue of defining 'community,' much less a particular community, is therefore a confounding one for researchers. While the needs of empirical research tend towards clarity and precision in language, those who participate and act within communities have no such obligation and often seem disinclined to examine the meaning of community in the way of philosophers and academics. As communities are often amorphous, unstable and lacking clear boundaries, attempting to assign a particular structure for the purposes of research may be futile or represent an artificial imposition of the researcher's own perspective, rather than respecting the shifting nature of the community as experienced by its members.[81]

Tönnies (1887) is widely credited with developing the structural-functionalist approach to conceptualising communities, which envisioned communities as relatively discrete and stable within spatial, temporal and social terms. Tönnies' term *Gemeinshaft* (community) was seen as being in opposition to *Gesellschaft* (society), with *Gemeinschaft* representing the close, positive and voluntary association between people based on common characteristics such as shared language, interests or belief systems, exemplified by groups of family and friends. Standing in contrast, *Gesellschaft* was based on an instrumental goal, for example the accumulation of profit through trade.[82,83] Despite being a very early academic conceptualisation of community, this way of distinguishing between community and society

continues to resonate with the general public, including in relation to Indigenous communities.[82]

In his 1975 work, Gusfield outlines two aspects of communities: the territorial aspect relates to shared geographical spaces, such as neighbourhoods, while the relational aspect incorporates interactions based on shared characteristics. While communities defined by the relational dimension may not have a geographical or territorial factor—such as in the case of virtual or global communities—those communities that are primarily territorial in nature must also incorporate some level of the relational factor. Throughout the abundance of definitions for 'community' developed from the fields of sociology, anthropology and psychology, many if not most incorporate some facet of the relational and territorial aspects.[84] The concept of 'identity' as a way of recognising shared experiences, similarity and commonality is also frequently encountered in definitions of 'community' and overlaps significantly with Gusfield's relational aspect.[85]

2.2.1.1 **Indigenous communities**

Dirlik (2003) contends with the tensions between Indigenous communities and the nations within which they reside. The creation and maintenance of Indigenous communities undermines homogenising rhetoric and challenges assimilation and forces disruptive to those communities. As Indigenous communities assert their sovereignty, they demand that their needs and rights be taken into account as the State pursues its political and developmental goals.[86] This analysis of Indigenous communities can be viewed alongside Tönnies' theoretical framework. Tönnies writes of the tensions between the *Gemeinschaft*, within which members remain connected in opposition to factors which seek to disunite them, and the *Gesellschaft*, which foments isolation while simultaneously bringing individuals and communities together in order to achieve rational and directive aims.[87]

The intertwining of community and territory is apparent at various levels of Indigenous identity. Due to the diversity of Indigenous peoples, territorial connection is not necessarily part of an understanding of indigeneity.[88] Nevertheless, in understanding Indigenous communities at the local and national levels, the territorial aspect of community is particularly relevant for those Indigenous peoples who share an ongoing experience of displacement and conflict over land use. For example, Bishop *et al* (2006) found that kinship, land and language were strongly intertwined in the way Aboriginal Australians conceptualised their communities.[89] Similar constructions of Indigenous communities are also apparent in areas

without a history of European settler colonisation. In Botswana, the identity of the San as Indigenous peoples is strongly connected to their relationship with their ancestral territories, which in turn is bound together with traditional customs.[90]

However, indigeneity is also increasingly being viewed as a global community, comprised of a network of Indigenous individuals, local communities and nations working together to build an international social movement.[91] From the 1970s to the present, there has been a proliferation of initiatives to strengthen global solidarity among Indigenous peoples and bring international recognition to their common causes.[86,92] In 1974, the World Council of Indigenous Peoples (WCIP) was founded. The WCIP would eventually go on to represent 600,000 people and gain observer status with the UN. In 1977, the International Indian Treaty Council was one of the first international Indigenous organisations to be recognised by the UN.[92] Today, international conferences, formal and informal networks and organisations centred on collectively discussing and addressing the rights, struggles and experiences of Indigenous peoples are numerous. Taken as a whole, the concept of Indigenous community therefore both centres around Gusfield's territorial aspect and supersedes it.

2.2.2 Conceptualising participation

One of the difficulties in defining 'participation' is that both the concept and its operationalisation are highly context-dependent. A number of factors affect the capacity of community members to actively contribute and the means by which they can do so, including: the 'openness' of the wider political system; social norms that determine how community members are able to provide input into decision-making processes; issues of access such as geographical, time and financial barriers; and high levels of illiteracy.[93] As such, the question of community participation is deeply rooted in political power governing whose voices are heard, level of involvement, how decisions are made, and the distribution of available resources.[94]

A number of different frameworks have been established to assess community participatory processes and resulting outcomes, each demonstrating its own emphasis on particular dimensions of participation. The centrality of power and its role in community participation is in reflected in Sherry Arnstein's classic 1969 paper, which visualises community participation using eight 'rungs' or levels of increasing control arranged in three groups: nonparticipation, degrees of tokenism and degrees of citizen power.[95] Arnstein is particularly concerned with the participation of 'have-nots,' that is, marginalised and oppressed communities, and her

model emphasises the role and distribution of power in the relationships between communities and those who create policy or provide services. In this model, the first steps represent 'nonparticipation,' where communities and individuals are informed or educated about policies or services, but are given no opportunity to give feedback or input. The next steps, placed within 'tokenism,' allow for the provision of community and individual opinions, but do not include processes to ensure that participants will be empowered to make changes. The highest steps, grouped under 'citizen power,' represent a redistribution of power by providing mechanisms for community control over key aspects of policy, design and implementation (Figure 4).

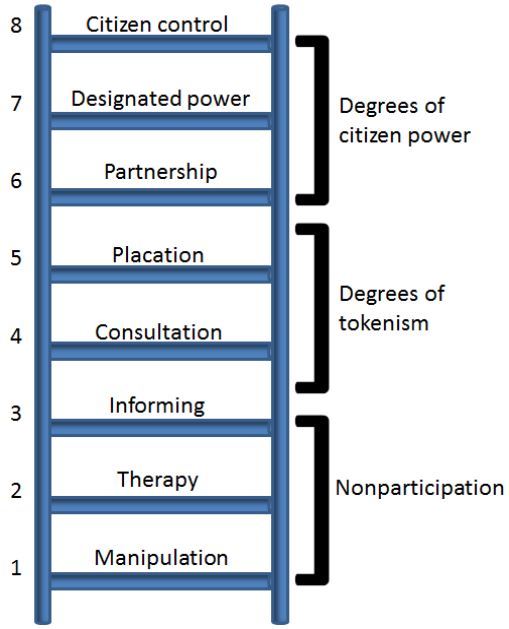

Figure 4. Arnstein's ladder of citizen participation

Arnstein's model remains influential, despite being criticised on a number of fronts and being redesigned by others to either add elements such as quality of engagement,[96] focus on specific communities or contexts[97,98] or create less hierarchical models.[99] However, many of the offered alternatives are vague, eschew a focus on marginalised or vulnerable communities and/or do not explicitly centre the role of power in considering various forms of participation. Without these elements, the redesigns tend towards more conservative typologies of participation.[100]

In contrast to Arnstein, who mainly positions participation as a fixed outcome, Rifkin (2014) argues for participation to be seen as a dynamic process, within which the operationalisation of participation, involved actors and interpersonal and interorganisational relationships may shift over time. Such an approach allows for the ongoing monitoring of how organisations and

individuals interact with the program and each other, changes in the implementation of the program and how participation processes respond to changes in the wider environment. Moreover, Rifkin argues, seeing community participation as a process, rather than an intervention, supports a stronger understanding of the mechanisms by which participation is linked to outcomes such as changes in service provision and utilisation.[101]

Rifkin's 'spidergram' is one of the most frequently and widely used methods for assessing five aspects of community participation. These aspects were derived from analysis of over 100 case studies:

- *Needs assessment*, how participants are involved in the identification of their health needs and program design;
- *Leadership*, the level of inclusiveness and representativeness of participants with respect to the wider community and its interests;
- *Organisation*, the level of collaboration and partnership between programs or services and community networks and/or existing organisations;
- *Resource mobilisation*, community capacity and available resources available to support meaningful participation and community control over how these resources are utilised; and
- *Management*, the ability of the community to have input and make decisions about program design and implementation.[102]

Each indicator is visualised across a continuum from 1 to 5, with 1 representing 'narrow' participation and 5 representing 'wide' participation. Respondents are asked to rate each indicator according to the level of participation involved in the program. The indicators are each linked together at the 'narrow' end, forming a pentagon. Figure 5 shows an idealised pentagon representing perfectly narrow and perfectly wide participation and Figure 6 is a fictionalised example of a program assessment using the method.

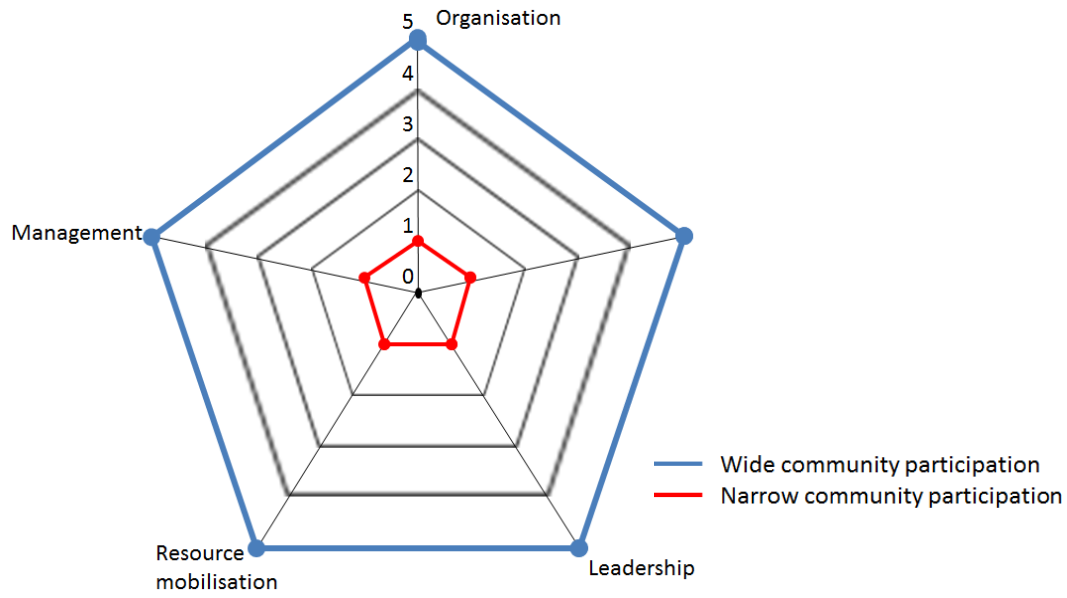

Figure 5. Idealised spidergram showing 'narrow' (red) and 'wide' (blue) participation

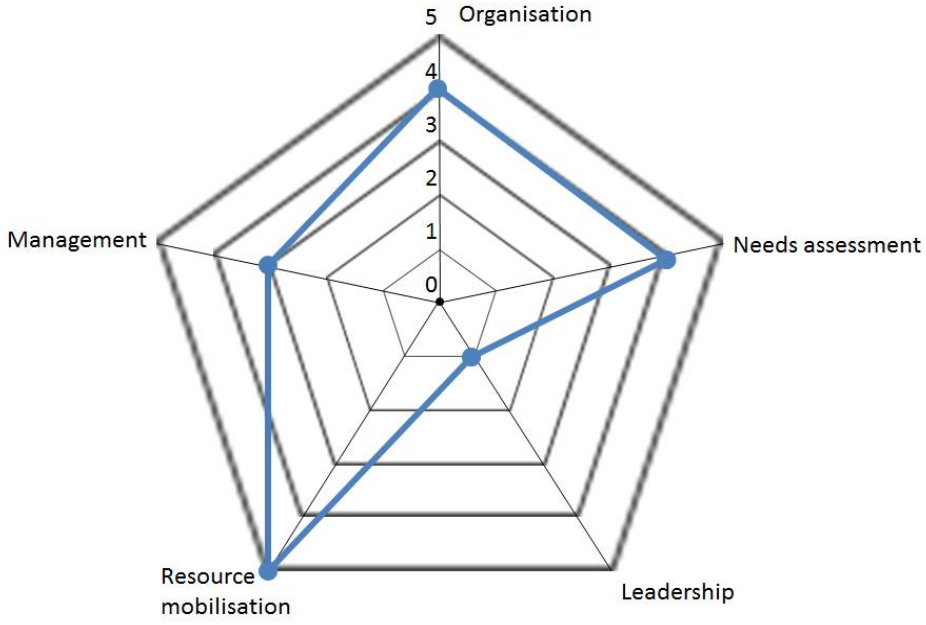

Figure 6. Fictionalised example of an assessment using the spidergram method

Rifkin makes the point that 'wide' and 'narrow' participation should not be seen to equate to 'good' or 'bad'—rather, the purpose is to comparatively assess community participation across different programs, different participants within the same program, or changes in participation within the same program over time from the point of view of the people involved.[102]

Spidergrams have been used in contexts as varied as Ghana[103] and Nepal,[104] and a similar tool has been used in Australia with Aboriginal communities.[105]

Distinct from Arnstein's work, which focuses on the relative control of citizens, or Rifkin's, which examines the degree to which community members are involved along various axes, Fournier and Potvin (1995) present a conceptualisation focused on the values expressed through participatory processes. In this model, participation is visualised as tensions between utilitarianism, democracy and empowerment, which are concerned with program efficiency, the representation of diversity and peoples' control over the conditions that affect their health.[106]

A fourth model for community participation focuses on the relationships between relative actors. In this model, Potvin (2007) utilises the framework developed by Callon (1986, as cited in Potvin 2007) to envisage the development and implementation of health programs as *socio-technical networks* that encompass the human knowledge and skills, objectives, resources, targets, and other elements that contribute to the program, including the social context within which it is situated.[106] Within this framework, the processes of *interest*, *problematisation*, *enrollment* and *mobilisation* are iterative stages in establishing, expanding or transferring health promotion programs.[106] *Problematisation* is the identification of an issue, developing its meaning and determining the relevant actors to address the issue. *Interest* involves attempts to draw in these relevant actors, aligning their own identities and priorities with the issue at hand, with *enrollment* referring to the successful engagement of such actors. *Mobilisation* is the process by which the system's 'mouthpieces' are selected from amongst the actors, imbued with legitimacy and undertake action on behalf of the network.[106] While these stages occur within a single network, Callon envisages *translation* as the process of engagement between separate networks whose interests partly overlap but who occupy differing perspectives and positions in relation to the issue at hand. Within the process of *translation*, the mouthpieces of the individual networks interact to express the will of their network and align differing perspectives in order to ensure that this desire is fulfilled.[106]

Potvin (2007) argues that community participation is a particular manifestation of socio-technical networks, within which multiple levels of translation are occurring simultaneously; such as a first level translation occurring within an organisation as internal decisions are made while a second level occurs through negotiation between the organisation and other actors within a broader governance structure.[106] Participation in health promotion is seen as the development of multiple mouthpieces of individual groups, each engaging in the first-level

translation of their own group's desires and objectives through mobilisation while simultaneously engaging in secondary-level translation with other networks in order to further their group's interests.[106] In this way, the entire system is shaped by the ongoing, simultaneous and dynamic translation processes being undertaken by multiple networks and groups (Figure 7).

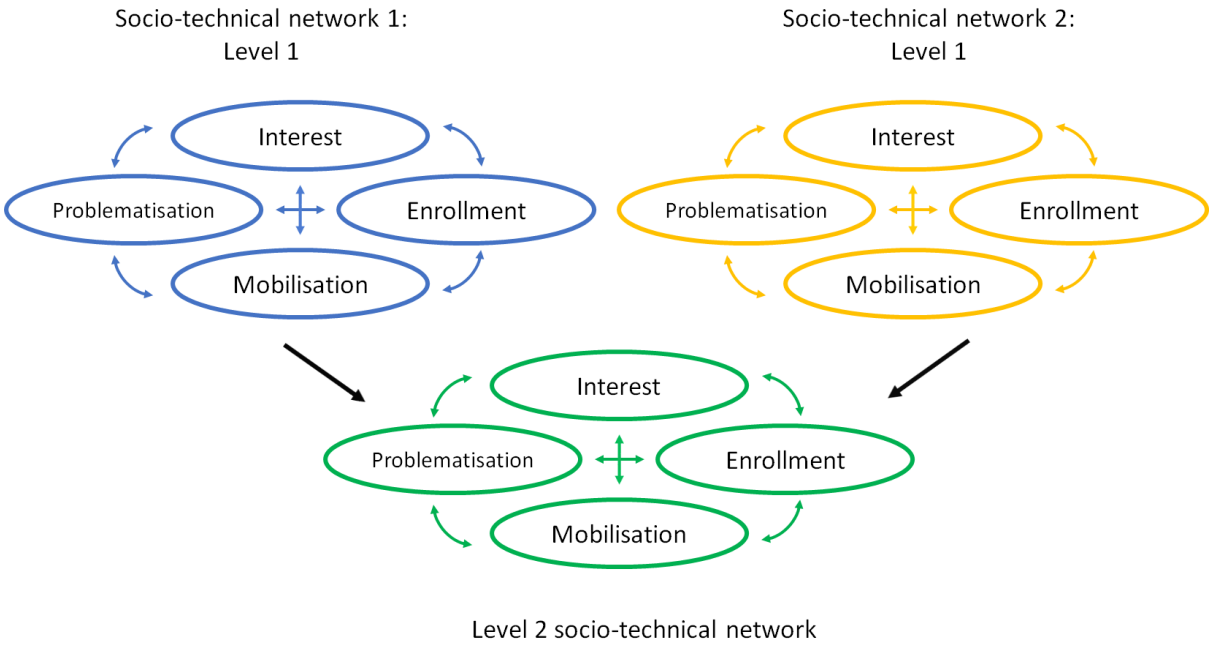

Figure 7. Community participation as multi-level translation within and between socio-technical networks. Adapted from Potvin (2007)[107]

2.2.2.1 Critiques of community participation in health

Community participation has become a basic principle in health promotion, and therefore often treated as a *prima facie* good. However, as noted, the concept and implementation of community participation is complex. Two major critiques include 1) difficulties in evaluating the effectiveness of community participation and the resulting lack of available evidence regarding its utility in producing positive health outcomes and 2) the potential of community participation to reinforce, rather than disrupt, existing inequitable distributions of power.

1) Difficulty in evaluation

A number of factors complicate the evaluation of benefits received from community participation processes. First, evaluating the 'effectiveness' of community participation interventions necessitates a level of agreement regarding its purpose and expected outcomes. Given the variability in ideologies underpinning community participation, there may be limited agreement even among actors within a project regarding this dimension.[71,72]

Relatedly, the lack of clarity around the term means that a wide variety of interventions and processes have been designed and conceptualised under the umbrella of 'community participation,' such that drawing conclusions across the genre is complicated.[72] As discussed, this is in part due to having no cohesive definition of either 'community' or 'participation.'[101] With the diversity represented by community participation processes, the question of how to assess participation can be complex. In her 2006 review, Butterfoss examined the use of process evaluation in assessing the contribution of community participation to health and social outcomes. Butterfoss found that the assessment of community participation largely coalesced around eight indicators:

- Diversity of participants/organisations;
- Recruitment/retention of new members;
- Role in the coalition or its activities;
- Number and type of events attended;
- Amount of time spent in and outside of coalition activities;
- Benefits and challenges of participation;
- Satisfaction with the work or process of participation; and
- Balance of power and leadership.[108]

However, Butterfoss also acknowledges weaknesses in these measures in that they leave aside questions regarding how the community is defined and represented.[108]

A third factor that inhibits the evaluation of community participation is the strong influence that local context wields on participatory processes and resulting outcomes. This limits the replicability of community participation initiatives and may make it difficult to draw explicit connections between participatory processes and outcomes. This was one of the conclusions from Rifkin's 2014 review of participatory approaches and their effects on health outcomes.[101]

Rifkin found that despite the pathways from community participation in health to improved health outcomes being heavily theorised, the current evidence is not sufficient to conclude that these pathways are, in fact, valid.[101] Rifkin echoes Butterfoss's assessment in saying that the lack of a defined definition for 'community' as well as 'participation' undermines the capacity to evaluate community participation initiatives.[101] Following from the review results, Rifkin argues that community participation is better viewed as a process by which an intervention is implemented, rather than an intervention itself. Using this framework, the intervention would have a defined approach and expected outcomes, with community participation being utilised to support uptake of the intervention. Rifkin's spidergram instrument could therefore be used to understand how community participation was operationalised within the context of the intervention.[101]

In 2015, Cyril *et al* conducted a review to examine the impact of community engagement on the health of disadvantaged populations. Of the 24 studies that were included in the analysis, fourteen (58%) were found to be of good quality. There was high variation in the types of initiatives represented in the review, with eleven categories of community engagement identified in the studies. A high proportion of the studies (n=21; 87.5%) reported improvements in health behaviours, health service access, health literacy and other health-related outcomes.[109] The authors identified five factors that affected health outcomes through community engagement:

- Real power-sharing;
- Collaborative partnerships;
- Bidirectional learning;
- Incorporating the voice and agency of the beneficiary communities in the research protocol; and
- Using bicultural health workers for intervention delivery.

However, the authors indicate that a small number of the studies achieved high levels of community engagement, such as community control and empowerment and highlighted that there was frequently a trade-off between the quality of the community engagement and the quality of the research methodology. The authors conclude that stronger frameworks are necessary for the adequate and rigorous evaluation of the impacts of community engagement on health outcomes.[109]

2) Reinforcement of existing power structures

The second major critique of community participation in health involves the reinforcement of existing power structures. One of the frequently cited benefits of community participation is its potential to disrupt inequitable power relations, leading to more empowered communities with increased capacity to effectively address their own health needs.[72] Despite this, community participation can lead to practices that reinforce rather than undermine larger patterns of exclusion. Several key critiques of community participation centre around the possibility of its implementation serving to reinforce patterns of dominance and oppression, frequently under the guise of empowering 'the community.' This set of critiques can broadly be categorised by whether the power relations in question are those between the community and external entities or within the community itself.

Governmentality

Drawing from the work of Foucault[110] and elaborated upon by numerous academics since,[111,112] governmentality explores the tensions between stated goals of increased democracy and community empowerment on the one hand and the ways patterns of power are reproduced and perpetuated through these structures on the other. Governmentality considers that decentralised governance structures, established to enable localised influence over policies, processes and services, are nevertheless contradictory in that they are strongly shaped by State power.

That is, seen through the governmentality framework, communities and community organisations balance the desire for autonomy with ongoing dependence on governmental funding, or working within governmental systems. State power is thereby reproduced through the same processes by which the government devolves decision-making, management and governance to communities and civil society.[110] Corresponding processes are those by which the State shifts responsibility for service provision to communities and community organisations, but retains control of how service is provided through imposition of regulations and obligations, normally tied to financial arrangements. For example, where community-based organisations seek State funding to pursue their own priorities, the imbalance of resources leads to community partners being tied to the agenda set by government, thereby limiting their capacity to initiate their own strategies.[111] Through this lens, the use of audits and other forms of financial accountability measures serve to ensure that community

organisations continue to adhere to the regulations set by the government and force such organisations to prove their ongoing capacity to govern.[111,113] Additionally, the burden of audit and compliance requirements that are tied to State allocation of resources may limit the time available for smaller organisations to do the work that particularly matters to them.[111]

Representativity in community participation: Who speaks for the community?

All communities are necessarily heterogeneous, made up of individuals differentiated by age, gender, class, social standing and political stance, among other factors, which leads to internal power differentials. If it is taken as given that not everyone in a community will be participating in a given initiative, the issue of representativity arises, at which point the question must be asked: Who in the community is 'participating'? The issue of representativity is central to community participation, as it is likely to be those representatives that have the power to give voice to community needs, determine community priorities and obtain and allocate resources according to these priorities. The processes by which individuals are selected to represent the community in health initiatives may not be democratic, but instead favour those with more social standing and therefore power within the community.[114] Taylor (2007) frames this as 'privileged access,' where the requirements of entry into participatory spaces demands community representatives that can align with dominant authority.[111] As such, participatory processes may paradoxically serve to reinforce existing inequitable power dynamics within the community.

Frits Muller considers the question of equitable community participation and draws a distinction between *direct* and *social participation*. In this framework, *direct participation* is concerned with the numbers of people that have involvement in the program. In contrast, *social participation* examines the extent to which marginalised groups within the community are able to participate (as outlined in Rifkin *et al* 1988).[102] In her review, Butterfoss found measures of community participation that sought to evaluate social participation through examination of the diversity of participants, membership of partnerships, and recruitment activities. However, the review found that in many community participation interventions to address health, substantial sectors of the community are not well represented.[108]

2.2.3 Indigenous community participation in health

Participation in health is particularly relevant for Indigenous populations, who are often excluded from decision-making and priority-setting processes in the development and implementation of mainstream health services. Indigenous participation involves rectifying this exclusion and reorienting relationships between Indigenous communities and health systems to be more balanced. Moreover, participation is tied to principles of social, economic and political equity. The ability of Indigenous peoples to have control over the health services that serve their communities is underpinned by the principles of Indigenous sovereignty and self-determination. Inclusion of Indigenous knowledges is also considered to improve the effectiveness of health services for Indigenous peoples.

The operationalisation of Indigenous participation in health frequently includes the use of Indigenous community health workers to support information exchange between practitioners and Indigenous clients, advocate on behalf of Indigenous clients and facilitate Indigenous clients' contact with and navigation through health services.[115] Indigenous community participation in health may also take the form of Indigenous bodies providing advice regarding health policy and program development,[116] or networks and partnerships between biomedical institutions and Indigenous healers and communities.[117]

There are also examples of what Arnstein labelled 'citizen control' and here is considered community control in Indigenous health; that is, health care services where Indigenous community members hold considerable power and influence over the administration, regulation and processes of service provision. In response to poor health outcomes in combination with a lack of accessible, affordable and appropriate health care services, Indigenous peoples internationally have developed systems of holistic health care that also aim to reinforce shared values of self-determination, social, political and economic equity and human rights. Community-controlled health services have been developed in Indigenous communities in the Americas,[4,118-120] Australia[121] and New Zealand[122] as a way of increasing health care coverage, accessibility and appropriateness for Indigenous communities. Some of these systems incorporate traditional health and healing knowledge[119,123] while others deliver biomedical services, but in a way that is appropriate, accessible and acceptable to their communities. In line with trends regarding community participation in health more generally, Indigenous community-controlled services are overwhelmingly positioned within primary health care. However, there are examples of Indigenous community-controlled hospitals or community-controlled services located within or associated with hospitals.[4,61,124]

2.2.3.1 **Policy frameworks for Indigenous community participation in health**

Despite being founded on similar principles, systems of Indigenous community participation and control manifest in unique ways, their structures and implementation influenced and underpinned by local, national and political contexts and values. The role of the government, for example, and the amount of support provided by the state is a strong factor in the ability of Indigenous communities to establish and maintain appropriate health services, as well as the forms that such services take. In Canada, the establishment of the innovative Tripartite Framework Agreement in British Columbia (BC) in 2011 represented a far-reaching example of community control in health policy, planning and implementation. The Agreement allowed for the transfer of First Nations health care to a new governance structure specific to First Nations people.[125] Under this agreement, responsibility for the planning, design, management and delivery of health programs for First Nations people in BC was transferred to the First Nations Health Authority (FNHA) in 2013, with funding from the federal government and support from the BC government. Having been created specifically as a decentralised governing body for the representation of First Nations people in BC, the FNHA is community-based and locally accountable. As such, the FNHA is better able to respond appropriately to the needs of First Nations communities, as well as appropriately incorporating cultural values and knowledge into health programs. While the agreement has limitations with regards to First Nations self-government and self-determination,[126] it represents an important step in increasing the ability of First Nations to develop a health care system that is coherent and provides accessible community services. This governance model may be adopted across the country if it is shown to be effective.

The Canadian Health Transfer Policy enabling First Nation community-controlled health care has developed over the past few decades to the point that in 2008 89% of eligible communities were engaged in planning, management or provision of community-controlled services at that time.[127] This has largely come about through the implementation of funding agreements that support communities to provide health care and other social programs, as well as the transfer of pre-existing services from the First Nations and Inuit Health Branch of Health Canada to community control.[127] However, there are differing levels of community control, each of which allows varying levels of flexibility and community management and implementation. At the highest level of community control, the Health Transfer approach, communities administer and manage their own health resources and design and implement health programs according to locally-identified needs and priorities. The lowest level of community control,

the Non-transferred/Non-integrated approach, allows communities to have some control over the implementation of programs and services, but little input into resource allocation or priority setting.[128]

With regards to Aboriginal and Torres Strait Islander health in Australia, community participation in health is largely viewed through the community-controlled primary health care model. Outside of the community-controlled system, participation also takes place through less-defined forms such as regional governance forums and community consultation in health planning. The National Aboriginal Community Controlled Health Organisation (NACCHO) defines an Aboriginal community-controlled health organisation as an incorporated organisation initiated by and based in a local Aboriginal community which is also governed by an Aboriginal board elected by the local Aboriginal community.[129] These services may be created *de novo* or administration of existing services may be transferred to Aboriginal community control.

In New Zealand, Māori participation in health represents the second pathway in New Zealand's Ministry of Health Māori Health Strategy (He Korowai Oranga 2014). Māori health providers, along with other Māori institutions, are seen as critical to Māori participation in health decision-making processes.[130] Māori health services are specifically developed and delivered by Māori providers and are distinguished by the incorporation of a Kaupapa Māori approach to health care, incorporating elements such as the utilisation of Māori beliefs and values; connections with Māori whanau, hapu, iwi and community organisations; and support by manawhenua and/or the local Māori community; and mainly Māori staff members.[131]

Under the Tribal Self-Governance Program, American Indian and Alaska Native (AI/AN) tribes in the United States are able to exercise community control through assuming the management of health care programs from the Indian Health Service (IHS) while utilising HIS resources as well as accessing funding from other sources.[132,133] Tribes are also able to develop their own organisations to facilitate the provision of services to their community. In 2011, over half of the IHS budget went to these community-controlled services. Alternatively, tribes may choose to have IHS manage hospitals and clinics on their reservation while simultaneously managing other health services, such as programs for the management of alcohol and other drugs.[132,133] Such services incorporate local knowledge and culture and conceptualisations of health and tend to focus on preventative and integrated care.[134] However, little information is available regarding governance arrangements in these services.

Brazil offers an example of Indigenous representativity and participation in health that spans jurisdictional levels. The Brazilian national health legislation outlines the principles of Indigenous community participation in health participation to be situated within the Health Councils (*Conselhos de Saúde*) in every level of the public administration (Municipal, State and Federal).[135] As part of this model, the Indigenous national health legislation establishes four types of permanent interlocking institutions of Indigenous participation.[136] However, the Brazilian system has been criticised for not fulfilling its promise of democratisation of Indigenous health services. Issues include a lack of accountability of the Health Councils to the communities they are meant to serve.[137] Moreover, while national Indigenous health policy may be developed through consultation, there is no obligation in place to ensure that it is implemented.

2.3 Mapuche health: The case of Chile

This thesis examines Indigenous community participation in health through a focus on two Mapuche health services as case studies. This section will therefore provide an overview of the relevant historical, social and political factors in this context.

Chile is a country of approximately 17.5 million people, according to the 2017 Census.[138] 40% of the country's population resides in the Metropolitan Region, which consists of the capital city of Santiago and its surrounds.[138] Chile is considered to be the most centralised country in Latin America in terms of its economic and political structures, with ongoing criticisms that the policies enacted by Santiago do not account for the differences or particularities of other regions.[139] The decentralisation of the Chilean government, bureaucracy and financing mechanisms has been a perpetual topic for the past two decades.[140] Chile's highly centralised structure is an enduring legacy of the colonial era, instituted in order to cement Chile as a united nation, and was largely carried through the Pinochet dictatorship. Although there has been some effort at decentralisation since the return of democracy, this has been a gradual and incremental change for the most part, and political and financial power remains highly concentrated in Santiago.[141]

Chilean law recognises nine Indigenous peoples: Aymara, Quechua, Atacameño or Likan Antai, Diaguita, Colla, Rapa Nui, Kawésqar, Yagán or Yámara and Mapuche.[142] Of these, the Mapuche are by far the largest group and amount to approximately 80% of the Indigenous population.[138]

2.3.1 Mapuche communities from the past to the present

The name Mapuche comes from two words from Mapudungun, the Mapuche language: *mapu*, meaning 'land' or 'territory,' and *che*, meaning 'people.' 'Mapuche' is therefore understood as 'people from the land.' Before the arrival of the Spanish, the Mapuche nation was economically and politically independent, with a social structure that united individual territories through alliances and intermarriage. At this point, Mapuche territory stretched from the Atlantic to the Pacific Ocean across what is now Chile and Argentina and between the Maule and Toltén Rivers.[143] This ancestral territory of the Mapuche is referred to as Wallmapu.

The majority of Mapuche currently live in what is now Chile with a significant minority living in Argentina, primarily within the provinces of Buenos Aires, La Pampa, Neuquén, Río Negro and Chubut. This territory is referred to as 'Puel mapu.'[144]

2.3.1.1 **Pre- and post-colonisation**

In his 2007 text *Government and territory in Mapuche independence*, the well-known Mapuche historian Pablo Marimán recounts elements of traditional Mapuche government, community and territory, as well as the links between them.[145] Within traditional Mapuche society, the *lof* (community) is an extended family unit headed by a *longko* and serves as the most basic social, political, territorial and economic element. The *longko* ('head' in Mapudungun) establishes and maintains the cultural norms of the *lof* and is charged with negotiating and forming alliances with other *lof*. In addition to the *longko*, traditional Mapuche social structure encompasses a number of authoritative positions, each with their own roles.[145] These include the *machi*, the primary spiritual leader and healer, as well as other health roles that will be discussed in more detail in Section 2.3.3.

Lof are represented by their *longko*, who have the responsibility to advocate and negotiate for the people within their territory. Individuals within the *lof* express their concerns and expectations to their *longko*, who then takes appropriate action on their behalf.[145] Marimán draws on historical and current accounts of Mapuche governance, including political negotiation between *longko*, decision-making regarding strategies to counter invading Spanish forces and negotiation with the Spanish to illustrate key roles and mechanisms. Marimán repeatedly highlights that the role of the *longko* is not to make decisions on his own account, but to be guided by his advisors and representatives, who each, in turn, have their specific

functions. In this way, Marimán argues, the *longko* asserts both the autonomy of the *lof* and presents a united resolution to protect its interests and territories.[145]

Under this structure, several *lof* come together to form a *rewe* (also spelled *rehue*), and several *rewe* (usually nine), form an *aillarehue*.[146] The *rewe* and *aillarehue* were bound through ties of intermarriage, trade, cultural similarities and common territory. Ruíz (2003) therefore indicates that traditional Mapuche society can be presented as a pyramidal structure, with the *longko* as the top of the *lof*, or alternatively as concentric circles, representing the interconnectedness of *lof*, *rewe* and *aillarehue*.[146] Fundamentally, the traditional Mapuche societal structure represents plurality, autonomy and compromise between units, as well as a respect for ancestral authorities.

The Mapuche nation is considered to consist of several Territorial Identities (Figure 8): *Williche*, from south of Región de la Araucanía; the *Pewenche*, whose territory covers the area where *pewen* (araucaria) grow; the *Lafkenche*, people of the coastal regions; *Nagche* from the plains regions; and the *Wenteche* from the valleys.[145] The *Pikumche*, whose territory was to the north of River Bío-Bío and were therefore the first of the Mapuche to encounter the Spanish, were eliminated.[144,146] While Mapudungun was spoken across Wallmapu, each of these territories exhibited cultural, social and political distinctions.[147]

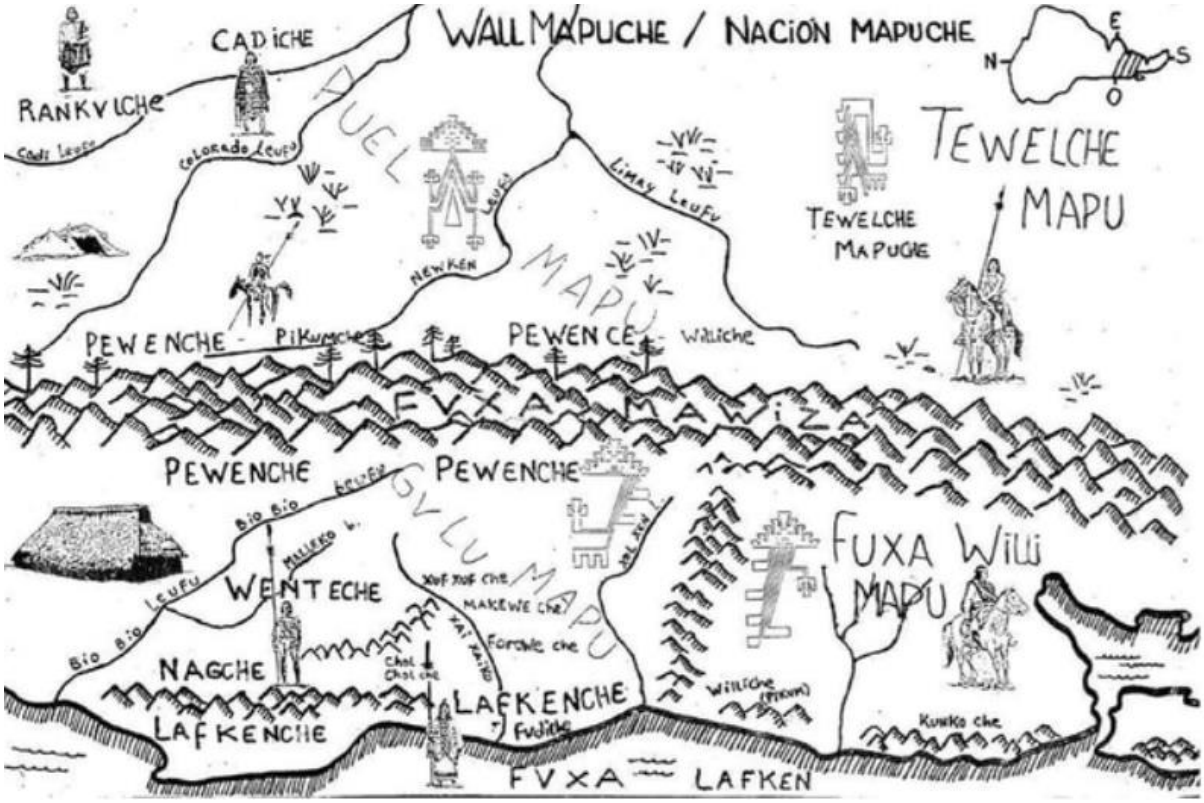

Figure 8. Traditional Mapuche territories. (Source: Werken Noticias[148])

The first contact between the Spanish and the Mapuche nation was in 1541, followed by one hundred years of extreme war and violence.[147] During this time the Mapuche were pushed from the northernmost part of their territory. In 1641, the Treaty of Quillin established the Bío Bío River as the division between the Mapuche nation and developing Chilean state and signalled the end of hostilities between the two.[147] In this way, the Mapuche established their territorial autonomy over the land south of the Bío Bío River, la Araucanía.[149] However, in 1860 the Chilean army invaded la Araucanía in order to take over this territory and expand the Chilean state, beginning a period of military occupation that lasted until 1881. This campaign and period of renewed war towards the Mapuche is euphemistically referred to as the 'Pacification of the Araucanía (*Pacificación de la Araucanía*).'[149] It has been estimated that at the time of contact with the Spanish, the Mapuche population in what is now Chile was approximately one million. The first Indigenous census in Chile, conducted in 1907, counted 107,000 Mapuche.[149]

Between 1884 and 1929, following military occupation of la Araucanía, the Chilean State created Mapuche reservations (*reducciones*) in the provinces of Bio Bio, Arauco, Malleco, Cautín, Valdivia and Osorno. During this time, approximately 3000 such reservations—called

Títulos de Merced (Titles of Mercy)—were established, which covered a total of approximately 500,000 hectares, or 5% of the initial territory controlled by the Mapuche nation (see Figure 9).[150,151]

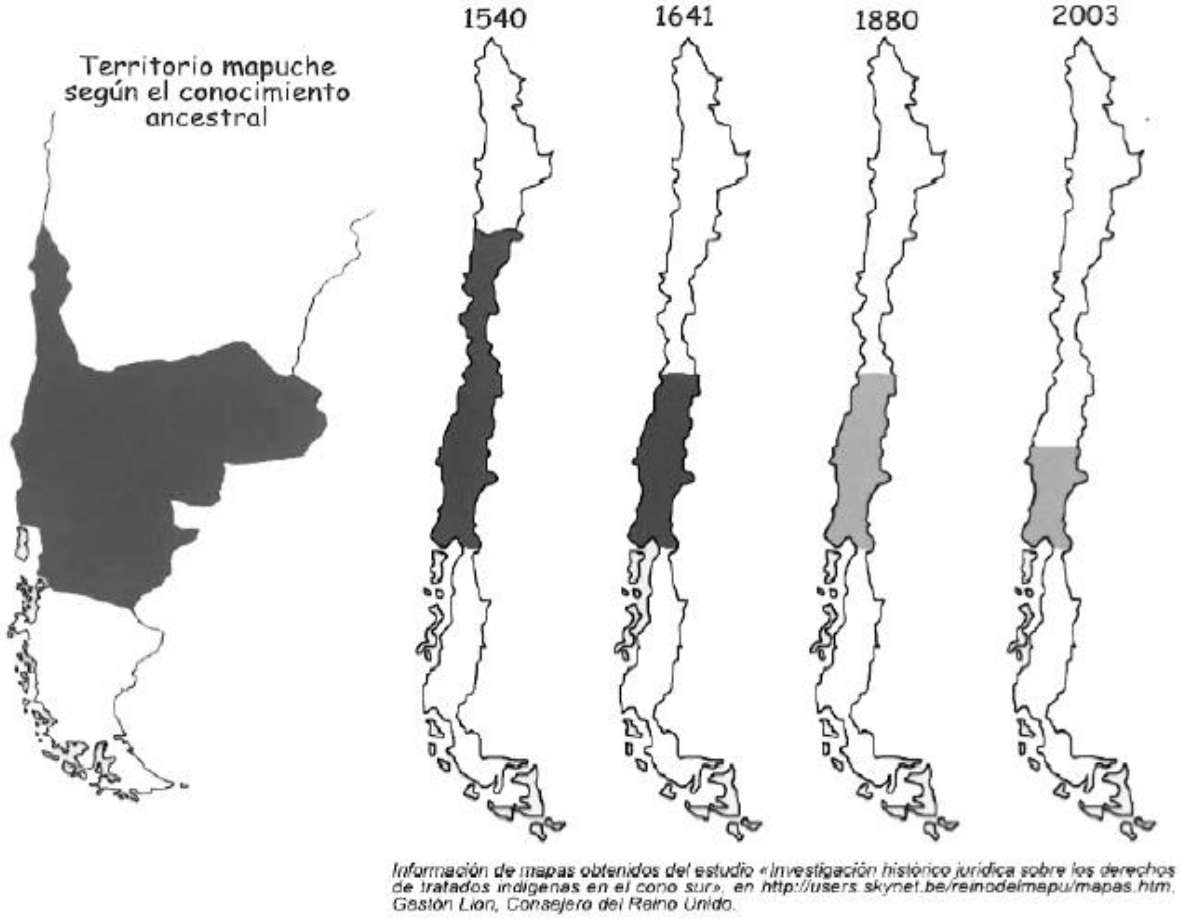

Figure 9. The loss of ancestral Mapuche territory since Spanish colonisation. From Bustillos (2016)[152]

The reduction in territory, in combination with Mapuche being relegated to lands designated by the State, forced families onto small plots of land inadequate to their needs and disrupted existing social structures by arbitrarily combining families from various *lof*.[147] In the intervening years, much of this assigned territory has subsequently been lost from Mapuche possession or reappropriated by the government through various processes, both legal and illegal.[153] Ultimately, the loss of territory and associated destruction of social, economic and political processes led to the end of independence for the Mapuche nation.[147,154]

2.3.1.2 **Mapuche communities in the present**

Presently, the way Mapuche communities are structured and understood is widely diverse. Some of this diversity is derived from the traditional ways that Mapuche societies have been organised. As alluded to in the previous section, individual *lof* have historically been relatively independent, which has contributed to communities developing their own structures and ways of operating.

There are also strong differences between urban and rural Mapuche communities.[155] In rural areas, Mapuche communities continue to live on lands allocated by *Títulos de Merced* and maintain traditional social structures and cultural elements. When the National Corporation of Indigenous Development (CONADI) was created by law in 1993 (presented in more detail in Section 2.3.2), the Inscription and Registry of Indigenous Communities and Associations was also formed, to be administered and maintained by CONADI.[142] In order to register, a community must present various forms of identification and validation of the Mapuche identity of community members, as well as the community's *Título de Merced*. Upon registering, the community is allocated a *personalidad jurídica*, which allows for official recognition by and interaction with the Chilean government.[156,157] As of this writing, 3,213 Indigenous communities were registered.[157]

However, Mapuche migration towards urban centres is apparent; approximately 70% of Mapuche live in urban areas.[158] This migration is driven in part by the displacement of Mapuche communities onto lands that cannot adequately sustain them,[143] and therefore necessarily represents the disruption of familial and land ties. This is particularly the case for Santiago and other cities to the north of Chile, which were never part of ancestral Mapuche territory.

Despite this diversity, the literature regarding Mapuche community and identity illustrates some broad trends which accord with the wider literature in reaffirming the relevance and interplay of territory, interpersonal connections and traditional structures introduced in Section 2.2.1.[145,159,160] The centrality of territory is evident both in terms of historical importance for the conceptualisation of the Mapuche nation and identity-building and for the current demarcation of Mapuche communities.[161,162] As with other Indigenous peoples worldwide, the importance of traditional roles and structures is also consistently highlighted as being key to a complete and accurate understanding of how Mapuche communities operate—how communities govern themselves, what authority exists and in which spaces and how individuals understand their place within the community.[145,159] Ruiz (2003) asserts that, in fact, in recent

decades there has been a resurgence of territorial identities and a corresponding strengthening of traditional social structures.[146] This has manifested in the establishment of organisations based in territorial identities and governed by traditional Mapuche cultural norms. This 'reconstruction of identity' based in traditional social norms has extended as well to Mapuche communities in Santiago.[146]

Pacheco (2012) examines the interactions between Mapuche communities and the Chilean State and the resulting changes in Mapuche society.[163] In particular, Pacheco describes the way Mapuche society has adapted to the need to operate within the dominant Chilean society from a marginalised position and within a context of ongoing conflict. The author concludes that the reorientation of cultural norms around power and decision-making may be seen as an expression of identity or resistance, in which Mapuche communities reinforce their internal structure as a way of enabling negotiation and advocacy with the government. This is framed as a way to strengthen, in particular, the political authority of the *longko* and the cohesion of the *lof* by expanding their space within Chilean politics. Pacheco labels such institutions *transitional structures* with three elements that characterise the adaptive process:

1. Conflict and negotiation of social norms between the dominant and dominated society—in this case the Chilean state and Mapuche society;
2. The reorganisation and adaption of social networks in order to stabilise and reinforce the internal community organisation and structure; and
3. The development of a counterculture of resistance rooted in an expression of identity and cohesion against a dominant society.[163]

2.3.2 The development of Chilean Indigenous policy

Marimán (1996) highlights the transition from the use of military force to subdue the Mapuche to the imposition of Chilean legislation and policy in order to accomplish the same.[147] Marimán frames the allocation of small, unproductive plots of land that were insufficient for subsistence farming following military occupation of la Araucanía as encouraging Mapuche dependency on the Chilean state. After the establishment of Mapuche reservations, there followed a period when Chilean policy was essentially blind to Mapuche affairs, with the exception of regulation of reservation land.[147,152] At the same time, the educational system, the imposition of Christianity, political ideology and the domination of biomedicine as a health care model each

contributed to systematic cultural assimilation.[147] Bustillos (2016) characterises this approach as being oriented towards the establishment of a cohesive, homogenous national identity which denied and negated ethnic, cultural and political diversity in favour of a centralised and unilateral form of governance.[152]

The return of democracy in 1990, after the dictatorship, bolstered Indigenous demands to participate in their governance and have some measure of control over the State programs and policies that affected them. Against this background, the newly elected government of Patricio Aylwin Azócar came into power with the promise of undertaking a wave of actions to improve Indigenous rights in Chile. Among these were the constitutional recognition of Chile's Indigenous peoples, the establishment of an Indigenous Law to improve government of Indigenous affairs, and the ratification of ILO 169, which Chile had abstained from voting on the year before.[164]

In 1993, the Indigenous Law (Ley N^{o} 19.253, Establishing regulations regarding the protection, "promotion and development of Indigenous people, and creating the National Corporation of Indigenous Development" (*Establece normas sobre "Protección, foment y desarrollo de los indígenas, y crea la Corporación Nacional de Desarrollo Indígena"*))[142] was adopted, within which the Chilean government officially recognised Indigenous peoples as descendants of those peoples living in the area before European colonisation and their rights to maintain their ethnic and cultural heritage and customs. This law also established CONADI to promote Indigenous economic, social and cultural development.[142]

Despite the promises of the Aylwin government, resistance towards ratification of ILO 169 and political conflicts saw the movement towards ratification taper off. This was in part due to fears that ratification would compromise the ability of private forestry and mining companies to access land. Mapuche demands for the return of their ancestral land and active resistance against State and private use of Mapuche land represent a permanent struggle and feature of the relationship between Mapuche and the State. As such, conflict between Mapuche groups and communities on the one hand and State forces of law enforcement, including the military, on the other is a frequent feature in la Araucanía and neighbouring regions.[165,166] A number of these conflicts centre around State protection of pine and eucalypt plantations that have been installed by forestry companies alongside Mapuche territories,[165,167,168] and have been linked to extreme water deprivation in Mapuche communities.[169]

In 2001, the Historical Truth and New Deal Commission was established to prepare a report which would outline the history between the Chilean government and the Indigenous peoples of Chile and form the basis of a new relationship and agreement between the two into the future. The report was completed in 2004 and offered a number of recommendations, including constitutional recognition of Indigenous peoples and the ratification of ILO 169, among others.[170] In 2006, then-presidential candidate Michelle Bachelet carried out an initiative to consult with Chile's Indigenous peoples regarding the strengthening of Chile's Indigenous policies. This nation-wide consultation highlighted a number of themes; among them were also the ratification of ILO 169 and constitutional recognition of Chile's Indigenous peoples.[171] These events reignited the question of ratification, and through a drawn-out process, approval of ratification was achieved in 2008, with ratification coming into power in 2009—nearly twenty years after the issue was first raised.[164]

The Chilean example illustrates how long and fraught the process to establish legislation to regulate Indigenous community participation can be. Within Chile, while ILO 169 carries with it the force of law, the principles of the Convention have not been embedded in national law in any coherent way. Under the government of Sebastián Piñera, Supreme Decree 66 (DS Nº 66), Approving regulations governing the indigenous consultation procedure under Article 6 Nº 1 Letter A) and Nº 2 Convention Nº 169 of the International Labour Organization and repealing stated regulations (*Aprueba reglamento que regula el prodecimiento de consulta indígena en virtud del Artículo 6 Nº 1 Letra A) y Nº 2 del Convenio Nº 169 de la Organización Internaciónal del Trabajo y deroga normativa que indica*)[172] was implemented in 2013 together with Supreme Decree 40, Regulation of the Environmental Evaluation System (*Reglamento del Sistema de Evaluación Ambiental (SEIA)*). In part, Supreme Decree 40 (DS Nº 40) lays out that the right to public (not only Indigenous) consultation with regards to public projects is only active with respect to those projects that were determined to need to undergo an Environmental Impact Assessment. Otherwise, the project is seen as having only minor impacts which do not necessitate consultation. This stands in contrast to principles laid out in ILO 169, which stipulates that Indigenous communities should be consulted on any matter that concerns them.[173] In essence, national legislation in the form of Supreme Decrees 66 and 40 have served to limit the circumstances under which governments are obliged to consult with Indigenous communities and the scope of such consultations.[174]

The Piñera government has asserted that DS Nº 66 was an attempt to clarify the consultative process in line with the ILO 169 requirements, as ILO 169 itself did not establish mechanisms

for consultation or decision-making processes.[175] However, despite directly concerning Indigenous peoples, the Decrees were implemented with little to no consultation with Indigenous communities. Both decrees, in fact, have been widely denounced as undermining the rights of Indigenous peoples to prior consultation in order to support business and economic interests, such as the facilitation of forestry and mining projects on or adjacent to Indigenous territories.[176-179] Indigenous leaders saw DS Nº 66 as giving increased rights and powers to State actors in all stages of the consultation process, thereby delegitimising Indigenous mechanisms and institutions in place to support prior, free and informed consultation as well as the right to Indigenous self-determination.[179,180]

There remains a lack of consensus on how to determine which Indigenous communities are 'affected' and therefore entitled to consultation or the types of measures and investment projects subject to consultation.[173] Moreover, cases brought before the Supreme Court have led to a series of contradictory rulings with regards to the right to previous consultation.[164,173] In 2010, the Supreme Court determined that if a citizen participation process had been undertaken as part of an investment project's approval process with the Ministry of the Environment, this would satisfy the prior consultation requirement. However, the Court later overruled its previous position and determined that a special consultation process must be carried out for Indigenous peoples, separate from the general citizen participation process. Subsequent challenges as well as consultation processes have been confounded by this lack of clarity.[173]

In addition to the issue of private eucalypt and pine plantations mentioned above, in recent years land-use conflicts between Mapuche and the State have also arisen regarding government-led development. This includes construction of hydroelectric dams, which has led to displacement of Mapuche communities,[181] as well as airports[182] and landfills on Mapuche territory, the latter of which has been linked to an increase in illness in neighbouring communities.[183]

The Antiterrorism Law (Ley 18.314, Defining terrorist conduct and establishing their penalty (*Determina conductas terroristas y fija su penalidad)*)[184] was introduced in 1984 as the Pinochet dictatorship was facing a wave of opposition.[185] While the law was modified following the return to democracy,[186] it continues to have the essential elements of the original version. Since 2001, the conflict between Mapuche groups and the State has been exacerbated by the use of the Antiterrorism Law, which has been denounced as a tool to classify Mapuche activists as terrorists and has underpinned the militarisation of Mapuche communities.[185,187] In

September 2017, four political prisoners were reported as being on a 108 day hunger strike;[188] in the following month, 34 Mapuche were listed as being political prisoners in Chile.[189] Since 1990, fourteen Mapuche activists have been killed by police (as of 2014).[167]

In recent years, there has been some movement towards greater political inclusion of Mapuche and avenues for political participation and representation, although this has not been straightforward. In 2006, the question of constitutional recognition of Indigenous peoples saw a resurgence, prompted in part by the previously-mentioned consultation process carried out by Bachelet.[171] While this was moved forward to some extent under Bachelet's presidential term, the election of Sebastián Piñera in 2010 saw this progress stalled. This process has been repeated with Bachelet's second term beginning in 2014 including a governmental plan for constitutional recognition;[171] however, under Piñera's current second term, this is unlikely to come to fruition.

In June 2017, then-President Michelle Bachelet offered a public apology on behalf of the Chilean Government to the Mapuche people 'for the errors and horrors that the State has committed or tolerated in our relationship with them and their communities.'[190] The apology was accompanied by *The recognition and development plan of la Araucanía*, which aimed to support Indigenous participation, reparation and economic development and the protection of victims of violence in the area.[190]

Discussion regarding the establishment of a Ministry of Indigenous Peoples (*Ministerio de Pueblos Indígenas*) has also been part of this move towards Indigenous political inclusion. In October 2017, the initiative to create the Ministry was approved by the House of Representatives[191] and subsequently approved by the Senate in January 2018.[192] The process to establish the Ministry has gone hand-in-hand with the creation of a National Congress of Indigenous Peoples (*Consejo Nacional de Pueblos Indígenas*).[192] In June 2017, the House of Representatives approved the creation of a National Congress of Indigenous Peoples (*Consejo Nacional de Pueblos Indígenas*).[193] Under this project, the National Congress of Indigenous Peoples would be an autonomous body composed of 15 members representing each of the nine Indigenous peoples recognised by law. The National Congress would work closely with the Ministry of Indigenous Peoples to ensure the protection and promotion of Indigenous rights, adherence to the principles of ILO 169 and the establishment of national Indigenous policy.[193] The same law establishes nine Congresses of Peoples (*Consejos de Pueblos*), each representing one of the nine Indigenous peoples recognised by law.[193] The Congresses would have the objective of advising State agencies regarding Indigenous rights and appropriate Indigenous

policy as well as working in conjunction with the National Congress.[193] In May 2019, Piñera signed the executive order to create the Ministry of Indigenous Peoples and the Congress of Indigenous Peoples;[194,195] however, a month following this date, the necessary funds had still not been released by the Treasury.[196]

In 2013, the World Bank released a report examining the evidence regarding the role of community participation in development. One of the key lessons that emerged was that participatory interventions work best when they are supported by a responsive state.[197] In essence, if the state is not open to community input or demands, participation is likely to be either severely curtailed or of limited use.[197] The report notes that in countries with unstable policies, particularly those that have a history of moving between dictatorship and democracy, there may be a reduced confidence in the ability of participation to make a lasting change. Within these contexts, there may be an authoritarian structure to the system as a whole, with local participation taking place on the periphery.[197] A distinction is drawn between decentralised systems, where power and finances are devolved to local authorities, and deconcentrated systems, where local administrators are held accountable to a central authority. As incentives are concentrated towards the centre, this is not generally a facilitative environment for local participation.[197]

Chile fulfils several of the characteristics that create an environment structured to obstruct community participation as described by the World Bank report. Its relatively recent history of dictatorship, deconcentrated systems (reflected in the health care sector), and closed mechanisms for developing policies and programs represent a systemic consolidation of power and a reluctance to cede decision-making processes to the regional or local levels. Distrust and conflict between the Chilean government and Mapuche communities therefore exists both for historical reasons and due to ongoing State policies and practices, such as the promulgation and use of the Antiterrorism Law, the militarisation of Mapuche communities and other forms of discrimination as well as Mapuche resistance to the same. Even in cases where supposedly participatory processes are followed, such as in consultation with Indigenous peoples at both local and national levels, this has proven to be problematic. A national consultation called by the Chilean government in early 2019 regarding reformation of the Indigenous Law has been denounced as utilising the language of participation to legitimise allowing Mapuche territories to be made available for purchase by forestry and agricultural companies, ultimately legalising the further reduction of Mapuche land.[198,199]

2.3.3 Mapuche communities and health

As with many other Indigenous peoples internationally, Mapuche ideals of health are holistic, incorporating spiritual and social aspects of well-being and closely tied to relationships with the land.[3,200] The Mapuche understanding of health centres around the concepts of '*kume mongen*,' a Mapudungun word meaning 'living well' and '*kume felen*,' or 'being well.'[159,201] The concepts of *kume mongen* and *kume felen* carry with them an equilibrium in all aspects of life and harmony between an individual and their community, family, the environment and spirituality.[159,202] Reciprocity (*kejuwün*) and respect (*yam*) are key principles that are seen to underpin harmony and balance in one's life. *Yam* refers not only to respect between human beings, but rather respect for the elements of nature and the energies manifest in all natural things.[203] Under this view of health, illness can be caused by disequilibrium which must be restored to balance. A distinction is made between illnesses that are caused by transgression against natural laws (*mapu kütran*) and those that have a biological origin (*re kütran*).[119,201] However, similarly to other Indigenous worldviews, Mapuche conceptualisations of health tend to see the body, mind and soul as intertwined, rather than separate.[56]

The traditional Mapuche health system has at its centre the *machi*, the primary spiritual and religious authority.[203] *Machi* are normally women, and they are selected by natural and cosmic energies to fulfil this role.[203] Other traditional health authorities include the *lawentuchefe* or herbalist, *püñeñelchefe* (midwife) and *ngütamchefe* (bonesetter), among others.[202] The importance of land and territory is manifest throughout the Mapuche health system. As mentioned above, maintaining equilibrium with the earth and nature is central to *kume mongen*. Moreover, the spiritual powers of the *machi* are intimately tied to the territory as are the *lawen*, or medicinal herbs that are used for healing and prevention of illness.

The introduction of biomedicine to Mapuche peoples is bound up in the history of colonisation and specifically Christian evangelisation. Biomedicine and Western education were brought alongside churches into Mapuche territories by missionaries intent on religious conversion and social control.[204] Under these circumstances, traditional Mapuche health care practices were viewed with suspicion and contempt and often banned, leading to the loss of healing traditions, knowledge and practices. Nevertheless, the traditional Mapuche health care system continues to be maintained.

Developing a complete picture of the current health status of Indigenous people in Chile is difficult, as data on ethnicity is not systematically collected, which severely limits the disaggregation of medical and health data.[205,206] However, the data that do exist consistently

demonstrate higher levels of morbidity and mortality among Indigenous people in Chile in comparison to their non-Indigenous counterparts. In 2006, the Ministry of Health (MINSAL) released a series of reports examining the health of Indigenous people in Chile by region. Indigenous people had higher rates of mortality across all regions (see Figure 10).[207-215]

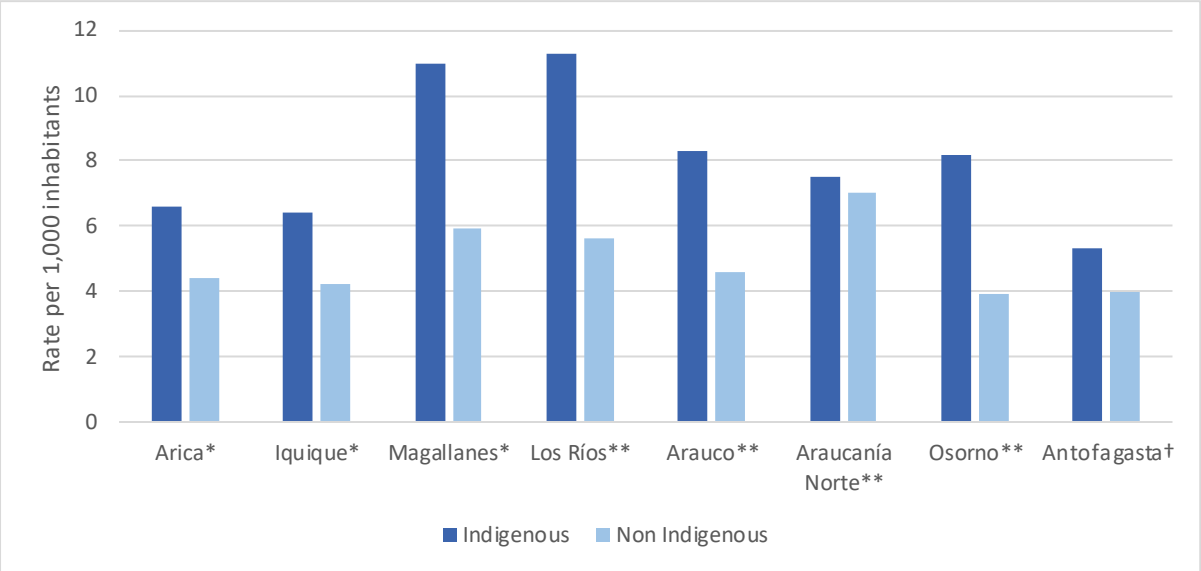

Figure 10. Rates of mortality by ethnicity, selected areas (Source: Ministerio de Salud de Chile[207-215]) **data from years 2001-2003; **data from years 2004-2006; †data from years 2007-2009*

Relatedly, Indigenous people in Chile are also more likely to be negatively affected in relation to social determinants of health than non-Indigenous people. In 2003, Border University (Universidad de la Frontera) and the United Nations Development Program released a report calculating the Human Development Index (HDI) for Mapuche people.[205] The HDI was calculated through the analysis of variables such as basic literacy and educational attainment, income and poverty and self-reported health status. The data for this was obtained mainly through the 2000 Census, which included an Indigenous identifier for the first time.[205] An HDI of 0.642 was calculated for people who had self-identified as Mapuche, as opposed to an HDI of 0.736 for people who had not.[205]

The theme of land rights also has its impact on Mapuche health. As alluded to previously, Mapuche communities have been strongly affected by water scarcity as a result of the installation of pine and eucalyptus plantations near their territory.[46] Land use issues affect Mapuche health through events such as removal from their territory due to the installment of

hydroelectric dams[181] and the negative effects of the installment of a landfill near their territory.[183]

2.3.3.1 **Intercultural health in Chile**

In Chile, much of the discourse regarding Indigenous health is framed around the concept of 'intercultural health,' with intercultural health playing multiple roles. As alluded to earlier (Section 2.1.4), intercultural health is an approach that attempts to strengthen the articulation between biomedical and traditional health care systems, which theoretically allows for the maintenance of Indigenous health knowledge. As such, intercultural health is seen as a mechanism to reinforce Indigenous cultural practices and sovereignty while also supporting increased access to biomedical services. In this way, intercultural health is also framed as a way of addressing inequities in health.

It should be noted that in other countries, Indigenous participation in health is framed very differently. For example, in Australia, the community-controlled health sector is the primary framework through which Aboriginal and Torres Strait Islander peoples realise the development of health services governed by communities and contribute to health policy and decision-making at various levels of government.[216] While there have been various movements to support stronger cohesion between traditional Indigenous and biomedical systems, this is not a central theme of community control in Australia. In Brazil, Indigenous participation in health is recognised as 'social control,' and is operationalised through an interlocking set of governance mechanisms set at different levels of government, as well as the national Special Indigenous Health Subsystem.[217]

The 1980 Chilean constitution guarantees the right to protection of health and charges the State with the coordination of health care services.[218] Despite this support for the health of the Chilean population as a whole, stark disparities in outcomes are apparent between various sections of the country; in particular between urban and rural areas and between Indigenous and non-Indigenous people, as highlighted in the previous section.[219] As such, the government articulates support for community participation as a way of expanding health service delivery while reinforcing social rights for marginalised Indigenous communities.[220,221] Finally, within Chile and Latin America as a whole, community participation in health, including intercultural health, has been incorporated into the health care system as part of a general push towards democratisation and decentralisation.[72,220]

As mentioned previously, the return of democracy to Chile in 1990 saw the strengthening of Indigenous demands for full political participation in relation to matters that affected them. Although ILO 169 was not ratified by Chile until 2008, it was introduced in 1989, which served to bolster support across Latin America for recognition and protection of Indigenous health knowledges as well as Indigenous participation in health.[222] In April 1993, the Pan American Health Organisation (PAHO) held the Indigenous Peoples and Health Workshop in Winnipeg, Canada to mark the beginning of the International Year of the Indigenous Peoples of the World.[223] At this meeting, Indigenous leaders gathered to discuss the health status of their communities.[223,224] PAHO subsequently adopted the recommendations that arose from the workshop in Resolution V.[225]

Against this background, and alongside the installation of the Indigenous Law, the first program focused on Mapuche health was created. The Mapuche Population Health Program (*Programa de Salud Mapuche,* PROMAP) was developed in 1993 to be administered through the South Araucanía Health Service (*Servicio de Salud Araucanía Sur,* SSAS) in order to improve Mapuche health at the regional level with an emphasis on strengthening the primary health care system and improving the quality of health care received by Mapuche.[65,222] This led to the recruitment and installation of Mapuche intercultural facilitators, whose role was envisaged to be that of health promotion and 'cultural brokers' between Mapuche patients and the formal medical system.[65] While intercultural facilitators were seen as a way to increase Indigenous participation in health, the role has since been criticised as being limited and mainly administrative.[222] From here, a number of workshops and meetings were held, including the 'First national meeting on health and Indigenous peoples: Towards a national intercultural health policy' held in 1996 in Puerto Saavedra, in the region of La Araucanía.[222] Following the creation and apparent success of PROMAP, the Special Program for Health and Indigenous Peoples (*Programa Especial de Salud y Pueblos Indígenas*, PESPI) was created under MINSAL in 1996 within the Primary Health Division in order to address Indigenous health issues at the national level.[204] PESPI was established with the support of non-governmental organisations as well as international co-operation.

The program Origins (*Origenes*) was developed in 2001 under an agreement between the Government of Chile and the International Development Bank (IDB) partly to advance the policy of 'intercultural health' in Chile, particularly in relation to the Mapuche, Atacama and Aymara peoples, through 'social participation.'[222] Between 2001 and 2009, the IBD invested 113 million USD into the Origins program.[204,222] However, throughout the program,

difficulties in enacting social participation emerged as State institutions overwhelmed and undermined Indigenous participants and traditional authorities.[222]

The principles underlying intercultural health were reinforced in 2008 when Chile ratified ILO 169, confirming Indigenous peoples' rights to self-determination and the responsibility of the government to ensure participatory processes in the development and implementation of those policies that impact on Indigenous peoples. In Article 24, ILO 169 specifically outlines the rights of Indigenous peoples to maintain their health and healing traditions as well as the right to access all social and medical services without discrimination.[226,227] Intercultural health is therefore recognised as a way of fulfilling the rights and obligations laid out in these policies.

At the national level, Law 20.584, Regulating the rights and responsibilities of the patient in relation to health care (*Regula los derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención en salud*) was enacted in 2012.[228] Article 7 of the law establishes the right of Indigenous peoples to receive medical attention that is culturally appropriate with respect to public institutions of care including public hospitals, health centres, family health centres (*Centros de Salud Familiar*, CESFAM) and Rural Health Posts (*Postas de Salud Rural, postas*) when situated in areas with high Indigenous populations. PSR are low-complexity centres and are the primary approach used to address the health needs of the local rural population. They serve inhabitants in areas that experience difficulty in accessibility for reasons of distance, geographical barriers, a lack of communicative media and/or a lack of adequate public transportation.[229] The provision of culturally appropriate health care for Indigenous people is to be accomplished through intercultural models of health, which include:

- The recognition, protection and strengthening of knowledge and practices of Indigenous health systems;
- The existence of intercultural facilitators;
- Signage in Spanish and the Indigenous language relevant to the territory; and
- The right to receive culturally relevant religious care. [228]

The development and implementation of health services administered and governed by Mapuche community organisations—most notably, Makewe Hospital (administered by the Mapuche Health Association of Makewe-Pelale), the Boroa Filulawen Intercultural Health Centre (administered by the Boroa Filulawen Health Coordinator) (see Section 3.2.3) and the

Nueva Imperial Mapuche Health Centre (previously administered by the *Newentuleaiñ* Mapuche Association)—have taken place within this context of shifting national and international policy regarding Indigenous community participation in health. Each of these centres represents a unique model in providing biomedical and/or traditional Mapuche health services in negotiation with, and with varying levels of support from, State institutions, in particular the SSAS.[230] Nevertheless, intercultural health as a policy has also been heavily criticised with regards to its application in Chile, with similar arguments as those presented in Section 2.1.4. Particular concern has been expressed that intercultural health models may cause traditional health systems to become warped or absorbed by State processes of funding and accountability.[231]

2.4 Exchange of international Indigenous health policy

Dolowitz and Marsh (2000) define policy transfer as 'knowledge about policies, administrative arrangements, institutions and ideas in one political setting (past or present)…used in the development of policies, administrative arrangements, institutions and ideas in another political setting.'[232] Policy exchange between countries has been increasingly common since the Second World War,[233] driven by improved communication and more tightly interwoven global governance and policy. Global trends in health policy highlight policy convergence as an overarching theme across health systems—meaning that national health policies and systems are becoming more alike over time.[234-236] However, this process is neither linear nor straightforward as convergence may be seen within particular elements of health systems between countries while simultaneous divergence is apparent in other system components.[234,237] Convergence and divergence therefore coexist, demonstrating the tensions between international trends towards similarity in health care systems and the need to respond to country-level variation in social and political values, economics and practice and implementation.[237,238] Rather than being strictly concerned with the implementation of policy as undertaken by governmental bodies, Stone (2012) makes a clear distinction between the transfer of policy and the transfer of knowledge, including the dissemination of ideas, evidence and norms through professional networks and the harmonisation of health programs across international boundaries by NGOs.[239] Stone argues that the 'soft transfer' that operates through the transmission of those ideas and standards that underpin the creation of new policy is more extensive than the 'hard transfer' of policy that incorporates executive decisions, legislation and regulation.[239]

In recent decades, there have been increased calls for greater global collaboration to address determinants of poor Indigenous health due to similar patterns of Indigenous health across national boundaries.[21] As outlined previously, common drivers of Indigenous health disparities across international borders include the ongoing impacts of dispossession of land, disrupted or weakened familial and community ties and suppression of Indigenous knowledges, languages and cultural retention.[24,25,28,29] While strategies to address Indigenous health have varied drastically, programs developed and implemented by communities tend to be driven by similar goals; namely, the maintenance and revitalisation of Indigenous cultures, a holistic understanding of health and health equity as it is intertwined with the fulfillment of social, political and economic rights (Figure 11). These similarities have driven the internationalisation of Indigenous health policy, including a growing number of international instruments regarding Indigenous rights[1,2,240] [2,240,241]and international formal and informal Indigenous networks aimed at facilitating the flow of ideas and knowledge.[338,339]

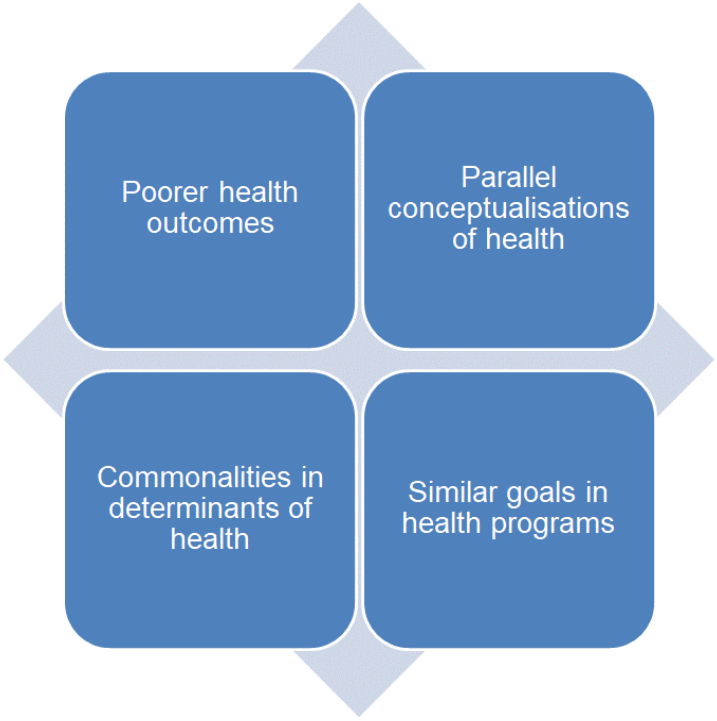

Figure 11. Factors underpinning international exchange in Indigenous health policy

In recent years, there has been an increased interest in developing international networks to support knowledge and information sharing between Indigenous peoples. This is related to the development of a global Indigenous community, discussed in Section 2.2.1.1. Organisations such as the World Council of Indigenous Peoples (WCIP), the International Indigenous

Academic Health Network (IIAHN)[242] and the International Network of Indigenous Health Promotion Professionals (INIHPP)[243] as well as international Indigenous health forums[244,245] centre around the recognition that Indigenous peoples worldwide are facing similar challenges with respect to health as well as having similar goals in relation to health care programs. The creation of these networks, as well as the history of advocacy that characterises Indigenous health care worldwide lends credence to Stone's assertion that civil society networks, knowledge transfer and 'soft' policy transfer may be more relevant than government policy, at least in this area.[239]

Strong trans-national influence on Indigenous policy has also come about in the form of international agreements regarding the rights of Indigenous peoples. This has been referred to as the 'internationalization of Indigenous rights.'[240] The acceptance of the UN DRIP and ILO 169 has led to the construction of an internationally recognised minimum standard regarding governments' obligations to uphold the rights of Indigenous peoples to self-determination and prior consultation in relation to matters that concern them.[240]

At the same time, however, consideration of policy transfer must also include an awareness of the influence of local factors. Underpinning the theory of convergence is the concept that similar issues across health systems may have similar solutions even within distinct contexts. Intrinsic to Indigenous sovereignty and self-determination is ensuring that programs and policies respond to the diversity of Indigenous peoples and are embedded in the local. This includes being shaped by the values, culture and priorities of those communities most immediately affected. Comparative health policy supports an understanding of similarities and differences in health systems approaches to particular issues between countries and allows an examination of how and why policies that are effective in one country may or may not operate similarly within another system.[235] Drawing on the literature regarding the balance of convergence and divergence across developed countries, Saltman suggests that an appropriate direction of inquiry is an examination of the balance between health system convergence and country-specific context in relation to setting health priorities and strategies at a particular point in time.[237]

Numerous studies have compared Indigenous health status and approaches to Indigenous health across Australia, New Zealand, Canada and the United States.[20,246-248] As less than 5% of the world's Indigenous peoples live in these countries,[10] this narrow focus may pose a significant barrier to useful knowledge exchange and collaboration. Similar research has also been undertaken across Latin America.[4,249] However, while Latin American countries have

demonstrated considerable innovation in developing strategies to improve Indigenous health,[249] these approaches have rarely been examined outside the region. A key aim of this thesis is therefore to utilise an examination of the Chilean experience regarding Indigenous participation in health to consider what lessons may be applicable to the wider international Indigenous health policy community.

In their 2003 paper, Mossberger and Wolman consider the question of how to assess the likely effect of adopting a policy from one country for use in another.[250] This *prospective policy evaluation* was developed as a conceptual framework to guide the investigation of policies used in other nations and make decisions regarding their suitability for adoption. It is one of very few such frameworks to both consider policy transfer as a prospective process, rather than taking a retrospective approach, and to be concerned specifically with cross-country transfer.

Mossberger and Wolman's (2003) criteria in relation to prospective, cross-country policy transfer are:

- Awareness of policy ideas, either through active or passive means, which includes *scope of information* about the contexts within which this policy has been implemented and consideration of the *adequacy and accuracy of information* with regards to the policy's implementation, goals and evaluation;
- Assessment of the *similarity of problems and goals* addressed by the policy in the lending country and to be targeted in the borrowing country, as well as the *policy performance* in attaining the desired outcomes and the *differences in setting* between the lending and borrowing countries that may affect implementation and outcomes; and
- Application of the policy in the lending country and how this may be adjusted in the borrowing country, such as through piecemeal adoption or incorporating modifications.[250]

2.5 Summary

This initial overview of the literature has served to introduce the concepts and theories that will form the basis of the thesis. The overarching aim of the thesis is to explore participatory practices in Indigenous health in Chile and subsequently consider how lessons learned in this context may support Indigenous participation in health in other settings.

Indigenous peoples worldwide experience health inequities in relation to their non-Indigenous counterparts, as well as similar aims in the development of health care systems designed to

reduce these disparities. Indigenous participation and community control in health has been seen as a way of strengthening Indigenous people's input into the health care they receive, as well as reinforcing holistic and culturally appropriate health service provision. This has also been the case in Chile, where Indigenous health policy has been strongly shaped by the concept of intercultural health: the attempt to provide stronger articulation between Indigenous and biomedical health systems.

The thesis builds on calls for stronger international collaboration to address the underlying determinants of Indigenous health inequities, which include marginalisation in formal health care systems and a lack of mechanisms to ensure adequate input into decision-making and health policy. As such, consideration of the Chilean case may provide some guidance regarding the benefits, challenges and opportunities in implementing effective participatory processes to improve Indigenous health.

Chapter 3. Methodology

This thesis attempts to address several gaps in the current literature. Generally, evaluation of community participation in health largely focuses on local programs and initiatives,[78,103,251,252] with a smaller number exhibiting some consideration of the effects of national policy contexts on participation.[137,253] Within Latin America, analysis of Indigenous community participation in health—mainly intercultural health programs—has mostly come from an anthropological, rather than health systems perspective.[117,254] As outlined in the previous chapter, the majority of comparative Indigenous health policy has focused on Australia, Canada, New Zealand and the United States,[14,217-219] leaving aside the vast majority of the world's Indigenous peoples;[10] few to no attempts have been made to consider how lessons learned in Latin America may be applicable outside the region.

The current research therefore contributes to the literature in several ways. First, it offers an examination of Indigenous participation in health as shaped by intertwined local, national and international factors. In doing so, it takes a health systems perspective, including dimensions such as funding arrangements, accountability frameworks and health governance structures. The thesis concludes by extrapolating from the Chilean case to reflect on how Indigenous participation in health may be better supported in other national settings.

The overarching objective of this research is to contribute to a more robust understanding of community participation in Indigenous health. In particular, the research examines what constitutes appropriate participatory processes and the influence of local and distant factors. In addressing this aim, the cases of Makewe Intercultural Hospital and Boroa Filulawen Intercultural Health Centre are used to interrogate different facets of Indigenous community participation in health in Chile.

The research has five main research aims:

1. Describe how the national and international policy and legislative context impacts on processes of Mapuche community participation in health in Chile;
2. Examine the governance structures set in place to allow Mapuche communities to govern health centres, including how they balance the demands of Mapuche social and cultural norms and State bureaucratic requirements;
3. Describe the relationships, social and cultural ties between each of the health centres, Makewe Hospital and BFIHC, and their surrounding communities;

4. Explore the perspectives of patients regarding the utility of having Mapuche administrators, the impact of Mapuche administration on the quality of care provided and the relationships between patients' communities and the centre; and
5. Explore the applicability of lessons from the Chilean experience of Indigenous community participation in health to international policy and practice.

In addition to answering these questions, the research has two practical objectives:

1. Provide information that can be used to create environments that facilitate Indigenous communities' participation in the formulation and implementation of health programs, services and policies and
2. Contribute to assessing the validity of learning from international contexts in the field of Indigenous health policy.

3.1 Phase 1: Literature review and scoping the project

As a first step, an in-depth review of the literature was undertaken in relation to Indigenous community participation in health and the establishment of Indigenous community-controlled health services internationally; the aims, implementation and outcomes of the Makewe Hospital and BFIHC models; and the history of intercultural health care in Chile. This literature review helped to formulate the research aims and guided development of the interview schedules (see Appendix 1).

3.2 Phase 2: Case studies

The second phase of the research was a multiple-case design, with Makewe Hospital and BFIHC each providing an example of Indigenous community control within a Chilean health care setting through distinct mechanisms and processes. The case studies were undertaken through the use of observation and key informant and patient interviews.

Initial plans were made to undertake additional methods to support triangulation of interview data; in particular, a document review and observation of professional meetings. The document review was intended to include administrative agreements, archives, and operational documents. Observation was to take place in meetings between hospital administrators and partner organisations, including SSAS, to better understand decision-making and negotiation processes. Both of these activities did take place to a limited extent during the course of the fieldwork; however, it was not possible to incorporate them into the case study methods in a

systematic way. Both methods were seen as being overly intrusive into the running of these two private organisations, as well as being an imposition on staff who were already under considerable time pressures.

3.2.1 Case study research design

In developing an appropriate research design, there are three principal considerations as described by Yin (2009):

1. The type of research question;
2. The control an investigator has over the behaviour examined; and
3. Whether the research focuses on current or historical practices and events.

In the case of the current research, the aim was to better understand the contextual factors that influenced participatory processes in Indigenous health in Chile from the point of view of both providers and government agencies as well as the effects of these processes. Yin advises that a case study design may be particularly suitable if the research question is framed around understanding the 'how' and 'why' of a phenomenon; when the researcher does not have control over the behaviour under examination; and when the research focuses on contemporary events (Table 1).[255]

Table 1. Relevant situations for different research methods (Source: Yin 2009)

	Form of research question	**Requires control of behavioural events?**	**Focuses on contemporary events?**
Experiment	How, why?	Yes	Yes
Survey	Who, what, where, how many, how much?	No	Yes
Archival analysis	Who, what, where, how many, how much?	No	Yes/No
History	How, why?	No	No
Case study	How, why?	No	Yes

Gerring (2004) also provides guidance around the usage of case study design, indicating that this method is useful 1) in drawing descriptive rather than causal inferences; 2) when a depth of analysis is valued over breadth and boundedness; 3) when case comparability is valued more highly than representativeness of the cases; 4) when the research aims to examine causal mechanisms over causal effects; 5) when the causal relationship being examined is invariant, rather than probabilistic; 6) when the research strategy is exploratory, rather than confimatory; and 7) when useful variation is limited to a small number of units.[256]

The current study fulfills each of these criteria laid out by Yin and Gerring. The research is exploratory and descriptive, seeking to examine the 'how' and 'why' of participatory processes and their outcomes. As such, it is concerned with causal mechanisms—that is, how different parts of the system interact, rather than primarily focusing on outcomes. Moreover, the causal relationship under examination is not probabilistic in a statistical sense—as described by Gerring, the relationship would be characterised as invariant, or 'deterministic.'[256] Rather than aiming for generalisability, the current research examines the selected cases in depth in order to draw descriptive inferences in relation to the community participation methods undertaken in relation to the two centres. For this reason, the cases were not selected on the basis of representativeness, but rather for the possibility of comparing how participatory mechanisms functioned in similar but different settings within Chile. Given the low numbers of Indigenous health centres in Chile and the exploratory nature of the research, a small number of units is considered sufficient. Finally, the processes being studied are current and not under control of the investigator.

Moreover, a case study design is flexible and allows for a phenomenon to be studied as it interacts with its context.[257] In keeping with principles of Indigenous research, the design and focus of the research was tentative in the beginning, and shaped by conversations with staff first at Makewe Hospital, then at BFIHC. While previous examinations of both Makewe Hospital and BFIHC had been undertaken, the prior research had, for the most part, not been done with a view towards the interactions between the Centres and the larger health system. Rather, the majority of studies that have focused on Makewe Hospital and BFIHC describe the function of the health centres in relative isolation or in relation to their surrounding communities. A flexible design was therefore necessary to accommodate the exploratory nature of the design as well as shifts and changes in enquiry.

3.2.2 Selection of case study sites

After an initial review of the literature regarding Indigenous community participation in health in Latin America, Makewe Hospital and Nueva Imperial Mapuche Medicine Centre (both located outside of Temuco, Chile) were contacted to discuss the proposed research. A trip to Chile was undertaken in April 2014 to meet the leaders of both Centres. Nueva Imperial Mapuche Medicine Centre is a clinic offering traditional Mapuche medicine, integrated into Nueva Imperial Hospital. The inclusion of Makewe Hospital and Nueva Imperial Mapuche Medicine Centre was therefore intended to allow a focus on two distinct hospital settings.

During this initial visit, the Director of Makewe Hospital agreed to participate in the research. The researcher also met with the President of the Newentuleaiñ Indigenous Association, the administrative body of the Nueva Imperial Mapuche Medicine Centre. At this time, the President signalled willingness to participate in the study. In March 2015, the researcher's local supervisor met with the President, who reiterated her willingness to participate.

The researcher arrived in Temuco to begin fieldwork in June 2015. Between April and July 2015, repeated efforts were made to contact the President of the Newentuleaiñ Indigenous Association in order to confirm whether the Centre continued to be willing to participate in the research. However, no response to phone messages or e-mails was received. Through local contacts and a phone conversation between the researcher's local supervisor and the President of the Newentuleaiñ Indigenous Association at the end of July, it became clear that due to an internal and administrative crisis, the Centre was no longer in a position to participate in the research. While the President indicated her continued willingness to participate, this was not possible for two reasons: first, the Centre and staff members were involved in an ongoing dispute and the entry of an unknown researcher would likely increase already-high tensions and conflicts. Secondly, due to ongoing disagreements, the SSAS had taken over administration of the Centre. At that time, the Centre was therefore no longer an example of community control and was not appropriate for inclusion in the study.

In an effort to recruit a second study site, a series of visits were made to the Huinkul Lawen Mapuche Health Centre, an intercultural clinic connected to Puerto Saavedra Hospital, over August 2015. The Huinkul Lawen Mapuche Health Centre was selected as a potential study site because it is the only other intercultural model connected to a hospital in the administrative region of South Araucanía, which would have allowed the research's focus to remain on hospital-based care. However, while the Huinkul Lawen Mapuche Health Centre indicated willingness to participate, under guidance from the student's supervisors and advice from

others in the area, it was decided that the Boroa Filulawen Intercultural Health Centre (BFIHC) would provide a better examination of a functional example of community participation in health. BFIHC was seen as being much more connected to the community than the Huinkul Lawen Mapuche Health Centre and was administered by an Indigenous association, whereas the Huinkul Lawen Mapuche Health Centre reportedly incorporated community input only through a limited consultation process. In addition, BFIHC has close and historical ties to Makewe Hospital, as well as a strong and stable connection to the local community. BFIHC had also welcomed students and researchers to work with them in the past, and so were presumed to be familiar with and open to the research process.

An initial visit to discuss the research with the Sub-director of BFIHC was facilitated by the Director and Sub-director of Makewe Hospital and held on 8 October 2015. The Sub-director of BFIHC expressed willingness to participate in the research and the investigator began weekly visits to the Centre from this time in addition to weekly visits to Makewe Hospital. As BFIHC is a primary care centre, rather than a hospital, its inclusion necessitated a shift in the focus of the research, from hospital-based care to a more general view of health care provision. However, this was considered appropriate, given the low-complexity nature of Makewe Hospital, which has an emphasis on primary care services, and in light of the factors outlined above, which made BFIHC a particularly strong comparator to the Hospital.

3.2.3 The cases

Both case study sites, Makewe Hospital and BFIHC, lie outside of the city of Temuco. Temuco is the capital of the region of La Araucanía, approximately 670km south of Santiago, and has a population of about 300,000. Temuco is considered the Mapuche's political and social centre and is the city with the largest proportion of people of Mapuche ancestry. The 2017 Census found that approximately 34% of the population of La Araucanía and 25% of Temuco's population belonged to an Indigenous group. Of the people who reported belonging to an Indigenous group, 97% identified this group as Mapuche.[258]

Makewe Hospital and BFIHC demonstrate two distinct models of community control. In selecting these cases, a number of considerations have been taken into account. First, both Makewe Hospital and BFIHC are well-known and represent two of the most well-established models of intercultural health care in the country. Makewe Hospital in particular is well-described in the literature. Cases that have previously been described in detail were selected to lessen the need to focus on preliminary work and enable a more thorough investigation of

the community control models. Second, a number of similarities in the contexts of the two cases help to reduce complexity and reduce the number of potentially relevant variables in examining the cases together. The centres are geographically close, separated by approximately 23 kilometers with abutting catchment areas and within the same administrative division, SSAS (Figure 12). They serve similar communities, that is, the Mapuche community of the city of Temuco and its surrounding areas. The centres therefore operate under similar social and political contexts. Both centres operate as private health services under Decree 36, Regulations to be applied in Health Department contracts (*Decreto con fuerza de ley 36, Normas que se aplicarán en los convenios que celebren los Servicios de Salud*).[259] DFL 36 was established in 1980 as part of the health care reform undertaken during the military dictatorship in Chile. Its purpose is to facilitate the privatisation of health care by allowing State health care funding to pass to private entities.[259]

However, there are also a number of important differences between the two health centers. The administrative structures of the models are distinct. Both centres are administered by their respective communities through Indigenous Associations: the Mapuche Health Association of Makewe-Pelale, *la Asociación Mapuche para la Salud Makewe-Pelale*, in the case of Makewe Hospital and the Intercultural Health Committee of Boroa Filulawen, *el Comité de Salud Intercultural de Boroa Filulawen*, in the case of BFIHC. However, BFIHC has a secondary layer of governance in that the Committee is accountable to and makes up part of the Territorial Organisation, which is the principal body by which matters are discussed and decided in the community. Another key difference is in the type of care provided. Makewe Hospital provides biomedical services while working closely with traditional healers in the community; in contrast, BFIHC is a primary health care facility offering both traditional and biomedical health services. As both centres are government-funded, in the case of BFIHC, the government therefore acts as an intermediary between the traditional healers and the community being served. The use of two models was decided upon to allow understanding of how similar structural and contextual factors may have differential impacts on participatory processes.

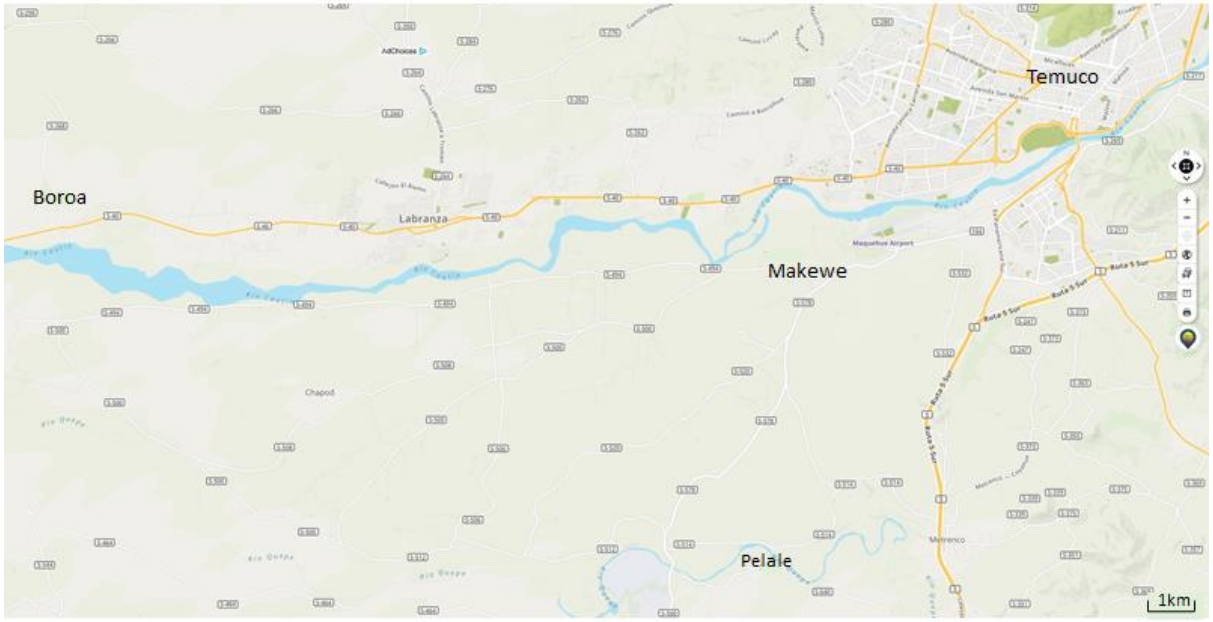

Figure 12. Map showing relative locations of Temuco, Boroa, Makewe and Pelale. (Source: MapQuest)

3.2.3.1 **Makewe Hospital**

Makewe Hospital was established in 1927 by the Anglican mission within the Mapuche community of Makewe-Pelale, 12 kilometres south of Temuco. Following financial problems in 1998, the hospital was sold to the state government. An association of Mapuche leaders, the Mapuche Health Association of Makewe-Pelale, subsequently lobbied for and obtained control of the hospital. The Association consists of approximately 35 representatives from the surrounding local communities, with a majority of members being Mapuche.[3,260] Health initiatives established by the Indigenous Association have been based on the principles of self-determination and social, political and economic development. The Makewe Hospital remains the only hospital in Chile that operates completely from a principle of intercultural health.[3,260,261]

Makewe Hospital is contracted by the Chilean government to provide biomedical health services, but cannot use government funding to pay for traditional healing practices directly. Therefore, while the hospital works closely with Indigenous healers, the healers themselves do not work directly within the hospital and are not employed by the hospital. Instead, they are based within and supported through the community.[260] Hospital programs are coordinated by a biomedically trained director and services are provided by a physician, nurses, midwives, specialists and a social work department. Makewe Hospital strives to incorporate and accommodate all aspects of Mapuche culture into its day-to-day processes. For example, the

Hospital has extended visiting hours and allows any family members or others to accompany the patient. The taking of patient history, physical examinations and western treatments provided by the hospital are undertaken in ways that adhere to Mapuche culture and incorporate patients' own understanding of their health and illness.[3] Active collaboration is undertaken with traditional healers, including referrals and co-treatment.[261] Intercultural initiatives are funded through overhead costs.

The hospital had approximately 20,000 patients on file as of 2009, approximately 80% of whom were Mapuche,[3] and as of 2016 ran the following programs:

- Children's Program
- Youth Program
- Adults' Program
- Women's Program
- Elders' Program
- Oral Health Program
- Explicit Health Guarantees Program (las Garantías Explícitas en Salud, GES), a government initiative to provide affordable diagnostic and treatment services in relation to specific health conditions.[262,263]

After years of negotiation with SSAS, in 2016 Makewe Hospital was granted funding to construct new facilities to replace the buildings that had been constructed when the hospital was first established.[264]

In 2006, Mignone *et al* selected Makewe Hospital as one of five case studies that represented best practices in intercultural health based on factors including *impact*, *sustainability*, *efficiency and flexibility*, *innovation*, *potential for replication*, and *capacity for evaluation*.[4,260] The model was found to support knowledge exchange between Mapuche and non-Mapuche practitioners, which improved relationships between the hospital and the surrounding communities. The Mapuche community also reported strengthened cultural pride and increased input, ownership and control over the health care system. These factors were found to facilitate appropriate referrals to health services and increase access to care.[4]

Figure 13 illustrates Makewe Hospital's catchment area.

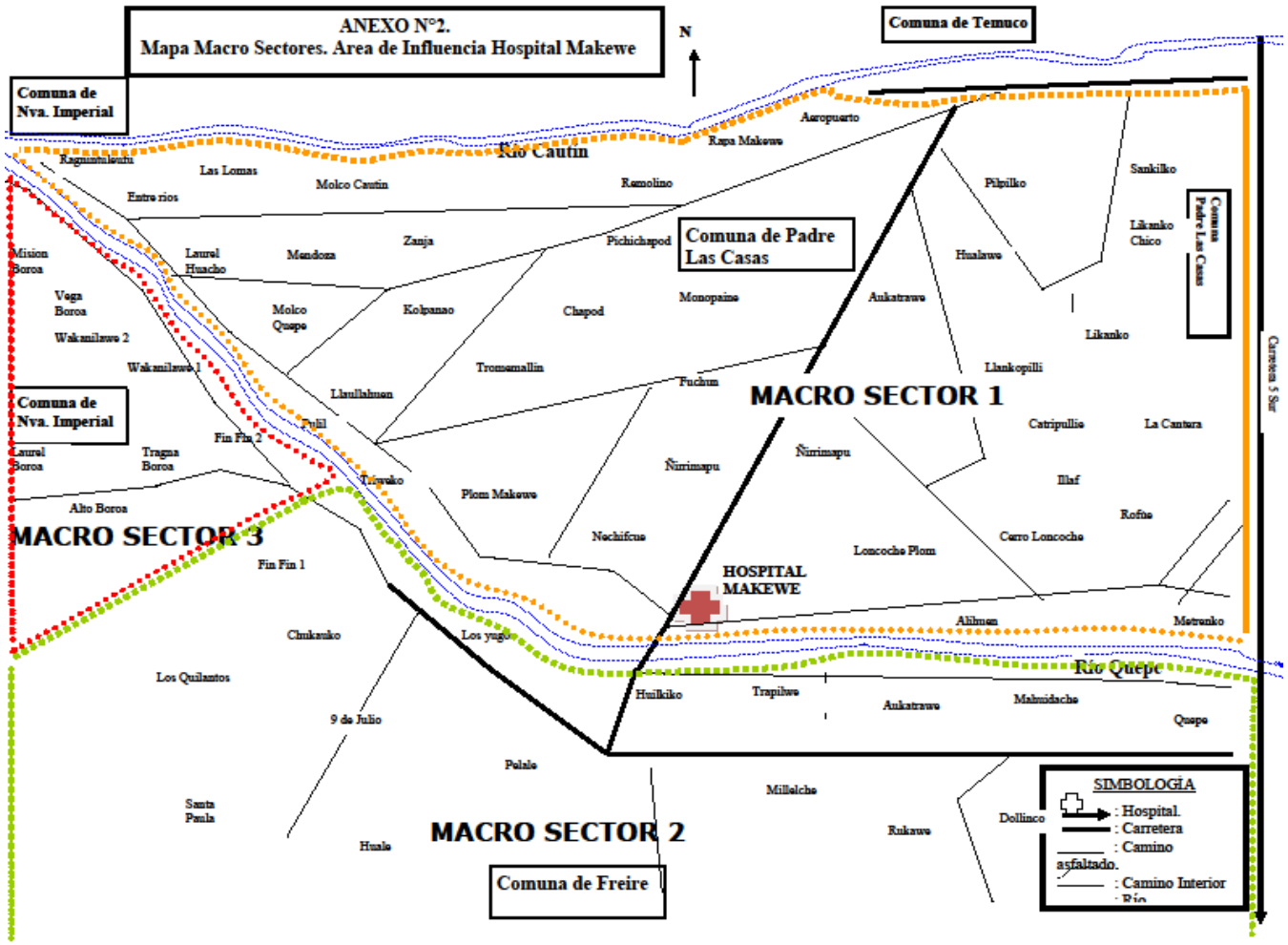

Figure 13. Map of Makewe Hospital catchment area (Source: Personal communication)

3.2.3.2 **Boroa Filulawen Intercultural Health Centre**

BFIHC is situated within the *Lof Mapu* (Territory) of Forowe Filulawen, which is made up of 35 Mapuche communities. The Territorial Organisation (TO) of Boroa Filulawen was established in 2000, with representation from 16 of the territory communities. The TO had grown from an initial Neighbours Group (*Junta de vecino*) in 1990 that had representation from four communities, and continued to expand to its present incarnation, which represents all territory communities. The TO established a number of initiatives to improve life in the community across various areas. As part of these initiatives, the Intercultural Health Committee of Boroa Filulawen was registered as a community organisation in 2001, with stated objectives being (in part):

- To construct an Integrated Centre of Intercultural Health in accordance with the Mapuche worldview
- Upskill community members to be able to administer this health centre
- The joint discussion and definition of policies by community families and the technical health team[5]

In 2004, the Committee obtained funding from SSAS to begin implementation of a territorial Integrated Health Centre project, consisting of the construction of a biomedical health service as well as a centre for Mapuche medicine. The Boroa Filulawen Intercultural Health Centre began operation in 2007, providing both biomedical and traditional health services not only to the communities within Forowe Filulawen, but also Mapuche families from neighbouring communes. The Committee that administers BFIHC is relatively small, consisting of approximately four members. However, they are accountable to the larger Territorial Organisation.[6,119]

The Centre has two primary health teams: the biomedical health service team and the Mapuche medicine team. Each of these teams occupy a different physical section of the centre, complete with appropriate infrastructure. Within the biomedical team, clinicians are non-Mapuche, although the administrative team members are Mapuche. The biomedical team consists of:

- Doctor
- Midwife
- Dentist
- Nurse
- Dental assistant
- Nursing assistant

Within the Mapuche medicine section, all team members are Mapuche, and the majority come from the *Lof* Boroa. The Mapuche medicine team includes:

- *Machi*
- *Lawenche*
- *Ragiñelwe*
- Other specialists as required.

Patients are able to select which services (biomedical and/or traditional) they would like to access. At times, providers may suggest to patients that they be seen by one facility or the other, but the final choice lies with the patient.[6,119] Due to the offering of both biomedical and traditional services on the same site and the close working relationship between the two sections, the model used by BFIHC has been highlighted as one of the best examples of good practice in community and intercultural health in Chile.[119]

However, the model represented by BFIHC is complicated by questions regarding the role of the State in the provision of traditional Mapuche health care. Unlike in the case of Makewe Hospital, the Centre is contracted by the government, namely SSAS, to provide traditional services to clients, and compensated on the basis of how many incidences of services are provided. In some cases, this is seen as being contrary to the cultural principles underlying the provision of traditional Mapuche health services. Within its traditional context, the payment of services is negotiated directly between the provider and the patient, in accordance with pertinent cultural norms—a process disrupted by the government taking on the role of intermediary. Secondly, as a *machi*'s power is derived from the land, it is seen as culturally incorrect by some for *machi* to practice outside of their traditional territory or within a clinical setting. Finally, the processes required by the government, such as quantification of services provided, is seen as culturally inappropriate, particularly as instruments do not exist to adequately and appropriately capture the integrated aspects of Mapuche medicine.[6,119,230] The different characteristics of Makewe Hospital and Boroa Filulawen Intercultural Health Centre are outlined in Table 2. Their approaches to strengthening the traditional Mapuche health system are illustrated in Figure 14.

Table 2. Characteristics of Makewe Hospital and Boroa Filulawen Intercultural Health Centre

	Makewe Hospital	BFIHC
Centre structure		
Number of beds	35	NA
Level of care provided	Low complexity hospital	Primary care
Governance		
Community-controlled	✓	✓
Mechanisms for community input established	✓	✓
Government-funded	✓	✓
Hospital processes		
Mapuche culturally significant symbols displayed, *ruka* used, religious holidays observed	✓	✓
Traditional medicinal herbs used in on-site treatment	✗	✓
Machi services provided on site	✗	✓
Biomedical services provided on site	✓	✓
Patients referred to *machi*	✓	✓
Referrals received from *machi*	✓	✓

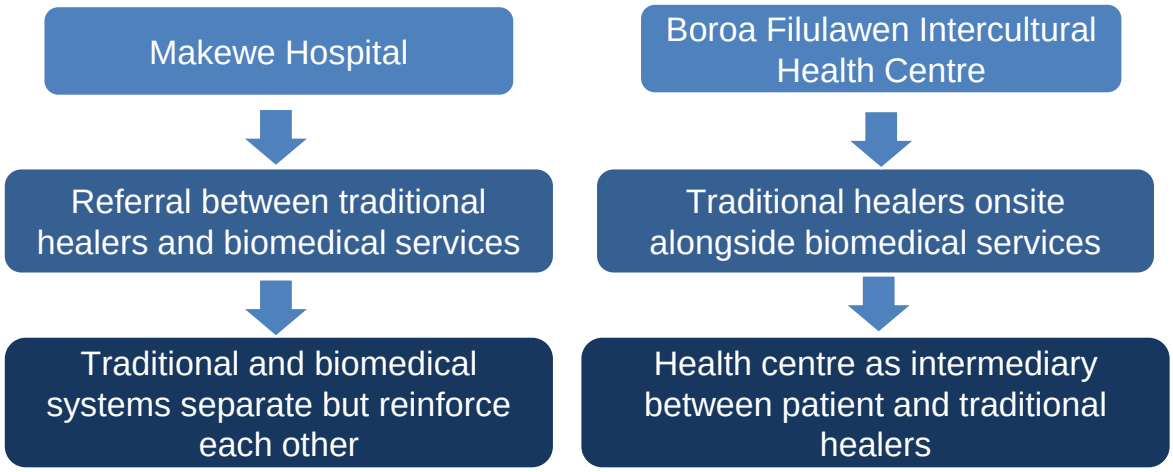

Figure 14. Different approaches to reinforcing and strengthening traditional health care systems in Mapuche intercultural health care centres

3.2.4 Data collection

All interviews were conducted in Spanish. Interviews with MINSAL staff occurred between November 2015 and April 2016. Data were collected between August 2015 and June 2016 at Makewe Hospital and between October 2015 and April 2016 at Boroa Filulawen Intercultural Health Centre.

3.2.4.1 **Key informant interviews**

All key informant interviews were semi-structured to allow for some consistency and comparison between participants while also incorporating flexibility to explore particular issues important to the individual. A summary of all interviews conducted is provided in Appendix 1 and interview schedules are provided in Appendix 2. For MINSAL staff and health service providers, the topics covered in the interview schedule were derived from literature regarding variation in the definition and perceived utility of community participation; the role of participatory processes in determining and defining the health needs of a community; the influence of contextual factors and institutions on community participation in health; and the level of decision-making power communities have through the processes of participation.[94,95] However, the interview schedules were tailored to reflect the roles of the different institutions.

Targeted sampling was used in order to undertake interviews with staff members from relevant MINSAL departments and programs. Seven interviews were undertaken with MINSAL staff from the following institutions:

- Health Service of South Araucanía (*Servicio de Salud Araucanía Sur*, SSAS)
- Mapuche Health Program (*Programa de Salud Mapuche*, PROMAP)
- Health and Indigenous Peoples Program (*Programa de Salud y Pueblos Indígenas*)
- Special Health and Indigenous Peoples Program (*Programa Especial de Salud y Pueblos Indígenas*, PESPI)
- Regional Ministerial Health Secretary of the Araucanía Region (*Secretaria Regional Ministerial (SEREMI) de Salud Región de La Araucanía*)
- Health and Indigenous Peoples Unit, Western Metropolitan Health Service (*Unidad de Salud y Pueblos Indígenas, Servicio de Salud Metropolitano Occidente*)

The interview schedule for MINSAL staff was designed to cover the following topics:

- Determining the health needs of Mapuche people
- Defining Mapuche community participation
- External factors that influence Mapuche community participation in health
- Institutional roles in supporting Mapuche community participation in health
- Decision-making processes in health

In Makewe Hospital, initial interviews were undertaken with hospital administrators and members of the Association. At the end of each interview, the interviewee was asked to name anyone else they thought would be useful for the researcher to speak to or interview. Each of these suggestions were followed up. In both MINSAL and Makewe Hospital, recruitment ended when no new suggestions were given. In BFIHC, interviews were undertaken with community leaders who were staff members but not part of the administering committee and BFIHC clinicians. The number of interviews was cut short due to issues discussed in Section 3.4.3.

Twelve semi-structured interviews were undertaken with Makewe Hospital staff members. Four interviews were undertaken with BFIHC staff members. The interview schedule was designed to cover the following topics:

- The organisation and structure of participatory processes relating to the health centres
- Identification of local health needs
- The influence of participatory processes on responding to local health needs
- Factors that influence participatory processes

All MINSAL and health centre staff interviews were audio-recorded with the permission of each participant and transcribed. In addition, a large number of informal conversations were held with staff members from the health centres over the fieldwork period, which were instrumental in developing an understanding of the relevant context and issues. In quotes provided from interviews, individuals are identified by their affiliation (MINSAL, Makewe Hospital or BFIHC) and, in the case of Makewe Hospital, by their role (Administration, Member of the Indigenous Association, Medical professional). Citations from interviews with BFIHC staff do not include the role of the interviewee, due to the small number of interviews, in order to preserve participant confidentiality to the extent possible.

3.2.4.2 **Community meetings**

The researcher attended numerous community meetings over the fieldwork period. This was to allow a fuller understanding of the community and organisational contexts, particularly with regards to the issues facing the community, how issues within the community were discussed and resolved and the role of the health centres within the communities. The researcher accompanied Makewe Hospital staff members to approximately one community meeting per month over the twelve moths of the fieldwork period. The community meetings focused on issues such as the project to bring potable water to the territory, consultation sessions between State health programs and the Hospital and the construction of the new hospital. In Boroa Filulawen, the researcher also accompanied BFIHC staff members to monthly meetings of the Territorial Organisation, community meetings regarding issues such as potable water or the improvement of roads in the territory, as well as meetings of community groups, such as Elders' groups or Women's groups. Apart from the monthly Territorial Organisation meetings, additional meetings were held approximately once every two months for the duration of the fieldwork period. Detailed notes were taken regarding the themes of the meeting, speakers and attendees in both centres. The meetings were occasionally audio recorded with the consent of all attendees at Makewe Hospital. In BFIHC, the meetings were not audio recorded. In both

Makewe Hospital and BFIHC, the researcher also attended religious ceremonies held by the health centres such as *We Tripantü*.

3.2.4.3 **Patient interviews (Makewe Hospital)**

Thirty interviews were conducted with thirty-nine Makewe Hospital patients. Patients were interviewed while waiting for appointments in the outpatient clinic of the hospital. Interviewees were selected to represent a range of ages. While it was attempted to interview approximately even numbers of men and women, women routinely outnumbered men in the waiting room, which is reflected in the final sample characteristics. Patient interviewees ranged in age from 20 to 80 and consisted of 26 women and 13 men. The length of these interviews were between one and eleven minutes. While interviewees were not asked their ethnic identity, it is likely that they were all Mapuche as all patient interviewees either currently lived or had in the past lived in the territories of Makewe and Pelale.

Patient interviews covered the following topics:

- Interaction between the patient and the Hospital
- Relationship between the patient's community and the Hospital
- Knowledge of the Indigenous Association and Hospital community activities
- Demographic information

The majority of patient interviews were audio-recorded and transcribed. However, a small number of patient interviewees indicated that they were willing to be interviewed but did not want to be audio recorded. For these, detailed notes were taken.

3.2.5 Analysis

NVivo 11 was used to analyse interview data. All interviews were undertaken in Spanish by the researcher and subsequently sent to an external transcriber. The data was analysed in Spanish, with translation into English undertaken only in order to present quotes in the thesis.

A grounded theory approach was used in analysing interview data. Starks and Trinidad (2008) indicate that:

> *The goal of grounded theory is to develop an explanatory theory of basic social processes studied in the environments in which they take place.*[265]

In the current thesis, grounded theory was used to understand the patterns and relationships between different actors within the participatory processes carried out within the contexts of Boroa Filulawen Intercultural Health Centre and Makewe Hospital. The use of a grounded theory approach is based on theoretical sampling, where participants with differing experiences of the studied phenomenon are recruited in order to explore various dimensions of the involved processes.[265] This is apparent in the recruitment of MINSAL staff, staff from the two health centres and patients, where each group is very involved with but will have a very different perspective of community participation in health.

Analysis was undertaken using an iterative process that involved an initial round of coding interviews into pre-determined codes derived from the themes presented above and the research questions. At this point, the data was also examined for unexpected and emerging patterns. This step allowed for data to be first categorised and conceptualised before a second round of organising codes through reorganisation based on relationships between the identified themes. These steps happened multiple times as the data was then examined in light of the reorganised themes and then further refined. From here, an explanatory model and organised theory regarding Indigenous participation in health was generated.

Analysis of the interview data was also informed by the researcher's understanding of the context through informal conversations, observations and attendance at community meetings.

3.3 Phase 3: Reporting and dissemination

During the data collection phase, the researcher was in constant contact with Makewe Hospital and BFIHC staff, and progress updates occurred throughout this process.

Dissemination of research findings has occurred through three main avenues:

- Community reports and presentations
- Academic articles and conference and other presentations
- The doctoral thesis

The production and presentation of community reports outlining the research results was set as a condition for undertaking the research in both Makewe Hospital and BFIHC by the leaders of the Centres. Reports were therefore written separately for each Centre, and an additional report was prepared in relation to the interviews conducted with staff from MINSAL.

Following data collection, the researcher returned to Chile in April 2017 in order to present these reports to the health centres and participants from MINSAL.

Conference and other presentations have taken place throughout the course of the research and a number of academic articles have been prepared. A list of these research outputs has been provided in Appendix 3.

3.4 Ethical considerations

3.4.1 Academia and Indigenous peoples

The relationship between academia and Indigenous peoples worldwide has a contentious history. Eugenic theories associated with academic institutions have formed the basis of policies and legislation that have had disastrous impact on Indigenous peoples. Such theories have been used to justify genocidal and assimilationist practices such as the forced removal of Indigenous children from their families and forced sterilisation and relocation of Indigenous people, or contributed to the dehumanisation of Indigenous peoples.[266-270] The dominance of Western academic thought has forced Indigenous epistemologies into an inferior position and has alternately delegitimised and exploited Indigenous knowledge.[269,271-273] In this way, it has contributed to the loss of Indigenous identity, cultural and religious beliefs and undermined how Indigenous peoples understand themselves and the world around them.[274,275]

The distrust that many Indigenous communities feel towards academics and academia as a whole is therefore rooted in long-standing experience that encompasses the ways that academia continues to sideline community concerns and engage in research practices that are not aligned to Indigenous priorities and values. However, well-conducted health research can improve the wellbeing of Indigenous peoples by providing high-quality and accurate health data to underpin appropriate policy; evaluation of health programs and policies to ensure that Indigenous communities are benefitting from these initiatives; and increasing understanding of cultural aspects of health and health care.[272]

Academic institutions are increasingly formalising ethical research practice and special ethical research considerations according to context and the intended participants and/or beneficiaries. Included in this is a growing number of ethical guidelines in relation to research carried out in Indigenous contexts. Tunón *et al* (2016) reviewed ethical principles in sets of documents relevant to ethical research conduct in Indigenous contexts from Australia, Aotearoa/New

Zealand, the Nordic Saami Parliaments (representing Saami communities across three Nordic countries), Canada and the United States, as well as international policy documents. Tunón *et al* also included documents that were not ethical research guidelines, strictly speaking, but were concerned with ethical conduct in relation to Indigenous peoples and influential in the development of ethical thought in this field as well as some ethical research guidelines that were not directly concerned with Indigenous research. While the review is not comprehensive, the comparison provides an overview of the principles commonly seen by Indigenous and non-Indigenous institutions to be ethically relevant to research in Indigenous contexts.[276]

Across the documents, they found eighteen listed principles, five of which were present in at least eleven of the thirteen documents. These five most common principles were:

- Full disclosure
- Prior informed consent
- Confidentiality
- Respect
- Reciprocity, mutual benefit, equitable sharing

In addition, each document was summarised into a single core principle which was seen to be its unifying focus:

- Respect
- Recognition of rights
- Responsibility as a scholar
- Mindfulness
- Participation
- Mutual benefits

3.4.2 Ethics of Indigenous health research in Chile

During the year spent undertaking fieldwork in Chile, the researcher had numerous conversations with Mapuche community leaders regarding the relationship between academic researchers and Mapuche communities and their perspectives on the conduct and utility of

Indigenous health research. These conversations have been complemented by discussions with Chilean academics reflecting on their own research practice.

During the researcher's time in Chile, it quickly became apparent that issues of distrust between Indigenous communities and non-Indigenous academics was a constantly recurring theme. Indigenous community leaders and scholars expressed dissatisfaction with the behaviour of non-Indigenous researchers and the lack of community benefits derived from the research, leading to reluctance around further participation and engagement. Community leaders recalled with frustration academics who entered Indigenous communities with their own agendas and left behind no record of their research findings that was accessible to communities, preferring to publish via academic journals or theses. Indigenous communities and organisations therefore had minimal control over how they are represented publicly and resented the time and effort spent in participating in research which went only to furthering researchers' careers. Nahuelpán, a Mapuche anthropologist and historian, writes in detail about how these concerns continue to carry echoes of suspicions borne from Mapuche communities' first encounters with research carried out to facilitate the processes of colonisation.[270] This history was alluded to from the very first meetings between the researcher and the directors of each of the Mapuche health centres. Due to previous experiences, presentation of a report detailing the findings for each of the health centres was established as a condition of undertaking the research from the beginning.

3.4.3 Ethical approach to the research

3.4.3.1 **Researcher positioning**

For non-Indigenous researchers working in Indigenous settings, personal reflexivity is a crucial part of conducting ethical and high quality research.[271,277,278] Reflexivity supports building interpersonal relationships and is a key strategy for researchers in recognising their own biases relevant to the research, thus enabling transparency and trust. Here, I reflect on my own positioning in relation to this research. In doing so, I provide some context regarding the path that led me to the area of Indigenous health and Chile, as well as exploring some of my experiences of undertaking the research.

Growing up black, the daughter of Caribbean migrants, in a small town that was nearly all white, I was acutely aware of issues of discrimination, racism, oppression and power. I grew

up with a keen sense of justice (or, perhaps more accurately, injustice), and struggled to come to terms with the pervasive nature of the systems of oppression upon which the United States is based. From the time I was young, when I envisaged 'what I wanted to be when I grew up,' the recurring themes were working in health (no doubt influenced by my parents, both of whom are nurses) and contributing towards equity and social justice.

Following completion of my degree in Biological Sciences, I went into lab-based research, which I quickly realised I was unsuited for. The work I was doing in the lab felt too far removed from people and disconnected from having a sense of purpose. After a couple of years, I moved to Melbourne, Australia to pursue a degree in public health. In doing so, I felt there was finally an articulation between the goals I had for my professional life—work that was rigorous, challenging, and based in health sciences, and an approach that acknowledged and responded to social inequities.

After graduating with my Master of Public Health, I was fortunate enough to start working with what at that time was the Centre for Health Policy, Programs and Economics, now the Centre for Health Policy. Over the following decade, I would work on projects that centered the health of Indigenous and migrant populations, and which brought into sharp focus the deleterious effects of systems that reinforced power differentials and disadvantaged marginalised populations.

My experience in working in Indigenous health in Australia cemented an interest in systems that facilitate and undermine equitable relationships between Indigenous peoples and the dominant culture. In contemplating undertaking the doctorate, I started to examine models that represented novel approaches to Indigenous health care, and in particular models that centered Indigenous sovereignty, cultural maintenance and holism. Having learned Spanish since I was in high school, this included models developed in Latin America. My reviews of the literature led me to Temuco and the health care services of Makewe Hospital and (initially) the Nueva Imperial Centre of Mapuche Medicine.

I began my fieldwork in a research setting that was very unfamiliar to me as a non-Indigenous and non-Chilean researcher who spoke Spanish as a second language. Of course this provided a multitude of challenges: difficulties with both expression and comprehension, especially in the beginning stages of the fieldwork; apprehension about being able to form relationships with health centre staff and community members to enable me to undertake data collection; an incomplete understanding of the historical, political and cultural contexts and how they

impacted on the factors under examination. In recognition of these limitations, I undertook the fieldwork over a year, and spent the first few months building relationships, forming a better understanding of the context and improving my skills and confidence in Spanish. This was in advance of scheduling any interviews. I was also fortunate to have the guidance of my local supervisor, Ana María Oyarce, who has over twenty years of experience in Mapuche health and was instrumental in supporting the research.

However, I also believe that my positioning as an 'outsider' was also a strength in some ways. While there is an ongoing divide and mistrust between Mapuche and non-Mapuche (Chileans), and particularly Mapuche communities and non-Mapuche (Chilean) researchers,[278] I was, to some extent, removed from this conflict. This was not wholly the case, as the next section details, but I was allowed some leeway where a Chilean researcher may not have been. My 'outsider' status may also have encouraged some interviewees to be more open, as I was seen as less of a 'threat', being removed from the organisations involved and therefore presenting a smaller risk of negative ramifications. Community members also were more open towards me than they likely would have been towards a Chilean researcher, and I am grateful to those families who took me under their wing and showed me incredible kindness and hospitality.

3.4.3.2 **Adherence to ethics guidelines**

As Chile does not have a formal set of guidelines or regulatory structures regarding research with Indigenous peoples, and the researcher's home university (University of Melbourne) is based in Australia, the ethical framework for the research was strongly influenced by Australian norms. Within Australia, Indigenous health research is highly regulated, as the National Health and Medical Research Council (NHMRC) national guidelines form a framework around acceptable research practices and the responsibilities of researchers. Individual universities have stringent and multi-layered ethical approval processes, all of which closely scrutinise applications regarding research involving Indigenous peoples. Australian Indigenous communities and community organisations also have their own processes, varying in formality and the extent to which their ethical frameworks are explicit.

While the NHMRC's Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research criteria were developed with regards to health research in Australia,[279] in this instance, they were used to inform appropriate ethical research conduct as it applied within the Chilean context in the absence of other guidance. While the guidelines have since been updated by the NHMRC,[280] the 2003 version was current at the time the

research was undertaken. The values of reciprocity (with its components of inclusion and benefit), equality, respect, survival and protection (Figure 15) were therefore each incorporated into the research design and process.

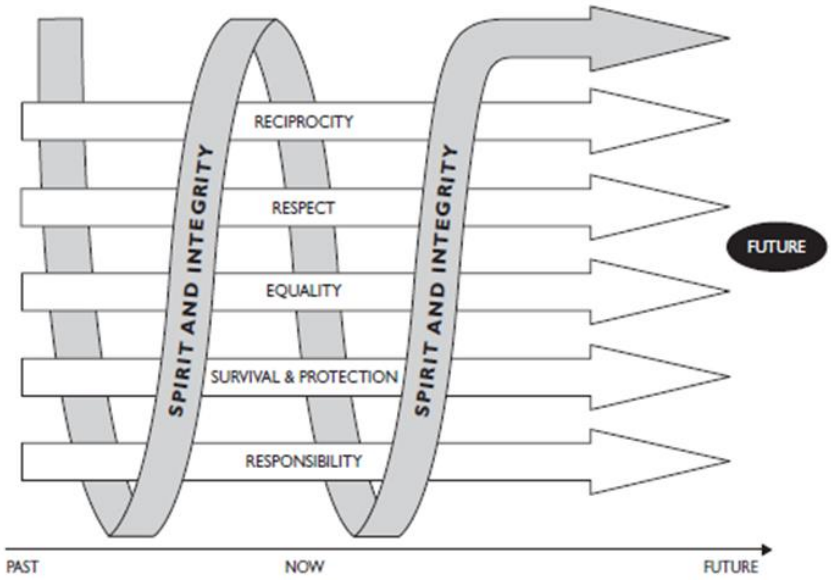

Figure 15. Aboriginal and Torres Strait Islander Peoples values relevant to health research ethics (Source: National Health and Medical Research Council, 2003)

Survival and protection: The research is underpinned by the knowledge that Indigenous peoples worldwide tend to experience exclusion from biomedical services while at the same time traditional forms of health care are marginalised and fragmented due to the dominance of biomedicine. This study therefore aims to support promising practices in Indigenous health by enabling the application of appropriate strategies to provide accessible and culturally safe care. This basis for the research encompasses the value of equality through the recognition that Indigenous peoples have the right to safe, accessible and appropriate biomedical care while simultaneously affirming and engaging in healing traditions that differ from those of the dominant system.

Respect was incorporated through early and ongoing consultation and engagement with relevant stakeholders. During the conceptualisation and planning stage of the research, the researcher undertook an initial visit to Makewe Hospital in April 2014 to consult with the Director regarding the acceptability of the research and interest in participating. A similar meeting was held with the sub-director of BFIHC in October 2015. In both BFIHC and Makewe Hospital, the researcher undertook fieldwork over a relatively long time period. This allowed for closer and ongoing consultation with Centre staff, enabled the formation of

professional and personal relationships and allowed the researcher a more in-depth understanding of the relevant context. It should also be noted that the resarcher socialised consierably with staff members particularly from Makewe Hospital outside of the professional setting. The researcher attended the funeral of the mother of the Director of Makewe Hospital, was invited to family gatherings of various staff and community members, and continues to maintain contact with many of these individuals years after completing the fieldwork.

Frequent meetings were also held between the researcher and the Director and other staff members through the course of data collection in order to ensure continued acceptability and active involvement in the research process. In both centres, the provision of a report detailing the results of the research was set as a condition of the research being carried out. The researcher returned to Chile in April 2017 in order to fulfil this obligation and disseminate findings to the centres. These measures to ensure transparency and accountability in the research also address the value of Responsibility.

Reciprocity has been demonstrated through the implementation of a research visit that enabled the sub-director of Makewe Hospital to visit with key Australian Aboriginal health organisations, including the National Aboriginal Community Controlled Health Organisation (NACCHO), the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), and the Victorian Aboriginal Health Service (VAHS), among others. This visit enabled a relationship to be established directly between the Mapuche and Australian Aboriginal communities and facilitated knowledge exchange between the University of Melbourne and Makewe Hospital.

Spirit and integrity are demonstrated through the researcher's ongoing commitment to addressing the health needs of Indigenous people in ways that engage communities appropriately, build community capacity and supports Indigenous input, ownership and control over health services and care.

A number of ethical questions arose during the fieldwork period, particularly in relation to data collection with BFIHC. Approval for the research to be undertaken had initially been granted and observation of meetings proceeded as planned. However, after approximately five months, when beginning to schedule interviews, disagreements regarding the research began to arise. Centre staff and directors expressed frustration and fatigue from being involved in a high number of research projects over the years. Not only had the Centre seen little benefit from the results of this research, but staff reported that researchers often did not disseminate results

back to the Centre, while themselves gaining professional benefit from the Centre's work in the form of publications, theses and other academic output. This reflects wider questions frequently raised regarding the burden of research on Indigenous communities and organisations in terms of their time and resources, the practical value and benefit they receive from research and how the two are weighed.[271,281]

Around this time, the researcher was also requested to make a donation to the Centre, which posed an ethical dilemma. For BFIHC, a monetary or material donation was seen as appropriate compensation for the time, resources and knowledge they were contributing to the research. However, from an institutional university perspective, the practice of providing money or material goods to an institution (as opposed to individuals) for participation in research is ethically complex and is generally avoided. This experience demonstrates the challenges that exist in balancing procedural ethics—that is, the steps a researcher must go through to obtain institutional approval to conduct research in Indigenous communities—and the viewpoints of Indigenous communities regarding research that affects them. There are numerous reports in the literature regarding conflicts between the positioning and perspectives of institutional research ethics committees and Indigenous communities—for example, where a community has offered ethical guidance that contravenes university- or federally-based ethical protocols.[282] These tensions have been reported to hinder collaboration between researchers and Indigenous community organisations as well as Indigenous autonomy in research. In the case of conflicting ethical mandates, a researcher may find themselves in the position of having the choice to either undertake practice that goes against institutional guidelines and thus risking their funding or professional reputation, or proceed against community advice, undermining the rights of Indigenous communities to have a say in research that concerns them.[283]

Centre directors also expressed concern that the research might have negative ramifications for BFIHC and spoke of being under constant scrutiny and having to continuously prove the validity of traditional medicine, the effectiveness of the intercultural model and the capacity of the Mapuche organisation to administer a health centre.

In response to these concerns, the interview schedule was significantly shortened and the number of interviews undertaken with BFIHC staff was reduced.

Ethics approval was granted by the University of Melbourne Human Ethics Subcommittee (Application number 1544845) on 20 July 2015.

3.5 Summary

This chapter has provided an overview of the research design and methods, as well as rationale for the design selected. In addition, ethical considerations in Indigenous health research have been presented and their application to the current work has been explored.

For the primary data collection phase of the research, a case study design was utilised in order to examine how the processes of Indigenous community control in health operated in two Chilean intercultural health centres. The interaction between the centres and the wider health care system, the relationships between the centres and their surrounding communities and the perspectives of patients comprised the particular focuses of this portion of the research. A case control design was selected in response to a number of criteria, including a need for flexibility in the research method, the types of research questions being asked and the exploratory nature of the research.

In the two case study sites, Makewe Hospital and Boroa Filulawen Intercultural Health Centre, interviews were undertaken with staff members and observation was conducted in various community meetings. In BFIHC, data was limited due to objections by the directorship and staff members regarding the research process. The experience of undertaking research with BFIHC posed a number of ethical challenges which resulted in the researcher withdrawing early from the site. Analysis of interview data was informed by a grounded theory approach in order to make sense of the relationships and patterns that make up participatory processes within Makewe Hospital and BFIHC.

Presentation of the research findings begins in the next chapter, which provides an examination of the political and legislative structures that shape and impact Indigenous community participation processes in health in Chile.

Chapter 4. Defining community

As covered previously, a key point of contention in conceptualising community participation is the level of ambiguity that exists around the term 'community.' Depending on who is taking on the task of defining a particular community, various aspects may be centred, among these territorial and geographical dimensions, identity and social interactions and networks. This is particularly the case for Indigenous communities, where identity, connections to territory and traditional social structures may be attenuated or disrupted due to experiences of colonisation.

This chapter reflects on constructions of Mapuche communities as represented in the literature as well as in participant interviews. This includes a consideration of how processes of colonisation have impacted the ways in which Mapuche communities are conceptualised. Contrasts are drawn between how Mapuche people construct and understand community and governmental structures for official recognition of Indigenous communities. Finally, the implications of the imprecise, heterogeneous and changing character of communities on community participation processes and their assessment are presented. As such, this chapter serves as an introduction to many of the underlying concepts to be explored throughout the thesis.

4.1 Defining Mapuche communities

In this text, the word 'community' is used and it is commonly understood in organisational contexts in Chile. However, it needs to be noted that this is not a concept that necessarily reflects traditional Mapuche social structures, as explained in the following quote.

...en general el concepto es un concepto apropiado para empezar, o sea no es un concepto nuestro, sino que es un concepto sociológico que se aplicó para tratar de dar cuenta de la organización nuestra que se entendió que tenía como un sentido comunitario entonces es un concepto que se ha instalado en la legalidad también y por eso hoy día existen comunidades indígenas pero no es un nombre que nos pertenezca en estricto rigor ni desde el mapudungun ni	…in general the concept is an appropriate concept to begin, I mean it's not our concept, rather it's a sociological concept that was applied to try to make sense of our organisation that was understood as having like a communitarian sense so it's a concept that has been established in the law as well and therefore today there exists Indigenous communities but it's not a name that belongs to us in a strict sense neither from the Mapudungun nor from our ideology because

desde la ideología nuestra porque lo que nosotros tenemos son Lof, Lof Mapu, Rehue, Haya Rehue, Meli Rehue…hoy en día yo utilicé el concepto comunidad en este contexto aquí de trabajo es solamente funcional… no obstante acá en la ciudad la gente usa mucho el concepto comunidad y lo hace como en referencia a un grupo que de alguna manera se asienta en un espacio, mantiene ciertos vínculos, se organiza y hace acciones conjuntas pero no es en estricto rigor que vengan todos de un mismo espacio, a veces coincide, a veces no.	what we have are *lof, Lof Mapu, Rehue, Haya Rehue, Meli Rehue*…today I used the concept 'community' in this work context here, it's just functional….However, here in the city the people use the concept 'community' a lot and they do it like in reference to a group that in some sense sits in a space, maintains certain ties, organises itself and takes actions as a whole but it's not in a strict sense that they all come from the same space, sometimes it matches, sometimes no. (MINSAL staff member 7, Mapuche)

While the definitions of a Mapuche community varied among interviewees, some common themes emerged. Across the different institutions, nearly all interviewees described territoriality as being central to the concept of a Mapuche community. Among MINSAL staff members, multiple people mentioned the CONADI system of designation of Mapuche communities (see Sections 2.3.1.2 and 2.3.2), but maintained that their institutions worked with Mapuche communities whether or not they were recognised by CONADI. Rather, MINSAL interviewees asserted that the institutions they represented worked with communities as they were defined by Mapuche people themselves, rather than imposing an outsider's definition.

Claro, es que las comunidades están definidas por otras organizaciones, no por el programa. Entonces, una comunidad indígena es la que está en sus espacios territoriales, que son comunidades que están ahí por años de años, y uno trabaja con todas las organizaciones, sean o no reconocidas por la CONADI, porque hay algunos que dirían que solo las comunidades reconocidas por CONADI con las que trabajan, y	Of course, it's that communities are defined by other organisations, not by the Program. So an Indigenous community is one that is in its territorial spaces, which are communities that are there for years and years, and one works with all the organizations, whether or not they're recognised by CONADI, because some would say that they only work with communities recognised by CONADI, but not us, we work with all; to the extent that we

nosotros no, es con todo; en la medida de nuestras posibilidades, claro, porque no alcanzamos a cubrir todo lo que quisiéramos.	can, of course, because we're not able to cover all we would like. (MINSAL staff member 3, non-Mapuche)
Pero en el caso nuestro, aunque hay algún tipo de vínculo con esas organizaciones, básicamente lo que nosotros en algunos casos hacemos es relacionarnos a través de los dispositivos sanitarios con las organizaciones o las comunidades mismas, que eligen sus propios representantes o que tienen sus propios interlocutores ante las instancias del Estado. Entonces, no es que nosotros tengamos una definición como operacional, y decimos: 'Esta es una comunidad y esto no es comunidad', no; la verdad es que se da un poquito más en la dinámica propia de la relación entre la sociedad civil digamos, en este caso indígena, con las instituciones del Estado.	But in our case, although there's some links with those organisations, basically what we do in some cases is interact via the health team with the [Indigenous] organisations or the communities themselves, who choose their own representatives or that have their own speakers at the request of the State. So it's not that we have an operational definition and say 'This is a community and this isn't a community.' No, the truth is that it's given a bit more in the relationship dynamics between the civil society, Indigenous in this case, and the State institutions. (MINSAL staff member 1, non-Mapuche)

Along the same lines, multiple interviewees from MINSAL noted a discrepancy between how they understood Mapuche communities to operate and be organised and the way the State characterised such communities. These interviewees indicated that the State relied only on well-defined territories in its determination of what constitutes Mapuche communities, without reference to interpersonal relationships or community structure as demonstrated by the CONADI system.

Sí, sí. Yo diría que, que la noción del Estado, es una noción que es meramente, digamos, descriptiva. Y apunta solamente a la vinculación del territorio. Pero, podemos tener – habitar el mismo territorio, ¿no?	Yes, yes. And I would say that, that the idea of the State, is an idea that is only descriptive. And it points solely to the territorial tie. But we can have—reside in the same territory, right? Destroy the other. So we don't have

Destruir al otro. Entonces, no tenemos comunidad. O no hay, o solamente en el espacio territorial, hay intereses individuales. No hay intereses colaborativos hacia la búsqueda del bien común. ¿No? Entonces, tiene que ver con un acento cualitativo distinto. Entonces, yo creo que hay una diferencia, ¿no?	community. Or there isn't, or only in the territorial space, there are individual interests. There aren't collaborative interests towards a search for common good. Right? So it has to do with a qualitatively different emphasis. So I think there's a difference, right? (MINSAL staff member 4, non-Mapuche)

As in the above quote, some interviewees spoke not only about territoriality but about the existence of a social structure. For some, this included the ties between community members and the fulfilment of traditional roles. Mapuche interviewees were more likely to speak specifically about the roles of traditional authorities in relation to defining Mapuche communities.

Y ahí existe en la comunidad, personas que son especialistas en salud, y que están definidas por su rol de llevar a cabo todo el proceso. Y en ese caso, reconocemos a las machis *como primera autoridad en salud, después están las* lawentuchefe*, que son las personas que se dedican a las hierbas; está la* püñeñelchefe*, personas que ayudan en el proceso de embarazo, parto y posterior crecimiento de los niños y niñas; hay también* ñiempin*, que son personas poseedores de la palabra... En cada una de las comunidades está de alguna manera la estructura fortalecida. Hay personas que se dedican, como el* ñiempin*, a llevar la palabra; hay otras personas que son* werkenes*, son como los mensajeros, los que se pueden enviar a otro lugar que vaya a escuchar la reunión,*	And there exists in the community people who are health specialists, and they're defined by their role to carry out the entire process. And in this case, we recognise the *machis* as the primary authority in health, after are the *lawentuchefe*, who are people dedicated to herbs, there are the *püñeñelchefe*, people who help in the process of pregnancy, birth and afterwards raising the children; there are also *ñiempin*, who are people possessing the word...In each of the communities there is in some manner the strengthened structure. There are people that are dedicated, like the *ñiempin*, to carry the word, there are other people that are *werkenes*, who are the messengers, who can be sent to another place to listen to meetings, who tell what they've heard; there's a

que comente lo que escuchó; o sea hay una estructura.	structure. (MINSAL staff member 2, Mapuche)
Yo diría, yo te definiría que una comunidad fundamentalmente Mapuche, es un – está definida por dos cosas. Por un lado, la territorialidad. Es decir, el espacio de lo territorial– es uno de los elementos. Pero, otro está dado por la calidad de los vínculos de cooperación que se tejen, entre las personas que viven dentro de ese espacio territorial. Es decir, el espacio territorial da un soporte, pero, no asegura necesariamente la construcción del espacio de comunidad.	I would say, I would define for you that a fundamentally Mapuche community is a—it's defined by two things. On the one hand, territoriality. That is to say, the space of the territory—that's one of the elements. But the other is the quality of the links of cooperation that tie people together, between the people that live within this territorial space. That is to say, the territorial space gives support, but, it doesn't necessarily ensure the construction of the community space. (MINSAL staff member 4, non-Mapuche)

Multiple interviewees drew strong distinctions between community leaders and traditional authorities as selected using a cultural lens and the community representatives (*e.g.* presidents) demanded under State regulations as part of the CONADI system.

Es que un dirigente de repente – depende cómo uno los tome, porque el presidente de una comunidad puede ser cualquiera, pero dirigente *yo creo que somos pocos porque de repente los presidentes de las comunidades son para casos puntuales. Y un dirigente con un conocimiento amplio no está solamente pidiendo si falta una canasta familiar en la casa o si falta un techo o si falta el agua potable, o sea, va más allá de una petición que haga un presidente de comunidades con un dirigente de comunidades, porque todos podemos ser presidente pero no todos*	It's that a leader maybe—it depends on how one takes it, because the president of a community can be whoever, but *leader* I believe that we're not very many because maybe the presidents of the communities are for particular cases. And a leader with a broad understanding isn't just asking if there's not enough food in the house or if the roof is missing or if there's a need for potable water, it goes further than a request that the president of the communities makes with a leader of the communities, because anyone can be president but not everyone has the

tenemos la claridad. Entonces esa es la diferencia.	clarity. So that's the difference. (Boroa staff member, Mapuche)

In relation to traditional Mapuche healing, the *machi* and *lawentuchefe* among other authorities derive their power through the connection with their particular territory.[284] Furthermore, the use of *lawen*, or traditional herbal and plant medicines, is dependent on being able to access a robust and healthy ecosystem within the traditional territory, as described by this interviewee from BFIHC. Here, then, the land itself as a component of territory is also part of the understanding of community, as it is intricately tied to the community social structure and roles of the traditional authorities. In the quote below, a community member speaks about the impact of forestry companies installing plantations adjacent to Mapuche territories. The plantations cause a lack of water in neighbouring communities, leading to the loss of *lawen*. *Lawentuchefe* then need to range further in order to find the needed *lawen*, including onto private areas.

…tenemos que ver igual con el tema de territorio, el tema de los remedios, de lawen, *que decimos nosotros que es la parte de la medicina mapuche, que sin la devolución de los territorios o del territorio en este caso, no hemos tenido buenos resultados en el tema de* lawen *que utiliza la machi, o todo lo* lawentuchefe, *porque de repente igual hay que salir a pedir, a buscar algunas partes privadas y es que le dan una autorización a las personas que están encargadas de recaudar eso, el* lawen.	…that has to do as well with the issue of territory, the issue of herbal medicines, of *lawen*, that we say is part of Mapuche medicine, that without the return of the territories, or the territory in this case, we haven't had good results regarding the *lawen* that the *machi* uses, or everything with the *lawentuchefe*, because maybe they have to go out to ask, to look for private areas and that give authorisation to people that are in charge of gathering that, the *lawen*. (Boroa staff member, Mapuche)

However, multiple Mapuche interviewees also spoke extensively about the wide diversity among Mapuche communities. One interviewee referred to the heterogeneity that exists between Mapuche communities and the need to acknowledge and respect such differences in the development and design of public policy and health programs.

¿En la política de salud intercultural? Claro, porque de alguna manera está enfocada a los pueblos indígenas originarios; pero las políticas públicas en general no están visibilizados. Entonces, no hay participación en la elaboración, no se consideran los diagnósticos, no se considera las identidades territoriales, porque nosotros aunque somos mapuches de la región de la Araucanía, Bío Bío, Araucanía, o sea Los Lagos, tenemos diferencias territoriales; aun cuando todos somos mapuches, hay identidades que nos caracterizan, por lo tanto también situaciones de salud que nos caracterizan.... Siento que ahí hay un error grave de las políticas públicas.	In intercultural health policy? Of course, because in any case it's focused on Indigenous peoples; but in general public policy isn't made visible. So, there's no participation in the development, they don't consider the territorial identities, because while we're Mapuche of the Araucanía region, Bío Bío, Araucanía, or Los Lagos, we have territorial differences; although we're all Mapuche, there are identities that characterise us, therefore there are also situations in health that characterise us… I think that is a grave error in public policy. (MINSAL staff member 2, Mapuche)

Furthermore, another interviewee strongly cautioned against a simplistic or idealised understanding of Mapuche communities, as in reality, community relationships and power structures are not necessarily organised as neatly or clearly as represented in texts. The following quote serves as a reminder that since communities are often amorphous, unstable and lacking clear boundaries, attempting to assign a particular delineation may be futile or represent an artificial imposition of an outsider's own perspective, rather than respecting the shifting nature of the community as experienced by its members.[81]

Entonces, yo no necesariamente dependo de mi territorio, no necesariamente dependo de lo que dice la comunidad. Y además que los indígenas, sobre todo en el mapuche de los cuales yo pertenezco, si yo quiero hacerlo no necesito que el longko *diga que esto es. Todo lo contrario digamos, porque eso es un decir, eso está escrito en los textos pero no es – esos*	So I don't necessarily depend on my territory, I don't necessarily depend on what the community says. And furthermore, Indigenous people, above all the Mapuche, to which I belong, if I want to do it I don't need the *longko* to say. To the contrary, because that's what's said, that's what's written in the texts, but it's not—those are

son los idealistas indígenas; pero en el fondo, si yo quiero hacer un centro de salud, y aunque se oponga la comunidad porque es mi tierra, mi territorio, ¿me entiende? No es necesario la validación, esa validación con tanto énfasis que la hacen los mapuchistas, los indígenistas.	Indigenous idealists; but at the bottom of it, if I want to build a health centre, and although the community opposes it because it's my land, my territory, you understand? The validation isn't necessary, that validation that the mapuchistas, the indigenistas emphasise so much. (MINSAL staff member 5, Mapuche)

4.2 Discussion

4.2.1 Identification of Mapuche communities

The maintenance of Indigenous communities represents the retention of the cultural knowledge, traditions and norms that make them distinct, and is therefore a form of resistance and resilience against assimilationist forces. Nevertheless, the experiences of colonisation continue to have impacts on how Indigenous communities are structured and understood both by community members themselves and the State. Where Indigenous peoples are recognised by the State as a distinct political or ethnic group, the mechanisms by which this delineation is established may be wholly apart from the criteria individuals use to make sense of their communities and social structures.

While disrupting established social structures, the historical dislocation of Mapuche has been enshrined by the State in the CONADI system of recognition of Mapuche communities. As referenced in Section 2.3.1.2, this system relies on communities producing their *Título de Merced*, which verifies that the Chilean government allocated the property to the community following the period of military occupation. With the *Título de Merced*, the community may apply for a *personalidad jurídica*, or official governmental recognition.[156,157] Mapuche communities by necessity configure themselves around this system, adopting the structures required for a *personalidad jurídica*—the bureaucratic installation of a community president, vice president, treasurer and secretary. However, interviewees were clear that State requirements for recognition of Mapuche communities ran parallel alongside a traditional understanding of Mapuche social structures, including that of the traditional authorities and the way community members interacted with each other. While two forms of community were each seen as valid within their particular sphere, interviewees saw them as being fairly distinct,

with their own purpose and roles. As such, the intent of the State to recognise the unique nature of Mapuche communities has led to a rigid framework that cannot accommodate the complex lived reality of community members.[285] In doing so, the Chilean State has installed mechanisms which lead to the organic internal logic of Mapuche communities being wholly invisible to the broader system.

Generally speaking, the State view of Mapuche communities may be seen to align with Tönnies' concept of *Gesellschaft*; that is, adoption of the requirements for a recognised community is largely instrumental and based in the need to interact with the State in order to procure various benefits and services—improvements to roads, access to potable water, grants for community projects and so on. This is an easily quantified and bounded conception of a community. In contrast, the traditional understanding of Mapuche communities may be more closely related to *Gemeinshaft*, as the view of community relating to traditional authorities and roles is more fluid, flexible, amorphous and comes out of the organic way that the community understands and organises itself. This understanding of community incorporates elements such as kinship ties and the regulation of interpersonal interaction.[83] In this framework for understanding Mapuche communities, Gusfield's territorial and relational aspects are also strongly represented, particularly as traditional authority is rooted in the connection with land and territory.[85]

Within the participant interviews, the question of who 'belongs' to the Mapuche community was not a strong theme—that is, reflection on Mapuche identity, who 'counts' as Mapuche or whether there may be some individuals that are geographically present but not considered part of the community was not apparent. This is in contrast to other communities based on identity, where a certain amount of gatekeeping may be present, with conflicting views about who can legitimately claim to be part of the community.[114] Rather, interviewees tended to focus on the various ways of understanding the interpersonal interactions that create a Mapuche community. This may be because the research focused on rural Mapuche communities that had geographically fixed boundaries and a very high proportion of Mapuche residents; if there had been a focus on urban Mapuche communities, it is likely that the question of Mapuche identity and belonging would have been a stronger theme.

4.2.2 Indigenismo and heterogeneity in Mapuche communities

'Indigenismo' is a term that covers a broad range of discourses that are concerned with the status and identity of Indigenous peoples against the backdrop of the State, nationalism and

colonisation, particular to the region of Latin America and the Caribbean.[286] A key facet of indigenismo has been the artistic and political representation and portrayal of Indigenous peoples, particularly by non-Indigenous people. The origins of indigenismo come from the work of Bartolomé de las Casas, who spoke out against Spanish violence towards Indigenous communities in the Caribbean in the 16th century. From there, indigenistas continued to call attention to and oppose injustices faced by Indigenous peoples, with the height of indigenismo placed between the 1930s and 1970s.[287] The many social movements and ideologies that have arisen under 'indigenismo' can be best understood as having a common theme of critiquing State policies with regards to Indigenous affairs and defending Indigenous peoples from violence and exploitation. Bengoa (2000) identifies three elements of indigenismo: denunciation of Indigenous oppression, political support for improving the situation for Indigenous peoples through their integration into society and, as a result, the recognition of the Indigenous nature of Latin America.[288]

However, the approaches taken by indigenistas have not necessarily been coherent, and could be variable or even, at times, contradictory.[286] In early 20th century Mexico in particular, indigenistas attempted to construct a national identity that centred the country's Indigenous heritage. However, this policy was transformed into an approach that advocated assimilationism of Indigenous peoples into Mexican culture, rather than strengthening the Indigenous nature of Mexico's national identity.[289] As such, indigenismo at this time was criticised for largely being composed of non-Indigenous people who carried paternalistic and colonialist attitudes towards Indigenous peoples.[286,287]

Encompassed within indigenist viewpoints are those that idealise or essentialise Indigenous communities, commonly as a defense against assimilationism or an approach towards decolonisation of Indigenous identity. That is, 'authentic' Indigenous peoples and communities are seen as having particular cultural features that cause them to be distinct from the dominant, non-Indigenous society.[290] While this perspective may serve to validate the rights of Indigenous communities to retain their cultural distinctiveness, it can also lead to an understanding of such communities and identities as static, valorising the 'traditional' or 'ancestral' over the 'modern,' ignoring the changes that occur in all societies over time, or rejecting the shifts that occur within Indigenous communities as a result of ongoing contact with the dominant society.[290]

While the Mapuche are considered a single Indigenous people, there is nevertheless a high level of heterogeneity in how Mapuche communities are structured and organised. As touched

on in Section 2.3.1, there are regional territories which each have their identity within being Mapuche. Each individual Mapuche *lof* has also traditionally been quite independent.[145] Distinct *lof* may therefore have very different ways of conducting internal business, despite being in close geographic proximity. The influence of migration is also relevant—urban Mapuche have historical ties to other parts of the country and therefore come together to construct an understanding of community that is not primarily based on a shared territoriality. For these reasons, while interviewees cited the roles of traditional authorities as being important in defining Mapuche communities, they also highlighted the need to be critical of discourses that paint these communities as static or uniform, as referenced in the final quote in this chapter.

4.2.3 Mapuche communities and participation

The two main frameworks presented for understanding Mapuche communities in this chapter—the rigid definition of community that fulfills the criteria for a *personalidad jurídica* or a more fluid and complex understanding based in the roles of traditional authorities, kinship ties and territoriality—can be seen as two distinct models overlaying each other, representing completely different ways of recognising community authority, deciding whose voice 'counts' and appropriate ways of making decisions. This raises a number of issues in considering Mapuche community participation. Indigenous community participation is based on principles of self-sovereignty and the right of Indigenous peoples to maintain their distinctiveness, which supports the strengthening and validation of traditional social systems. In this model, the traditional necessarily interacts with the State in order to be recognised and legitimised, necessitating the adoption of bureaucratic elements. Given that community participation therefore involves the interaction between the traditional, cultural 'model' and its bureaucratic counterpart, there is a question of how participatory processes facilitate the two models 'speaking' to each other. That is, how participation is constructed to be both culturally relevant and legitimate within State frameworks. This is particularly complex as the State has no mechanisms in place to be able to 'see' traditional authorities or respond to internal decision-making processes. This implies multiple levels of decision-making, whereby communities undergo their own culturally relevant processes to come to a decision, which representatives must then 'translate' to be communicated to the wider bureaucratic system. This is reminiscent of Potvin's model of community participation in health promotion, based on Callon's socio-technical networks theory (presented in Section 2.2.2, see Figure 7), with the community and the State each engaging in their own first-level translation, as well as secondary translation

with each other. Applying this view to Mapuche community participation, the role of each network's representatives or 'mouthpieces' is to ensure communication across the differing models and advocate for their group's own interest.[106]

The high level of variability in how Mapuche communities are constructed and understood by Mapuche themselves highlights the importance of local context in developing and implementing community participation processes, as what is acceptable in one community may not function in another. Moreover, the heterogeneous nature of communities dictates that there is likely to be some level of internal tension regarding how the community should operate. This also has implications for community participation processes, as internal community dynamics influences who is allowed to participate and how, who has the authority to speak on behalf of the community and how the community as a whole interacts with the broader system.[111] Therefore, in addition to negotiating between differing ideas of what is meant by 'community,' participatory processes in this context must also account for the variations between Mapuche communities and, potentially, internal factions.

4.3 Conclusions

This chapter presents varying perspectives about what constitutes a Mapuche community, and in so doing illustrates complexities inherent in defining the term, even within a relatively bounded context. Concepts introduced in previous chapters, including various models of community participation and its assessment, have been presented in relation to the current research context. Reflections on how Mapuche communities are constructed draw from the available literature and participant interviews.

Internationally, Indigenous peoples' sense of community has been strongly impacted by colonisation, urbanisation and cultural shift, and this is apparent in relation to Mapuche communities. The Chilean government, through bureaucratic methods of defining and recognising Mapuche communities, undermine and ignore Mapuche social structures through the imposition of criteria that do not necessarily align with Mapuches' understandings of community.

From the participant interviews, two main frameworks regarding the conceptualisation of Mapuche communities emerged: one arising from the perspective of the State, where the requirements for recognition of an Indigenous community were fixed and invariable, and the other encompassing the roles of various traditional authorities and the shifting and amorphous nature of social interactions. The disjuncture between State and community perspectives, in

combination with the high level of variation between and within Mapuche communities, demonstrates the extent to which community participation is context-dependent. This in turn necessitates a level of variability in participatory processes as a way of accommodating discrete understandings of appropriate expressions of authority and decision-making processes.

In exploring definitions and models of community and implications for community participation within the research context, this chapter lays the groundwork for key themes of the thesis. As has been seen, consideration of State structures is necessary for a complete understanding of how communities are supported or constrained from participating within the broader system. The next chapter therefore examines the policy and legislative environment of Chile in relation to Mapuche community participation in health. Following from this, Chapters 6 and 7 revisit themes elaborated in this chapter regarding how Mapuche communities are understood and how this influences relationships between Mapuche health centres, their communities, and the broader health system.

Chapter 5. Policy and legislative environments

Effective community participation in health is dependent on having a facilitative political and legislative environment. International frameworks provide high-level guidance and principles regarding the rights of Indigenous communities to be involved with matters that affect them.[2,291] Within countries, the policy landscape has the potential to expand the ways and extent to which Indigenous communities can meaningfully influence and participate in the design, development and implementation of health care programs and policies. This may manifest in the form of mechanisms that enable community consultation and shared decision-making, policies that allow for community control of service provision, and funding arrangements that support resource allocation according to local needs, among others.[72,111] In addition, having a strong policy framework to systematically address Indigenous health needs enables more efficient funding, planning and execution of health programs, and increases accountability by explicitly allocating responsibility and creating more transparent processes.[292] At the same time, however, State structures and funding arrangements may exert pressures along various axes that strongly shape, and can limit, the forms that community participation may take.[111] In this way, the role of the State in community participation can be highly contradictory.

This chapter responds to the first research aim. It provides an overview of the policy and legislative environment of Chile in relation to Indigenous community participation in health. In particular, the effects of national and international policy and funding mechanisms on the means by which Indigenous communities can participate in the health sector are explored. This includes the influence of funding arrangements on Indigenous priority-setting and decision-making as considered through the lens of Indigenous community autonomy and independence. The role of Indigenous community activism and advocacy is examined as a key driver in shaping health policy.

5.1 Conflict and distrust

In considering how Mapuche communities interact with State agencies and the health care system, a crucial factor that must be acknowledged are the broader patterns that shape the relationship between the two, which is largely characterised by conflict, tensions, violence and mistrust. These stem from the history and continuing legacy of colonisation, dispossession and genocide enacted upon Mapuche by the Chilean State as well as the ongoing resistance by Mapuche communities. As covered in Section 2.3.2, the militarisation of Mapuche

communities, imprisonment of Mapuche activists under the Antiterrorism Law and land use conflicts, particularly as regards the forestry industry, are regularly occurring examples of State violence towards Mapuche. This background has implications for how Mapuche communities work with governmental agencies, including within the health sector. Even where no outstanding conflicts currently exist between the particular Mapuche community and governmental institution at hand, this context can shape interactions between these entities. More broadly, an ongoing distrust and fear between the Chilean State and Mapuche communities leads to a resistance on the part of the State to cede decision-making power to communities and a corresponding reluctance of communities to engage with the State.

Ahora, todo esto hay que entenderlo también en un contexto en que había una historia digamos represiva, digamos una historia de despojo de territorio, de discriminación; en ese contexto hay que entender todo esto, no se da en el vacío; hay una historia, y que tiene, bueno, la historia de lo que ha sido la relación del Estado chileno, y de los muchos estados con las poblaciones originarias. Entonces, no es que esto se dé digamos en una superficie lisa y libre de conflicto, eso no es así; existen conflictos, existen tensiones, las han existido y las siguen existiendo. Y ocasionalmente, con mayor o menor intensidad, los conflictos políticos más amplios se expresan también en los conflictos que se dan entre las organizaciones mapuches y las instituciones de salud.	Now, all this also has to be understood in a context within which there's been a repressive history, a history of territorial dispossession, of discrimination; in this context one has to understand all this, it doesn't happen in a vacuum; there's a history, and that has, well, a history of what the relationship has been with the Chilean State and many States with Indigenous populations. So, it's not that it occurs on an even surface, free of conflict, it's not that way; conflicts exist, tensions exist, they have existed and continue to exist. And occasionally, with lesser or greater intensity, broader political conflicts are also expressed in conflicts between Mapuche organisations and health institutions. (MINSAL staff member 1, non-Mapuche)

The issue of community distrust of the government was also raised as creating challenges to increased community participation. For example, interviewees indicated that communities were wary of investing time and resources in participatory processes when previous efforts had yielded little.

...estamos recién empezando, pensando cómo hacerlo, porque nuestro gran tema ... es: cómo hacemos para no levantar tantas expectativas que después no vamos a poder cumplir. Ese es nuestro temor básicamente...Que hemos perdido credibilidad, y después – y eso igual no es bueno para el programa. Es eso básicamente, porque en el fondo: 'Ah, claro, nos traen', es como el discurso que tienen, o sea: 'Nos traen, nos hacen participar, y después no hacen nada de lo que nosotros sugerimos que había qué hacer.'	...We're just starting out, thinking about how to do it, because our big issue ... is: how do we not raise such high expectations that we won't be able to fulfill them afterwards. That's our fear basically ... That we have lost credibility, and then - and that's also not good for the program either. That's it basically because at the end, 'Oh, of course, they bring us' is the discourse they have: 'They bring us, they make us participate, then they do not do anything that we suggested that you had to do.' (MINSAL staff member 3, non-Mapuche)

And participants indicated that this distrust went both ways, with the State resisting giving up its power to create more equitable decision-making processes.

Lo otro es que, bueno, el sector probablemente como otros sectores, no les gusta perder el control. Muchas veces la participación se ve como una 'amenaza al orden', y eso también es una dificultad, yo creo que son dificultades propias del sector salud a su interacción con el otro más que otro tipo de dificultades externas.	The other is that, well, the sector probably like other sectors does not like losing control. Often participation is seen as a 'threat to order,' and that's also a difficulty, I think they are difficulties within the health sector in its interaction with the other more than other external difficulties. (MINSAL staff member 1, non-Mapuche)
Yo siento que todavía –pero es por un tema histórico– las instituciones públicas en general le tienen susto a la gente.	I think that still—but it's because of a historical issue—the public institutions in general are afraid of the people. (MINSAL staff member 3, non-Mapuche)

5.2 MINSAL interviewees' perspectives on Indigenous community participation

As stated in the first pages of this thesis (see Section 2.2.2), part of the appeal and challenge of community participation is its amorphous nature—there is no universal agreement regarding the precise purpose of community participation, what it entails, what outcomes it is meant to achieve or who should be involved. The effect of this lack of clarity regarding the underlying conceptual foundations of community participation is that it lends itself to any number of discourses, including some that may be in direct conflict. MINSAL staff members were therefore asked about their perspectives regarding the conceptualised purpose of community participation, what form it would ideally take and what they saw as the potential benefits and disadvantages to participation.

5.2.1 Conceptualisation of Mapuche community participation in health

Nearly all MINSAL interviewees indicated in-principle support for Mapuche community participation in health and reported that their respective organisations valued community participation highly, even as they acknowledged that the practice proved complicated. In describing just what form Mapuche community participation in health would ideally take, interviewees described the end result of enabling the community to have input into priority-setting and decision-making. This was a common theme and seen as particularly crucial.

Que pudieran definir las prioridades a trabajar desde el programa.	That they could define the program's work priorities. (MINSAL staff member 3, non-Mapuche)
Yo creo que primero las comunidades tienen que estar informadas con conocimiento de lo que existe y de lo que hay. Y después, cuando se les invita a participar, tiene que haber una participación en las decisiones, en la toma de decisiones; no puede ser solo una participación pasiva donde le informen, y ya, le informamos y ahí están; sino que cómo se involucran también a nivel de todos los programas, de los proyectos definitivas de las decisiones de las políticas, que las	I think that first, the communities have to be informed with knowledge of what exists and what's there. And after, when they're invited to participate, there has to be participation in the decisions, in making the decisions; it can't be just a passive participation where they're informed and that's it, we inform them and there it is; but how to involve them as well at all the levels of the programs, from defining projects to political decisions, that Mapuche people are increasingly able to

personas mapuches cada vez más están en condiciones de hacer aportes efectivos a eso. Y si se le consultara frente a todas estas políticas tan negativas, habría otra voluntad de trabajo, y se efectuaría un trabajo de alguna manera complementario, en armonía.	support this effectively. And if they were consulted before all these negative policies, there would be another will to work, and to carry out work in a complementary way, in harmony. (MINSAL staff member 2, Mapuche)

However, the process of participation was seen as just as important—including communities from beginning to end and ensuring a broad set of the community has the opportunity to participate.

Bueno, la incorporación de las organizaciones y de la comunidad en todos los momentos del ciclo de la política, digamos desde el diseño hasta la evaluación, con capacidad de influir en las decisiones...	Well, the incorporation of the organisations and of the community at all times during the political cycle, from the design to the evaluation, with the ability to influence the decisions. ... (MINSAL staff member 1, non-Mapuche)

One interviewee spoke about the possibility of actively working in conjunction with communities and community organisations from the design to implementation of programs and initiatives.

Sí, algo así me lo imagino yo, haciéndose cargo en conjunto con las instituciones digamos, con las organizaciones, haciéndose cargo de la implantación o la implementación de políticas a nivel local, tomando decisiones sobre ella, estando muy cercana, muy vinculada, incluso incorporada en el sentido no de subsumir, sino de estar presente, con capacidad de toma de decisiones en los distintos niveles de	Yes, something like that, I imagine, being responsible together with the institutions, the organisations, taking charge of the development and policy implementation at the local level, making decisions about it, being very close, very connected, even incorporating in the sense of not subsuming, but of being present, capable of decision-making at various levels of the State organisation in health in particular, things we

la organización del Estado en salud en particular, cosas que ahora no vemos.	don't see now. (MINSAL staff member 1, non-Mapuche)

The above quotes reflect aspirations that rely heavily on the empowerment element of community participation in health—that is, enabling communities to play an active role in identifying their health needs, developing relevant approaches to these needs and undertaking implementation.[72]

The need for State recognition of traditional Mapuche social structures and authority was highlighted as being necessary for true community participation and to allow communities to make decisions in a way that aligned with cultural norms. In addition, this participant indicates that recognition and incorporation of traditional roles within Mapuche communities supports improved participatory processes by ensuring that decision-making power within the community is distributed appropriately.

Yo creo que hay que reconocer y valorar la propia organización tradicional porque ahí está todo involucrado, con todo sus roles y funciones, y participando activamente. Porque, ¿qué va a pasar? Que si no visualizamos eso con el longko, *con el* ñiempin, *con todas las autoridades tradicionales, más los especialistas en salud, las formadoras que yo llamo, las* kimche, *las personas que saben o las personas más adultas, vamos a encontrarnos con que el sistema avasalla…. Entonces, si hubiera una comunidad organizada, empoderada, abarrotando – va formando otras personas para que asuman eso, y va creyéndole en su comunidad como de la forma colectiva y horizontal.*	I think you have to recognise and value the traditional organisation itself because there it's all involved, with all their roles and functions, and actively participating. Because what will happen? If we do not see that with the *longko*, with the *ñiempin*, with all the traditional authorities, plus health specialists, forming what I call the *kimche*, people who know or the most adult people, we're going to find that the system overwhelms…. So if there was an organised community, empowered, building up—it builds up other people so they take that on and go believing in your community as being collective and horizontal. (MINSAL staff member 2, Mapuche)

The need for reciprocity and accountability on the part of both the State and community organisations as part of community participation was also mentioned. In this image of community participation, both communities and the State alike share responsibility with each other.

...también con necesidad de dar cuentas, de rendir cuentas; una participación – cómo llamarlo – de abajo hacia arriba, o sea con amplia distribución en los territorios, y que se vaya digamos concentrando hacia los niveles más centralizados del Estado. Una participación –bueno, ya lo dije– con capacidad de decidir, con capacidad de influir en la toma de decisiones, en la definición de prioridades, en las asignaciones de recursos, en la rendición de cuentas tanto de los agentes del Estado como de las propias organizaciones.	...Also in need of giving accountability, providing accountability; participation—what to call it—from the bottom up, that is, widely distributed in the territories, and moving away from concentration in the most centralised levels of the State. Participation—well, as I said—capable of deciding, with the ability to influence decision-making, priority-setting in the allocation of resources, accountability of State agents as well as the organisations themselves. (MINSAL staff member 1, non-Mapuche)

This interviewee also related the concept of community participation in health to participation across the entire political system.

Ahora, yo creo que ahí entonces hay una dimensión que no había mencionado antes, que es la dimensión política de la participación, más allá de la participación sectorial digamos, la participación en el sector salud o en las instituciones de salud que es la participación política más amplia en la sociedad, y yo creo que ahí en términos de la participación indígena hay unas definiciones de Estado que no están tomadas, o que están declaradas pero no ejecutadas, y que tiene que ver efectivamente con el rol de	Now, I think that there's a dimension that hasn't been mentioned before, which is the political dimension of participation, outside of sectorial participation, the participation in the health sector or in health institutions—which is the broader political participation in society, and I think that there in terms of Indigenous participation, there are some State declarations that aren't taken up, or that are declared but not executed, and that effectively have to do with the role of the communities in the control of their own

las comunidades en el control de sus propias condiciones de territorio, de tierras, de participación política; eso es un mundo digamos más amplio que solo el tema de la participación en salud. Y ahí tenemos como país creo mucha deuda, pero es una dimensión distinta.	territorial condition, of lands, of political participation; that is a broader world than only the theme of participation in health. And there, as a country, I think we owe a lot, but that's a different dimension. (MINSAL staff member 1, non-Mapuche)

5.2.2 Potential benefits

MINSAL interviewees described a wide range of benefits that they felt would come from constructing enhanced participatory processes in health, drawing on both the democratic and utilitarian perspectives of community participation in health. From the democratic perspective, community participation, community empowerment, increased equitability in power relations and increased accountability on the part of the State were frequent and interconnected themes. In particular, the possibility of community empowerment and being actively engaged with political systems through the process of participation was mentioned several times.

Y lo otro, bueno, es el empoderamiento de la propia comunidad, o sea hacerse cargo o considerar digamos que los procesos de salud y enfermedad son procesos colectivos, por lo tanto en que las propias comunidades tienen algo de decir más allá de cuáles sean las prioridades que se definan.	And the other, well, is the empowerment of the community itself, or taking charge or considering that the processes of health and disease are collective processes, therefore the communities themselves have something to say beyond what have been the identified priorities. (MINSAL staff member 1, non-Mapuche)
Yo creo que lo que hace es que efectivamente las organizaciones la gente se involucre, se involucre en el desarrollo de una tarea, y no sea un sujeto pasivo de la entrega de política, o de bajada de políticas públicas.	I think what it does is effectively, organizations, people get involved, get involved in the development of a task, rather than being a passive subject of the delivery of policy, or under public policies. (MINSAL staff member 3, non-Mapuche)

It was envisaged that from increased community empowerment and engagement, the transparency of State systems to communities would be improved, hence allowing communities to demand more accountability on the part of the State.

Y el otro tema es la rendición de cuentas, la rendición de cuentas de las organizaciones del Estado, las organizaciones de salud en función de lo que teóricamente están mandadas a hacer. Entonces, cuando existe una participación de mayor grado, de más empoderamiento, de más autonomía, es necesario – y las comunidades exigen digamos – son capaces de pedir cuentas sobre lo que se está haciendo.	And the other issue is accountability, accountability of State organizations, health organizations depending on what they are theoretically sent to do. So when there is a greater participation, more empowerment, more autonomy, it is necessary—and communities demand—that they are able to ask for accountability regarding what is being done. (MINSAL staff member 1, non-Mapuche)

This interviewee speaks more explicitly about community participation in health intertwined with a more equitable distribution of political power between Mapuche communities and the State.

Yo creo que tienen que ver con el poder, ganar poder político. Ganar poder político por un lado, y tomar decisiones de manera desde el punto de vista de la autodeterminación y autonomía, en relación a cómo querer articular un sistema de salud más central. O sea, sumarles de ventaja en, en el fondo, es poder decirle al estado: 'Esta es la forma que nosotros creemos que se enferman los Mapuches. Esta es la forma en que nosotros creemos, quizá, que se pueden sanar los Mapuches.' Desde una visión cultural. Y, que eso sea validado, ¿no es cierto?– por el estado. Y, que de una u otra manera, eso entre en una conversación, ¿no	I think they have to do with power, with gaining political power. To gain political power on the one hand, and make decisions from the point of view of self-determination and autonomy, regarding how to want to relate with a more central health system. In other words, adding up to an advantage, basically, it's the power to tell the State: 'This is the way that we believe that Mapuche get sick. This is how we think, perhaps, that Mapuche can be healed.' From a cultural perspective. And that is validated by the State. And that in one way or another, that gets into a conversation. As symmetrical as possible, with the medical, biomedical

es cierto? Lo más simétrica posible, con el sistema médico, biomédico, ¿no?	system, right? (MINSAL staff member 4, non-Mapuche)

In line with the utilitarian perspective of community participation in health, several MINSAL interviewees believed that community participation in the development of programs and initiatives would increase effectiveness and relevance for the involved communities.

¿Beneficios? Bueno, pueden ser varios. Una es la pertinencia de las políticas en el territorio digamos, en el nivel local. Muchas veces las políticas públicas, las políticas de salud, se diseñan y se busca su implementación a partir de lo que son los resultados promedio en un país. Y cuando uno tiene una contraparte que es capaz de identificar cuáles son las condiciones particulares de un territorio que hacen que los promedios se expresen de otra manera, es más posible o más factible adecuar la implementación de las políticas – el diseño también, y la implementación de las políticas a los diferentes contextos en lo que se está aplicando; eso sin la participación de la comunidad no se puede hacer, o sea desde ese punto de vista teórico digamos es más difícil.	Benefits? Well, there could be a few. One is the relevance of policies in the territory at the local level. Often public policies, health policies, are designed and their implementation is sought from the average outcomes in a country. And when you have a counterpart who is able to identify the particular conditions of a territory where the averages are expressed differently, it's more possible or more likely to adapt the implementation of the policies—the design as well, and implementation of policies in the different contexts within which it is being applied; that without the participation of the community cannot be done, that is from the theoretical point of view it is harder. (MINSAL staff member 1, non-Mapuche)

One interviewee suggested that community participation in health would increase State understanding of the need to consider health in a more holistic way and improve its capacity to address Mapuche health from a broader perspective. Given that this need was a recurring theme, as outlined above, this quote lends weight to the possibility that improved participatory processes would increase the relevance of the health system for Mapuche communities.

Yo creo que sí, porque los ven – son circunscritos a una sola área que es la de salud. Entonces, no visibilizan este concepto más integral, y por lo tanto pasan como por el lado. Yo creo que en la medida que ellos tengan esta información, de que la salud es vista desde la integralidad, desde los equilibrios, podrían hacer aportes efectivos y concretos en muchas – el tema del medioambiental, y todo lo que significa el agua, el tema de infraestructura, o sea muchas, muchas gentes que podrían hacer aporte, pero por desconocimiento no lo hacen.	I think so, because they see—they're limited to just one area, which is that of health. So they're not able to see this more integral concept, and therefore they pass it by. I think that to the extent that they have this information, that health is seen holistically, in harmony, they could provide effective and concrete support in many—in environmental issues, and everything that means—the water, the issue of infrastructure—many, many people that could be supportive, but because they don't know they don't do it. (MINSAL staff member 2, Mapuche)

Considerations of health as tied to broader questions concerning water and land use and environmental issues led one participant to question entirely how participation could benefit the community while being set against a background of conflict generated by State policies and actions. In discussing whether Mapuche communities benefit from participating in health, the interviewee says:

Entonces no, y menos con todos los niveles de agresividad y de conflictividad que existe todavía en los territorios, que el mismo Estado pues propició.	So no, and even less so with all the levels of aggression and conflict that still exist in the territories, that the State itself contributed to. (MINSAL staff member 5, Mapuche)

5.2.3 Potential disadvantages or harms

The majority of interviewees rejected the idea that there would be disadvantages to increased community participation in health, although conflicts around different styles of working and expectations around timelines were mentioned as difficulties. These interviewees stressed, however, that such challenges did not mean that participatory processes should be avoided.

¿Desventajas? Bueno, una mirada puede ser que en términos de tiempo digamos, los procesos de participación toman su tiempo, y eso a veces entra en conflicto con los tiempos de la ejecución de las políticas y los tiempos presupuestarios, y los tiempos de las lógicas del Estado; eso pudiera – puede ser una dificultad pero no digamos eso no implica que no se tenga que hacer.	Disadvantages? Well, one view might be in terms of time, participatory processes take their time, and that sometimes conflicts with the timing of the implementation of policies and budgetary times, and times of State logics; That could - may be a difficulty but that does not mean that it shouldn't be done. (MINSAL staff member 1, non-Mapuche)
No, no. No, es que yo creo que en la medida en que uno aprende a trabajar en conjunto, no debieran haber como – o sea, inconvenientes siempre pueden haber, pero desventaja no creo; yo creo que uno puede sumar más cosas que perder.	No, no. No, I think to the extent that you learn to work together, there shouldn't be—that is, there may always be problems, but disadvantage? I don't think so; I think you can gain more than lose. (MINSAL staff member 3, non-Mapuche)

However, while they were not explicitly framed as disadvantages, several costs to the community as a result of participation were mentioned. These were mainly framed around the burden taken on by community members as they take the time to engage, as well as financial costs.

Claro, entregando – o sea, dando los espacios necesarios, otorgando financiamiento para temas básicos; porque si bien, la gente muchas quieren participar, no todos tienen las posibilidades económicas de hacerlo, y ahí es donde muchos dicen: 'Pero eso es paternalismo', pero también hay que tener claro de que hay mucha gente empobrecida. Entonces, en la medida en que nosotros entregamos algunos como – no	Of course, giving—that is, giving the necessary spaces, providing funding for basic issues; because although many people want to participate, not everyone has the economic means to do so, and that is where many say: 'But that's paternalism,' but we must also be clear that there are many impoverished people. So as far as we deliver some—not necessarily to the person, but maybe, like, a breakfast, a lunch, some

necesariamente a la persona, pero sí a lo mejor, no sé, un desayuno, un almuerzo, compensan algo también esto de la reciprocidad que se da, que ellos igual van a instancias que si bien les interesan, tienen un costo también para la gente.	compensation—that's also reciprocity, so that they'll also go to proceedings that interest them but that also have a cost for people. (MINSAL staff member 3, non-Mapuche)

While only one interviewee made explicit mention of possible disadvantages to communities as a result of participation, their points reflected those made by other participants regarding the imposition of State bureaucracies and norms on communities, thereby furthering the subsumption of Mapuche culture and tradition.

Las desventajas, yo creo que tienen que ver con que de una u otra manera, hasta qué punto las comunidades tienen que entrar a negociar, ¿no es cierto? Y, a veces renunciar a/o acá a, a formas, digamos, que son las tradicionales, y cambiarlas en un diálogo que el estado impone, muchas veces. Y, que de una u otra manera direcciona, ¿no? Como tú ves en este centro, que las machis *tengan que llenar ciertas estadísticas, tengan que llenar una ficha, ¿no es cierto? O, tengan que atender en un box, no en su territorio, ¿no?*	The disadvantages, I think they have to do with that one way or another, up to what point the communities have to come to negotiate, and sometimes give up forms which are the traditional ones, and change them in a dialogue that the State imposes, many times. And that directs them in one way or another, right? As you see in this centre, where *machis* have to fill certain statistics, have to fill out a form, right? Or have to provide care in a box, not in their territory, right? (MINSAL staff member 4, non-Mapuche)

This quote serves as a reminder that community participation in health is not without its risks of grave harm to Indigenous communities, as it may not only fail to address power differentials between communities and governments, but actually serve to maintain or reinforce existing power relations.[71] In the case of Indigenous peoples, this dynamic may ultimately undermine the values of sovereignty and self-governance by enveloping communities within State structures that are not designed to accommodate Indigenous ways of working.

5.3 Policy and Indigenous community participation

As outlined in Section 2.3.2, Chilean policy regarding Indigenous participation is shaped by both national and international legislation. Chile's ratification of ILO 169 in 2008 obligated the government to consult with its Indigenous peoples on matters that concern them. Multiple participants voiced the perception that in recent years, there has been a shift towards increased political will in expanding consultation with Indigenous communities, as demonstrated in part by the intensive nation-wide consultation regarding Article 7 of Law 20.584 (see Section 2.3.3.1) conducted over 2015 and 2016. The consultation was undertaken with the nine Indigenous peoples recognised under the Indigenous Law (Law 19.253)[142] in all regions as well as on Easter Island with the aim to come to a shared understanding regarding the concepts relevant to the rights and responsibilities of patients to culturally appropriate health care articulated in Article 7.[293] This was the first national consultation undertaken with Indigenous peoples by the Ministry of Health.[294] As the MINSAL staff member indicates below, the increase in expressed acceptance towards Indigenous community participation has both driven policy changes and been driven by a need to comply with established policy, including the principles of ILO 169.

Bueno, de que ahora hay una política de participación ciudadana que está potente, y que en el fondo obliga igual a las instituciones a incluir a los usuarios, en este caso de salud, en las decisiones, y que se han generado una serie como el Convenio 169, está la ley de derechos y deberes, y todas esas te obligan efectivamente – incluir a participación ciudadana en sus actividades. Entonces, yo creo que eso igual es un factor importante a considerar, sobre todo en este trabajo. Igual están los respaldos hoy en día para que la participación se dé.	Well, now there is a policy of citizen participation that is powerful and that basically forces institutions to include users, in this case of health services, in decisions, a series has been generated such as Convention 169, there's the law of rights and responsibilities, and all those that effectively oblige you to include citizen participation in their activities. So I think that is also an important factor to consider, especially in this work. At the same time there is support today for participation. (MINSAL staff member 3, non-Mapuche)

However, the promulgation of Supreme Decree 66 in 2013 installed particular parameters around who is entitled to consultation and how such consultation should occur (see Section

2.3.2). This has largely been interpreted as an attempt to limit the right to consultation outlined in ILO 169.[180] The contradictory approach to Indigenous participation was brought up by interviewees from MINSAL as a barrier for government agencies seeking to undertake consultation with Mapuche communities.

Sí, por ejemplo, el Decreto 66, digamos, ¿no es cierto? Que es un decreto que regula la forma de consultar a la – puede ser la prioridad – una clara barrera, digamos, de cómo el estado pone, digamos, ciertos elementos que de una u otra manera condicionan, ¿no?	Yes, for example, Decree 66 is a decree regulating the form of consulting—maybe the priority—a clear barrier in that the State imposes certain conditions in one way or another, right? (MINSAL staff member 4, non-Mapuche)

The damage that following the Decree could inflict on consultative processes is clear in the following quote, where a MINSAL staff member states that following the Decree to the letter would result in a loss of community trust, possibly up to and including rejection of State institutions by Mapuche communities. The quote below is in relation to the Article 7 consultation process mentioned above.

Y entonces, frente a ese rechazo, nosotros como sector salud que nos importa mucho mantener la confianza de los pueblos, decidimos que no íbamos a usar la reglamentación vigente lo cual ha sido muy complicado porque nos han hecho la guerra por eso; pero nosotros no queremos transar, porque si nosotros aplicamos al pie de la letra el reglamento vigente que se llama Decreto 66, vamos a perder la participación de los pueblos y nos van a rechazar, aunque tengamos confianza igual nos van a rechazar.	And then against that rejection, we as the health sector, because it's important to us to maintain the trust of the people, we decided we were not going to use the current regulation which has been very difficult because we have waged war for that; but we do not want to compromise, because if we apply the letter of the existing regulation which is called Decree 66, we will lose the participation of the people and they will reject us, although they trust us, nevertheless they will reject us. (MINSAL staff member 6, non-Mapuche)

While there was a general belief from MINSAL interviewees that there was a growing discourse around Indigenous community participation in health, there were also acknowledgements that this support tended to be individualised, rather than embedded within institutional structures. Not only this, but in moving from a left-wing to right-wing government, this progress can be reversed in a short period of time. This point continues to be relevant, as in 2017 the Piñera government, which instituted Supreme Decree 66 during its first term, was re-elected and continues to be in power. The quote below demonstrates this historical variability of political will.

Bueno, sin duda la voluntad política es tremendamente fuerte como en el sentido de que si no existe la voluntad política los procesos se pueden incluso llegar a detener profundamente. Y en torno a lo que ha sido el desarrollo del programa, ha habido periodos en que, como te decía antes, ha estado poco firme la voluntad política que fue principalmente en los comienzos de este trabajo, solo personas pero no instituciones apoyaban este trabajo, incluso personas que tenían cargos importantes también lo apoyaba, pero no era un tema de país...En torno a esto, la voluntad política yo creo que ha continuado a lo largo de los años, exceptuando el periodo de gobierno de derecha, que se produjo una situación muy delicada porque hubieron muchos despidos de gente que llevaba muchos años trabajando en el programa, y que por razones políticas fueron despedidos.	Well, certainly the political will is extremely strong in the sense that if there is no political will processes can even stop. And around what has been the development of the program, there have been periods when, as I said before, there has been shaky political will, which was mainly at the beginning of this work, only individuals but not institutions supported this work, even people who had important positions also supported, but it wasn't a topic in the country ... around this, I think the political will has continued over the years, except for the period of right-wing government, which caused a very delicate situation because there were many people that were laid off who had spent many years working in the program, and were dismissed for political reasons. (MINSAL staff member 6, non-Mapuche)

Even where participatory processes were put in place, these were seen as being relatively superficial in that they do not provide avenues for shared distribution of power or allow for autonomous decision-making on the part of the communities.

Teóricamente existe una disposición de Estado sobre la participación de la sociedad civil en las instituciones del Estado. Desde mi perspectiva...ese instructivo de participación es un instructivo que tiene una mirada a la participación bastante instrumental; no se canaliza por esa vía definiciones o estrategias de participación que tengan que ver más con la experiencia o con decisiones vinculantes, o con la transferencia de poder, o con la autonomía en la toma de decisiones.	Theoretically, there is a willingness of the State regarding the participation of civil society in State institutions. From my perspective ... that participation guideline takes a view of participation that is rather instrumental; it is not channelled by definitions or participation strategies that have more to do with the experiences or decisions of people involved, or the transfer of power, or autonomy in decision-making. (MINSAL staff member 1, non-Mapuche)

In speaking about difficulties in incorporating participatory processes into government decision-making, several people mentioned the structure of government institutions as an obstacle. Interviewees named both the siloed nature of government departments and the vertical, top-down characteristics of public institutions as preventing wider dialogue between sections of the government and between government entities and communities. This is a reflection of Chile's centralised nature.

No es fácil, sobre todo cuando las organizaciones públicas siempre han estado acostumbradas a hacer lo que ellos quieran. En que no preguntan por tomar decisiones, siempre son organizaciones más verticales las organizaciones públicas.	It's not easy, especially when public organizations have always been accustomed to doing whatever they want. In that they don't ask in making decisions, the most vertical organisations are always public organisations. (MINSAL staff member 3, non-Mapuche)

The tendency of government institutions to operate without outside input is also seen in general differences in the way communities and government institutions functioned, which created difficulties in bringing the two together. For example, interviewees often mentioned the issue

of short timelines imposed by the State that did not correspond with the need for in-depth dialogue with communities.

Pero que como este otro sistema es metas, fechas, tiempo; a mí me gustaría ir de comunidad por comunidad, familia por familia, invitarnos, trabajar, de qué se trata, qué hacemos; pero el tiempo, no; hasta tal fecha porque después se cierran los plazos y se rinde todo y no hay más, si no se rinde los recursos se devuelven. Entonces, es un constante problema eso.	But as this other system is goals, dates, times; I'd like to go community by community, family by family, invite us, work, what's it about, what we do; but time, no; only until such-and-such date because after the deadlines are closed and everything's given out and there's no more, if resources haven't been used they're returned. So that's an ongoing problem. (MINSAL staff member 2, Mapuche)

5.4 Indigenous health needs assessment and resource allocation

As can be seen, interviewees highlighted the growing political discourse with regards to Indigenous participation in health. At the same time, however, the ability to identify and address health needs specific to Indigenous communities or take a localised approach to such is curtailed by systems-based barriers. When MINSAL interviewees were asked about how the health needs of Indigenous populations were identified and resulting resource allocation, they indicated that there was generally little attention given to ethnic disparities in health or differential health needs of Indigenous people.

As covered in Section 2.2.3.1, PROMAP was developed as a section of the SSAS in order to improve Mapuche health at the regional level with an emphasis on strengthening the primary health care system and improving the quality of health care received by Mapuche.[65,222] However, as can be seen in the quote below, the priorities for PROMAP were pre-defined through the Ministry, with any subsequent consultation being undertaken against these priorities.

Entrevistadora:Y con el programa, con PROMAP, ¿cómo se identifican las prioridades…?	Interviewer: And with the program, with PROMAP, how are the priorities identified?

Entrevistada: Por orientaciones ministeriales. El Ministerio envía, y define cuáles son, como las líneas de trabajo, y en base a eso se organizan las actividades; en las comunas donde haya asesor cultural, es el asesor cultural con su equipo que define qué se va a realizar en esa comuna, dependiendo de las prioridades que ellos tengan. *Entrevistadora: Y en este proceso, ¿hay la posibilidad de participación de la comunidad?* *Entrevistada: De los asesores culturales en casi todo. Nos ha costado un poco el tema de la participación, nos ha costado un poco la participación acá, pero estamos empezando con ello. Pero nosotros como programa no, no lo hemos hecho todavía. Esa es la verdad.*	Interviewee: By ministerial orders. The Ministry sends, and defines what are the lines of work, and based on this the activities are organised; in communities where there's a cultural broker, it's the cultural broker with their team that defines what will be done in the community, depending on the priorities that they have. Interviewer: And in this process is there the possibility of community participation? Interviewee: From the cultural brokers in almost everything. The issue of participation has been a difficult one for us, it's been a bit difficult for us here, but we're starting with it. But for us as a program, no, we haven't done it yet. That's the truth. (MINSAL staff member 3, non-Mapuche)

In cases where community members have been invited to participate, an additional consideration was that the program may not be able to carry out the wishes of participants, generating further resentment and resistance to future participatory processes.

Y otra cosa es de lo que hablaba desde la gente, por la frustración que tienen cuando ven que sus solicitudes no se canalizan, o sus demandas, o las propuestas no son consideradas; entonces te dicen: 'Bueno, entonces para qué me invitas si después no,' y ahí es donde salen y nos invitan para	And another thing is that which is talked about from the people, because of the frustration that they have when they make requests and they're not carried out, or their demands, or the proposals aren't considered, then they say, 'Well, why did you invite me if afterwards no,' and it's there that they leave and they invite us to justify why they

justificar que tienen que hacer participación.	have to participate. (MINSAL staff member 3, non-Mapuche)

Rather, the interviewee below indicates that in general, health needs are assessed in accordance to the epidemiological data collected, including population size and density and the proportion of the population living in poverty. As the use of Indigenous identifiers in the collection of epidemiological and clinical data is neither widespread nor standardised, it is difficult to systematically and accurately identify the health needs of Chilean Indigenous populations.[206]

Pero en términos de política, así como de política indígena, yo creo que más bien ha habido una desconcentración de esfuerzos institucionales más que unas definiciones específicas de prioridades sanitarias; o sea, desde el nivel central se les entrega recursos a los servicios, para que los servicios trabajen con las comunidades o con las organizaciones y allí se definan las prioridades, pero ha sido un ejercicio asimétrico…Pero en términos de prioridades así, prioridades sanitarias, en primer lugar diría yo, o sea por dónde hay más daño, más mortalidad, más morbilidad de algún tipo; y se ha abordado de una manera más o menos clásica o occidental o hegemónica, esos daños en población mapuche, más que construir digamos una organización desde las percepciones compartidas de las organizaciones indígenas en la propia institución. Creo que no ha sido muy así.	But in terms of policy, as well as in Indigenous policy, I believe that rather there's been a diffusion of institutional effort more than some specific definitions of health priorities; that is, from the central level resources are provided to the health departments, to allow the health departments to work with the communities or organisations and from there the priorities are defined, but that's been an asymmetrical exercise…But in terms of priorities like that, health priorities, in the first instance I would say, that is, where there's more harm, more mortality, more morbidity of some sort; and it's been approached in a more or less classical or western or hegemonic way, those harms in the Mapuche population, rather than constructing, we'll say, an organisation from shared perceptions from Indigenous organisations in the institution itself. I think it hasn't been much like that. (MINSAL staff member 1, non-Mapuche)

The following MINSAL interviewee indicates that where the needs of Mapuche communities are considered in a focused manner, it is through the lens of high rates of poverty and resulting health disparities, rather than incorporating an understanding of the historical, political and cultural factors that continue to impact Mapuche health. From this biomedical and epidemiological perspective, there is no space to consider Mapuche understandings of their own health or health needs.

Bueno, ahí en general, las políticas públicas no hacen diferencia porque ellos elaboran políticas desde el Ministerio para todo el país, son políticas uniformes, y no hay diferenciación en relación a las características propias culturales. Entonces, ¿cuándo uno reconoce? Cuando uno tiene las cifras negativas. Entonces ahí es casi como una justificación de recurso, decir: 'Ah no, si ahí están los Mapuches con su pobreza…'	Well, there in general public policy doesn't differentiate because they develop policies from the Ministry for the entire country, they're uniform policies, and there's no differentiation in relation to the cultural properties themselves. So, when are they recognised? When they have negative statistics. So there it's almost a justification for resources, to say: 'Oh, no, there are the Mapuche with their poverty…' (MINSAL staff member 2, Mapuche)

Moreover, the speaker above relates this policy back to the highly centralised nature of Chile. As the previous quote alludes to, this has a strongly limiting impact on the recognition of Mapuche health needs, either as a population or at the community level. This is seen in more detail in the following section.

5.5 The view from the ground

In contrast to MINSAL interviewees, the topics of ILO 169 and Article 7 were not prevalent themes in interviews with Mapuche service providers, indicating that the principles inscribed in these structures, such as consultation processes with the State, had little direct bearing on their day-to-day work. Rather, service providers described a legislative and political environment that limited community input and severely restricted their capacity to ensure services were appropriate to the local cultural and social context. Mapuche service providers spoke in strong terms about a system that had no structures to enable or facilitate Indigenous administration of health care services; centralised resource allocation and needs assessment mechanisms that did not allow for responsiveness to local contexts; and ongoing budgetary and

financial burdens that served to undermine the sustainability of Indigenous community control. A desire to shape the political and legislative landscape of Chile to be more response to Mapuche needs and demands therefore drives the Centres and their communities to engage in advocacy as an aspect of community participation.

5.5.1 Financing Indigenous service providers

In Chile, private health care providers are funded by the State under DFL 36 (see Section 3.2.3), with the level of funding influenced by the assumption that they will charge patients to offset the costs of providing care. At the same time, there is also funding set aside to address Indigenous health, for example through PROMAP in the region of La Araucanía. However, in the communities of Makewe-Pelale and Boroa Filulawen, where a high proportion of patients live in poverty, it is not possible to charge users for services. At the same time, neither does Makewe Hospital receive funding allocated towards Mapuche health, as it is funded as a biomedical hospital. The funding that Makewe Hospital receives from SSAS is governed by a contract that is renewed and signed four times annually. This exceptionally short contract creates significant levels of insecurity and uncertainty. In addition, under DFL 36, non-governmental organisations administering health centres are obligated to leverage an economic guarantee each year to demonstrate that they have the financial capability to fulfil their commitments, a stipulation that is impossible for Hospital Makewe to meet.

El Estado, a través de Contraloría, tiene un mecanismo, puede ser un tema pensar en lo privado, en la empresa, no hay un tema pensado en el pueblo indígena, en donde si tú necesitas 100 millones de pesos, tiene que dar el 10% o el 20% ponerlo como boleta en garantía; para eso tú tienes que tener esa plata. Significa, si postulas 100 millones de pesos, tienes que tener 10 millones de pesos si fuera el 10%; y si son 20%, 20 millones de pesos; pero son puros agricultores y mapuches, ¿de dónde sacan 20 millones de pesos?... Entonces, prácticamente te están	The State, via the Auditing Office, has a mechanism, maybe thinking about private companies, or businesses, they're not thinking about Indigenous people, where if you need 100 million pesos (approximately 200,000AUD), you have to give 10% or 20% as a guarantee; so you need to have that cash. So that means, if you're applying for 100 million pesos, you have to have 10 million pesos if it were 10% and if it's 20%, 20 million pesos; but they're all farmers and Mapuche, where are they going to get 20 million pesos from?...So in reality you're imposing this requirement that you know

haciendo valer un requisito que sabes que no van a cumplir.	they're not going to meet. (Makewe staff member, Mapuche)

In reaction to the imposition of this guarantee, Makewe Hospital, Boroa Filulawen Intercultural Health Centre and other Mapuche service providers joined together to demand that the Ministry of Health rectify this requirement under ILO 169.

Entonces en ese tiempo se tuvo que juntar la plata, nos endeudamos y juntamos la plata, y no obstante…no era posible porque hay un convenio internacional que el gobierno ha firmado… el 169 de la OIT. Entonces yo me inquieté y le dije que yo iba a salir a demandar esto con las otras organizaciones que estaban sufriendo la misma amenaza económica….Y ahí hicimos nuestra demanda, pero ellos llamaron a la jefa de servicio y le dijeron que había un convenio, el 169, y que se debía dar un trato distinto al pueblo mapuche porque el pueblo mapuche es un pueblo que como le dije al principio, empobrecido, que antes no lo era…Y que era necesario buscar alguna forma de no poner en dinero sino poner alguna garantía económica que fuera en un documento que nosotros nos obligamos a tener… Así que se hizo eso, o sea que lo que hubo voluntad política, voluntad política y yo creo que ellos también cumplieron en cierto modo el convenio 169, donde dice en el Artículo 25 que los pueblos [indígenas], que los servicios de salud, los ministerios tienen que apoyar y fomentar las decisiones propias	So at that time we had to get the money together, we put ourselves in debt and got the money together, but nevertheless…it wasn't possible because there's an international convention that the government has signed…the ILO 169. So I roused myself and I told him that I was going to go to demand this with the other organisations that were under the same economic threat…And there we made our demand but they called the head of the health department and told her that there was a convention, the ILO 169, and that the Mapuche people had to be treated differently because the Mapuche people are, as I told you at the beginning, an impoverished people, which they weren't before…And that it was necessary to look for some way to not put cash but to put some economic guarantee that would be a document that we would be obliged to have…So they did that, there was political will, political will and I believe that they also complied to some extent with ILO 169, where it says in Article 25 that the [Indigenous] peoples, that the health departments, ministries, have to support and

autónomas de los pueblos. Entonces nos quedamos tranquilos, nos quedamos tranquilos.	facilitate the autonomous decisions of the [Indigenous] peoples. So we were calm, we were calm. (Makewe staff member, Member of the Association, Mapuche)

While this strategy has been successful to some extent, when Makewe Hospital began the process of building new premises, the issue of an economic guarantee rose again, provoking very high levels of anxiety that the construction of the new hospital would ultimately be obstructed. Below, the same member of the Association goes on to reference this situation, and ties the recurrence of the theme to the relative ineffectiveness of ILO 169 without additional legislation at the national level to embed structures that support Mapuche governance.

Entonces yo estoy porque a mediano o a corto plazo revirtamos esa situación, pero ya no que sea por una voluntad sino que se pueda haber un decreto de ley o algún decreto del parlamento que pueda hacer valer realmente el convenio 169.	So I'm here because in the medium to short term we've come back to this situation, but not because anyone wants it, rather there needs to be a law or parliamentarian degree that can really give force to Convention 169. (Makewe staff member, Member of the Association, Mapuche)

Apart from this economic guarantee, a repeated theme raised within Makewe Hospital in particular was frustration with seemingly arbitrary decisions made by State agents that had a profound impact on the ability to plan appropriately and meet contractual obligations.

Nos dicen 'ya, para el próximo año le vamos a tener el presupuesto del año más el infractor' que le llaman ellos, que es como un re-ajuste al presupuesto, que en este caso fue por un tres punto cinco por ciento de re-ajuste y siempre, yo no sé como ellos sacaran ese porcentaje de infractor que siempre es menor al IPC, al indicador de precio al	They tell us, 'Okay, for the next year we're going to give you the budget for this year plus the infractor,' as they call it, which is like a readjustment of the budget, which in this case was some 3.5% readjustment and always, I don't know where they get this infractor percentage from which is always below the CPI, the consumer price index. Or

consumidor. O sea nosotros les decimos 'es imposible, o sea me estás dando el tres punto cinco por ciento, por otro lado el IPC es de un cinco por ciento y más encima el sector público de los trabajadores con el Estado concuerdan con una actualización de los sueldos de seis por ciento' … eso es lo que no nos cuadra de repente un poco.	maybe we tell them, 'It's impossible, you're giving me 3.5%, on the other hand the CPI is 5% and moreover the public sector workers have an agreement with the State for a salary hike of 6%'…That's what maybe doesn't quite make sense to us. (Makewe staff member, Mapuche)

Although BFIHC is funded for the provision of Mapuche traditional medicine, unlike Makewe Hospital, this also carried its own frustrations. The BFIHC directors spoke in informal conversations of their weariness of being under constant scrutiny, particularly regarding auditing, reporting and accountability mechanisms. The directors relayed their experience of having to continuously prove to the State the validity of traditional medicine, the effectiveness of the intercultural model and the capacity of a Mapuche organisation to administer a health centre. Below, one of the community leaders echoes this perception, saying that it is only recently that the State has come to have some credence in the validity of traditional Mapuche medicine.

Entonces yo creo que de ahí recién fue entendiendo el Estado por medio de las autoridades regionales y comunales, fueron entendiendo que nosotros como Mapuche teníamos una medicina creíble, una medicina que hizo bien a la gente, que se ha mejorado, que incluso no es una medicina que está tratando de mejorar, tiene una medicina preventiva….	So I believe that only from recently the State was understanding by means of the regional and communal authorities, they were understanding that us as Mapuche we had a credible medicine, a medicine that made people well, that makes them better, that is not even a medicine that is trying to cure, it has a preventative medicine. (Boroa staff member, Mapuche)

One of the BFIHC clinicians also articulated frustration that even with the amount of evidence indicating that Mapuche providers were capable of delivering high-quality services, the centralised nature of decision-making prevented the sufficient allocation of funds at the needed levels.

O sea, lo que siempre se hace todos los años, es un convenio, donde de acuerdo a lo que nosotros trabajamos el año anterior, son los recursos que nos entregan para aumentar las prestaciones. Y, yo creo que ahí todavía lo que es el gobierno central, ha quedado en deuda. Porque, hemos demostrado con el paso de los años, que somos capaces de prestar más utilidades a la población, pero, los recursos no están.	I mean, what's always done, every year, is a contract, where depending on how we worked in the past year, are the resources that they give us to increase services. And I believe that there still the central government remains indebted. Because we've demonstrated over the years that we're capable of delivering more utility to the population, but the resources aren't there. (Boroa staff member, non-Mapuche)

In order to demonstrate compliance with the requirements of State funding, including implementation of the specific programs mandated by the Health Department, the health centres regularly submitted to auditing and composed in-depth reports on their service delivery. Compiling these statistics was a major time burden for workers across the health centres. The strong pressure on the Centres to strictly adhere to the funding requirements was seen as severely undermining the organisations' autonomy.

Por ejemplo… ¿cuántos pacientes por hora? ¿Qué es lo que se administra? ¿Cuáles son las metas que tiene que cumplir? ¿Cuántos pacientes tiene que tener en tal programa? ¿Cuánto es tu población bajo control? A nosotros todos esos parámetros nos mide el servicio salud. Te puedo presentar estadísticas, nosotros lo más importante dentro del mes para poder recibir los sueldos, son las estadísticas… Nunca había una libertad total o una autonomía total para poder hacer o decidir.	For example… How many patients per hour? What is being administered? What are the aims we have to reach? How many patients have to be in which program? What is your population? These are all the parameters the Health Department measures us by. I can show you statistics, for us the most important thing in the month to be able to receive the salaries are the statistics.…There's never been total freedom or autonomy to be able to do or decide. (Makewe staff member, Mapuche)

This point about the way financial and bureaucratic restrictions placed limits around the autonomy of Mapuche service providers was also articulated by interviewees in MINSAL.

…no tenemos un sistema intercultural de gestión de administración de financiamiento…los centros de salud que son más autónomos o auto gestionados como el que tú visitaste funcionan por el DFL36…que les da un poco más de autonomía de alguna manera pero que les obliga igual a generar cierto tipo de estrategias o de trabajo que no se sale de la norma establecida. Por eso es que la autonomía como yo te decía es súper relativa, o sea autonomía sí en el sentido de que hay una idea pensada detrás pero en el plano de la práctica e ilación no porque ese financiamiento amarra a la gente, los obliga a cumplir metas y les ha quitado autonomía según lo que yo entiendo…	…we don't have an intercultural system of governing financial administration…the health centres that are more autonomous and self-governing, like the one you've visited, function through DFL 36 … which gives them a bit more autonomy in some way but which obliges them at the same time to develop certain kinds of strategies or work that doesn't deviate from established norms. That's why, as I said to you, autonomy is really relative, that is autonomy, yes, in the sense that there's an idea behind, but in the plane of practice and inference, no, because that funding ties people up, it forces them to adhere to objectives and removes autonomy from them, according to what I understand… (MINSAL staff member 7, Mapuche)

Perpetually being short of funding, the unpredictable nature of the provided budget and a lack of mechanisms to allow Mapuche organisations to meaningfully negotiate with the broader system thwarted attempts to engage in long-term planning and constrained the Hospital's ability to identify and align priorities with their own identified needs.

Yo creo que ese tema es súper complejo porque yo no sé hasta qué punto estos centros…tienen tanta autonomía como para hacer un trabajo más focalizado en las necesidades más originales y sentidas de la gente porque en general en salud lo que yo veo y lo que pasa acá con los otros establecimientos…es que siempre independientemente de la autonomía en la	I think that the issue is really complex because I don't know to what extent these centres… have that much autonomy such as to do work more focused on the more original and felt needs of the people because in general in health what I see and what happens here with the other establishments…is that always independent of autonomy in governance and all that, they

gestión y todo eso, tienen que responder a meta sanitaria y una serie de otros requerimientos…entonces al final igual pasan como a mediar intereses entre los se les exige para poder recibir financiamiento y lo que tienen que cumplir para responder a la realidad territorial….	have to respond to health objectives and a series of other requirements…so in the end nevertheless they mediate interests between those that are demanded to receive funding and what they need to achieve to respond to the territorial reality…. (MINSAL staff member 7, Mapuche)

5.5.2 Advocacy for autonomy in health service provision

Mapuche service providers' frustrations with the Chilean health care system were located within a framework that valued Mapuche participation in health as a means to increase Mapuche political power, representation and autonomy. Service providers at Makewe Hospital therefore saw the Association's relationship with the wider health system as a way of demonstrating the legitimacy of Mapuche self-governance. At the same time, there was recognition among both service providers and MINSAL staff that the Hospital's need to be viewed as a legitimate actor placed the Association under obligation to conform to State requirements, which simultaneously undermined Mapuche autonomy. The following quote illustrates the utilisation of participatory processes to increase Mapuche independence while at the same time being mindful of the necessity of compliance with State-imposed regulations in order to maintain this position.

…esas instituciones uno las tiene que fortalecer y para fortalecerlas indudablemente como estamos insertos dentro del estado chileno tenemos lamentablemente, digo lamentablemente, tenemos que cumplir sus normas, sus reglas y sus leyes y todo eso, no nos queda de otra porque si no cumplimos esas reglas ellos lamentablemente van a decir 'ya, esta institución no cumple reglas por lo tanto queda fuera del sistema' y al quedar fuera del sistema perdemos representatividad, perdimos voz, perdimos nuestra de alguna	…these institutions [such as the Mapuche Association], one has to strengthen them and in order to strengthen them indubitably as we're located within the Chilean State unfortunately, I repeat unfortunately, we have to adhere to their policies, their rules and their laws and all that, there's nothing else for it because if we don't adhere to these rules they'll regrettably say, 'Right, this institution isn't following the rules and therefore it is outside of the system,' and once we're outside the system we lose representativeness, we've lost our voice,

manera el desarrollo dentro de la sociedad chilena.	we've lost in some way our development within the Chilean society. (Makewe staff member, Mapuche)

Participants described the damaging effects that differential power structures had on community participation in various ways. For example, this interviewee spoke about the chilling impact that inequitable power distribution has on participation if communities fear that their resources will be cut if they are too critical of the State:

Entonces, ese es el miedo con el tema de la participación, la interculturalidad, y la equidad, porque finalmente el programa no es un programa que contiene todas las atenciones de morbilidad en salud. Entonces es reforzar eso, de cómo llega esa oferta de salud a los territorios, creo que esa es la misión; pero no somos escudos, porque si nos ponemos como escudo el Estado no le va a pasar nunca nada. Y yo creo que nosotros estamos invitados, misionados a exponer al Estado, a incomodar los poderes del Estado.	So that's the fear with the issue of participation, interculturality, and equity, because ultimately the program is not a program that contains all of the health care relating to morbidity. So it's to strengthen that, how to bring that offer of health to the territories, I think that's the mission; but we are not a shield, because if we act as a shield, the State is not going to give anything ever again. And I think we are invited, we have a mission to expose the State, to disturb the powers of the state. (MINSAL staff member 5, Mapuche)

One Makewe Hospital staff member explicitly linked the pressures exerted on the Hospital by way of financial structures and the Association's position that advocacy is a central part of its mission.

Si no tengo los recursos, ni siquiera para lo mínimo, que es lo biomédico, ¿en qué momento me va a quedar la tranquilidad para pensar? Yo creo la solución es negociar políticamente.	If I don't have the resources, not even for the minimum, which is the biomedical, when will I have the calm to be able to think? I think the solution is political negotiation. (Makewe staff member, Mapuche)

As was seen in the previous chapter, MINSAL interviewees frequently spoke about the State as being 'afraid' of the people, or 'threatened' by delegating power, and acknowledged the requirements and restrictions around Indigenous health governance and service provision as resulting from the reluctance of the State to fully relinquish control in decision-making, priority-setting and health program development.

Entonces ahí hay una situación súper compleja que no deja, que no da espacio de participación porque dar espacio de participación significa cambiar el switch, dar más poder y ellos le tienen terror al poder…	So there there's a really complex situation that doesn't allow, that doesn't give space for participation because to give space for participation means to change the 'switch,' give more power and they're terrified of power… (MINSAL staff member 7, Mapuche)

For this reason, this interviewee from MINSAL stressed the amount of effort and advocacy it has taken over decades and up to the current day to improve political support and frameworks for Indigenous community participation in health.

…o sea no son procesos de reformulación del estado y sus políticas sino que son movimientos territoriales o comunitarios que de alguna manera toman conciencia de que tienen que organizarse, de que tienen que hacer algo por su gente y yo creo que eso de alguna manera ha generado una presión que ha obligado al estado, a los ministerios, al servicio de salud a entregar recursos y abrir un poco la visión interna.	…that is, they're not processes of reforming the State and its policies, rather they're territorial or community movements that in some way become aware that they have to organise, they have to do something for their people and I think that that in some way has generated pressure which has forced the State, the Ministries, the health department, to give some resources and open their internal vision a bit. (MINSAL staff member 7, Mapuche)

Interviewees from BFIHC also made the point that it has only been through concentrated advocacy and pressure from the community that the Centre has been able to achieve the current level of support it has from the State. The following quote notes the importance of ongoing community advocacy in ensuring that the State continues to be held accountable.

Entonces, ya el hecho de tener un centro de salud más grande, donde se puedan dar todas las prestaciones de atención primaria, es lo – es donde hemos conseguido mayor apoyo, por parte del gobierno central. Y, en eso se está trabajando, pero es, es ahí donde los, los dirigentes, los representantes de las comunidades de la organización, han estado trabajando fuertemente, y presionando para que las promesas hechas, se cumplan.	So there's already in place to have a larger health centre, where all the primary health services will be provided, it's the—it's where we've gotten the most support, on the part of the central government. And in that it's working, but it's, it's there where the community leaders, the community representatives of the organisation have been working hard, and putting pressure to make sure that the promises made are kept. (Boroa staff member, non-Mapuche)

This advocacy was visualised as being part of the concept of community participation insofar as it aims to increase the power of Mapuche community organisations to act autonomously, respond to local needs, and push against the top-down imposition of planning frameworks. In addition to the example provided in the previous section, the following quote from the Director of Makewe Hospital illustrates the type of political engagement the Association undertakes.

De hecho…iba a hacer una travesía por Santiago, Valparaíso para ir a decirle nuestras falencias, para ir a decirle al ministro, a los políticos allá cuáles son nuestras necesidades y cuáles son las falencias del estado que no ha puesto los recursos aquí y voy a hacerla, estoy planificando…¿Por qué? Porque hay muchas cosas que el estado chileno no, no, porque en otros lados los tiene, ¿Por qué es este hospital no los tiene?, ¿Por qué somos mapuches? ¿Por qué hay una organización mapuche? Nos sentimos discriminados frente a otros hospitales, te lo digo de	In fact, for example…I was going to make a journey to Santiago, Valparaíso to go and tell them our needs, to go and tell the Ministry, the politicians there what are our necessities and the failures of the State that hasn't allocated resources here and I'm going to do it, I'm planning…Why? Because there are a lot of things that the Chilean State, no, no, because in other places they have it, why is it that this hospital doesn't have it? Because we're Mapuche? Because it's a Mapuche organisation? We feel discriminated against in relation to other hospitals, I'll tell you the truth…And we're working with more

verdad…Y está haciendo un trabajo con personas más vulnerables, debiera estar mejor pagado mi profesional que el otro profesional de por allá…	vulnerable people, my professionals should be paid better than professionals in other places… (Director of Makewe Hospital, President of the Association, Mapuche)

5.6 Discussion

In the time since the Mapuche Health Association of Makewe-Pelale took over administration of Makewe Hospital from the Anglican Church in 1998, there has been a sharp increase in health services controlled or administered by Mapuche organisations as well as intercultural health approaches.[6,295,296] There is also evidence of increased acceptance and support of Indigenous engagement in health in Chile (Section 5.2). Nevertheless, there continues to be sharp barriers to Indigenous engagement and participation. Legislative and policy barriers include an inability to formally recognise Indigenous health care providers as such and inadequate acknowledgement of the particular challenges they face in providing adequate care to their communities; contradictory legislation regarding Indigenous consultation and engagement; and inequitable funding arrangements that disallow discretion, flexibility and responsiveness in the delivery of Indigenous health services.

5.6.1 MINSAL perspectives on Mapuche community participation in health

The understanding of Mapuche community participation in health as articulated by MINSAL interviewees drew from both the utilitarian and democratic perspectives, as did the expected benefits. MINSAL interviewees thought of Mapuche community participation in health not only in terms of outcomes, such as community input into decision-making, but in terms of processes that fostered ongoing and broad dialogue, collaboration and inclusion at all levels of health policy-making. Appropriate recognition and validation from the State of traditional and current forms of Mapuche community structures were identified by Mapuche interviewees within MINSAL as being central to functional processes of Mapuche community participation in health, including genuine dialogue with State institutions and appropriate decision-making.

Benefits relating to the utilitarian model included more relevant and effective health programs and increased accountability on both the part of community organisations and State institutions. Reciprocal accountability was highlighted as ideally being both integral to and an outcome of Mapuche decision-making processes in health. MINSAL interviewees identified

empowerment of communities and more equitable power relations as potential benefits, drawing from the democratic perspective. Interviewees also spoke about possible risks or costs of participatory processes, including the time and resources necessary to participate, which may serve as a barrier for some in the community. On a broader scale, the risk of further reinforcement of power differentials between communities and the State through participatory processes was also mentioned. In particular, the imposition of inappropriate State bureaucracies, structures and requirements through community participation processes was identified as causing cultural changes that damaged communities and undermined Mapuche traditions, a trend which has previously been described in Mapuche health.[230]

There was a clear tension between the perspectives of individual MINSAL interviewees and what was seen as the Ministry's official institutional perspectives. For example, MINSAL staff members spoke about the issue of Mapuche participation as being explicitly political and encompassing not only health but all aspects of Mapuche community life, including control over their territorial lands, as well as connecting Mapuche political power and autonomy to health and wellbeing outcomes. However, while interviewees characterised Mapuche participation in holistic and political terms, MINSAL systems utilised participation in an instrumental way. Even where organisational processes were installed ostensibly to increase Indigenous input, such as PROMAP, the reality was contradictory in that program priorities were still defined by the Ministry. Community consultation was then undertaken in relation to these pre-defined priorities. Relatedly, whereas interviewees spoke positively about the prospect of community participation leading to shared priority-setting and decision-making, they also acknowledged the limits imposed by the institution's 'fear' of relinquishing control. Interviewees spoke about consultation processes that led to community disillusionment when the demands of Mapuche participants went unfulfilled. Such cases foster widespread reluctance to participate and rejection of participatory processes. Ultimately, each of these factors contribute to participatory programs (including the health centres) that are localised, have limited decision-making power and spheres of influence, and operate on the fringes of the wider system.

5.6.2 National and international frameworks for Indigenous community participation in health

Service providers largely saw the political and legislative landscape of Chile as a crucial limiting factor in the extent to which Mapuche communities were able to be situated within the

health care system. Interviewees spoke with frustration and resignation when describing the obstacles faced in attempting to navigate a system that was hierarchical, closed, and not designed for the reality of Mapuche needs either at the macro or micro level. A key way that the State was seen to curtail Mapuche community participation in health was through the number of institutional barriers to establishing and validating Indigenous governance structures. Administering Mapuche organisations had few avenues to provide systematic input within the broader health sector or engage in shared decision-making. There was therefore consistent agreement across the interviews with both MINSAL and health centre staff members that the failure of the Chilean State to facilitate Mapuche governance in health placed strong limitations on the extent to which community participation either influence policy or develop localised responses to community needs. The centralisation of the Chilean government compounds the issue, as health programs are determined at the national level, leaving little possibility of responding adequately to the particular local situations.

Chile's ratification of ILO 169 was a hard-won and long-outstanding victory for the country's Indigenous peoples. It represented an important milestone in their relationship with the State and the hope that State processes would, as a result, become more open and participatory. However, the lack of facilitative mechanisms and legislation at the national level and, moreover, the installation of contradictory legislation in the form of Supreme Decree 66, continue to form roadblocks to Indigenous community participation at all but local levels. As interpreted through DS N^{o} 66, the right to previous consultation outlined in ILO 169 is triggered only in relation to particular issues that have been determined to concern Indigenous peoples directly, without regards for the ways in which health policies and programs designed for the general public may have a disproportionate or unanticipated effect on Indigenous communities. In the case of Chile, international legislation without reflection at the national level is particularly unhelpful because of the ways the system is 'blind' to the needs of Indigenous communities generally—demonstrated, for example, by the lack of mechanisms to systematically collect health data for Indigenous people, or a policy of recognition of the social and cultural determinants of Indigenous peoples' health. That is, because the special needs of Indigenous peoples are largely unrecognised by the system, so are issues that affect them, and the legislation that regulates consultation and participation therefore does not come into play. Furthermore, in a study comparing the Indigenous health policies of Australia, Brazil, Chile and New Zealand, Chile was found to be the only country that did not have a national Indigenous health policy and no mechanism to allow for formal recognition of Indigenous

understandings of health in the formulation of policy.[297] This correlates with the perspectives expressed by interviewees, indicating that Chile has little formal recognition of Mapuche health needs and relatively unsystematic avenues for addressing them. Taken in conjunction, these points illustrate that international frameworks, despite their strategic importance, may not be sufficient to instigate substantiative change on their own, without national level legislation and policies to support them.

These arguments are not to discount the benefits that having a legislative framework regarding appropriate Indigenous community participation can provide. ILO 169 has been successfully used by Indigenous groups to challenge inappropriate development and resolve land use disputes when the respective State has not adhered to its obligations.[44] In Chile, ILO 169 has been utilised successfully by Indigenous peoples to take legal action when processes of prior consultation have not been adhered to.[174] Nevertheless, the limits of international legislation as outlined above indicate that alternative or additional tools are needed to support adequate and ongoing Indigenous community participation in health. Some of these tools include approaches to strengthen Indigenous health governance, explored in the following chapter. The development of a national Indigenous health policy would be an important step to formalise recognition of the importance of community participation, install participatory mechanisms and provide a demonstration of participatory processes in policy creation. This is further discussed in Chapter 9.

5.6.3 Indigenous community participation in health: Autonomy and advocacy

Indigenous governance and participation in health are underpinned by and intersect with rights to self-sovereignty, autonomy and health equity. These principles are therefore central to many of the underlying values of Indigenous-centred health care models, which include political and social equity and cultural strengthening and retention.[4,118,119,216] Similarly to community-controlled Indigenous health services worldwide, interviewees saw the role of the Mapuche Health Association of Makewe-Pelale, in part, as strengthening Mapuche self-determination and social, political and economic development through appropriate health service provision.[118,121,298] Taken as a whole, the interviews with staff of Makewe Hospital highlighted a dual discourse around community participation and the relationship between the Hospital and the State: interviewees expressed resentment regarding the responsibilisation of communities on the one hand and on the other, a desire to increase Mapuche autonomy through the assumption of roles that allow for engagement and representation within the Chilean State.

'Responsibilisation' refers to the process by which communities assume both the risks and responsibilities for functions in ways that reduce the scope of the government while continuing to maintain government control.[111,299] In this case, interviewees positioned Makewe Hospital as taking on the responsibility to fulfil the State's obligation to provide adequate health care to all citizens, as enshrined in the Chilean constitution[218]—but with inadequate financial resources and support structures. While Makewe Hospital has been considered a success for its level of community autonomy and governance and retention of Mapuche healing and cultural knowledge, the model is underpinned by a context of low resources, including a lack of biomedical care for Mapuche communities, ostensibly the responsibility of the Chilean government. The state's in-principle support for intercultural health systems is therefore perceived as superficially validating Mapuche culture and knowledge on the one hand while justifying lower levels of financing on the other.[220]

With regards to community participation in health generally, funding arrangements strongly influence the extent to which communities are capable of meaningfully setting priorities that align with their needs. Taylor (2007) discusses the ways in which government funding shapes the spaces within which community participation is allowed to take place, with funding attached to specific purposes causing community organisations to either align their work with centrally-determined priorities and objectives or struggle to undertake any work at all in the absence of needed resources.[111] Organisations may restructure themselves to better comply with State demands in order to demonstrate their legitimacy, shifting their focus from the needs of the community they are initially established to serve.[111] This dynamic, examined through the lens of governmentality theory (see Section 2.2.2.1), highlights the ways processes of community participation serve as mechanisms to enact State power, even as communities are more closely engaged in providing services and implementing projects.[111]

For Indigenous health organisations, this has particular implications, as mechanisms to ensure accountability in the use of State funding may impinge on the ability of Indigenous organisations and communities to develop autonomy and realise the objective of self-determination.[154,300] In addition to mechanisms to ensure financial accountability, Mapuche service providers spoke of being under higher scrutiny than their non-Indigenous counterparts. They saw the level of surveillance undertaken by the State as a measure of distrust that Mapuche communities had the capability to successfully manage health care services, despite the available evidence to the contrary. In the case of BFIHC, there was an additional stressor

of repeatedly having to prove the validity of traditional health services and the effectiveness of the intercultural health model.

As mentioned in Section 2.3.3.1, in Chile the language of Indigenous community in health is largely centred around the concept of intercultural health. In critiquing the processes of Mapuche community participation, Cuyul (2008) speaks about the 'bureaucratisation' of intercultural health, whereby the Mapuche administrators of intercultural health centres act simply as an extension of the Chilean State, implementing those programs and services that have been developed centrally.[65] Cuyul uses the examples of Makewe Hospital and BFIHC to illustrate that while the official discourse centres around intercultural health and strengthening Mapuche values in health, the financial support of these institutions is purely tied to standards regarding service provision developed and imposed by MINSAL, rather than any sort of health promotion, systematic health data collection, or action to address social determinants of health.[65] Both Cuyul (2008, 2013) and Boccara (2007) see this as a particular threat to both Mapuche autonomy and the maintenance of Mapuche medicine.[65,154,301] In the case of BFIHC and other models where the State finances traditional Mapuche health services, it is the State that determines the assigned monetary value for such services and the means by which accountability for service provision is demonstrated. In this way, through processes established to strengthen Mapuche medicine and community control in health, the State begins to shape and distort the traditional system, a process Boccara refers to as 'ethnogovernmentality.'[301]

The experiences of Makewe Hospital and BFIHC are in line with literature indicating that historically, Indigenous organisations and communities have borne the brunt of accountability in terms of being expected to justify funding received by their respective governments in the form of onerous reporting requirements and other mechanisms to demonstrate legitimacy.[302] As has been seen, this has the effect of reducing community capability to respond to local needs and the maintenance of State control over resource allocation, as funding obligations are tied to those priorities determined by the State. The tension between autonomy from and dependence on the State in the area of Indigenous health reflects the contradictory nature of participatory forms of governance more generally.[111]

In response to these tensions, the Association strives to influence broader policy both within and outside of the health care sector to further Mapuche development. In particular, the need to position Mapuche communities and organisations as active participants in policy- and decision-making processes was a primary motivating factor as articulated by staff interviewees. BFIHC interviewees spoke about the ongoing advocacy undertaken not only by the Centre

itself but by the wider community in order to ensure that while the Centre demonstrated accountability to the State, the State was also held accountable for keeping its promises. In these ways, political advocacy at multiple levels and in various forms was incorporated into processes of community participation as a way to reorient institutional frameworks towards Mapuche perspectives and demands and disrupt inequitable power relations between communities and the State. Cuyul (2008) also makes this point more broadly in stating that the advances that have been made in Mapuche health in Chile over the past years have been, at their base, the product of community mobilisation to force political change.[65] In view of the assertion from MINSAL interviewees that support for Indigenous community participation is largely dependent on individuals within State agencies, the advocacy undertaken by the health centres can be seen as a push for the institutionalisation of participatory polices.

Within Indigenous health, the principle of reciprocal accountability has been introduced as a way to enhance Indigenous participation, control and engagement.[125,303] Under the terms of reciprocal accountability, each party has clearly delineated roles to play in achieving health goals.[125] In Canada, this has taken the form of British Columbia's Tripartite Agreement, which was introduced in Section 2.2.3.1. In Australia, there have been calls for funding mechanisms in the Aboriginal community-controlled health sector to utilise a circular rather than linear understanding of accountability—that is, a model of accountability that acknowledges the responsibilities of all stakeholders to each other.[303] Both these approaches utilise reciprocal accountability in the development of forms of Indigenous health governance that allow for more equitable power relations between Indigenous communities and the State. The next chapter will examine this theme in more detail.

5.7 Conclusions

This chapter outlined the political and legislative landscape of Chile with respect to facilitating or obstructing Indigenous community participation in health. The last few decades have seen growing political support and discourse around Indigenous community participation in health in Chile. This has taken the form of increasing adoption of intercultural health approaches and establishment of health services administered by Indigenous governance structures.

However, the centralised nature of Chilean health policy, decision-making and priority-setting restricts the extent to which Indigenous service providers can respond to the health needs of local communities and undermines the values of autonomy and self-determination that underpin these organisations. In response to these tensions and as a way to increase their

political power, respond to determinants of health that lie outside the health sector and ensure their ability to have input into policies that affect them, Mapuche service providers saw advocacy as part of their core business. The cases of Makewe Hospital and Boroa Filulawen Intercultural Health Centre thereby exemplify one of the central criticisms towards community participation—that is, its potential to be used as a mechanism to entrench inequitable patterns of power, even as communities are more engaged in the delivery of programs and services.

Effective Indigenous health governance has been positioned as essential to reforming inequitable power imbalances between Indigenous communities and the State in decision-making processes. Having explored the policy and legislative environment of Chile, the next chapter will go on to examine the how the health care centres manage their unique position between their respective communities and their wider political, social and cultural context. The next chapter draws on ideas of 'community' presented in Chapter 4, as well as the policy and legislative structures expounded upon in the current chapter, in order to explore how Indigenous health governance is operationalised.

Chapter 6. Indigenous health governance structures

While there is no single accepted definition of governance,[304] it may be considered simply as 'the process of decision-making and the process by which decisions are implemented (or not implemented).'[305] 'Governance' is a broader concept than 'government,' in that it denotes a complex web of interactions between a wider range of stakeholders, including civil society, non-governmental organisations and the private sector.[306] Indigenous health governance therefore refers to the decision-making and subsequent implementation processes which impact on Indigenous health and wellbeing.[307]

The United Nations recognises governance and human rights as mutually reinforcing,[308] and the relationship between the concepts is apparent in the context of Indigenous health. Indigenous governance is central to self-determination, as it allows Indigenous peoples to assume shared power and responsibility in the design, development and implementation of programs, including determining allocation of resources. This helps to ensure that approaches to support Indigenous health adhere to Indigenous priorities and values.[309,310] In this way, effective Indigenous health governance is a key aspect of Indigenous community participation in that it forms the mechanisms that allow Indigenous people to have a role in decision-making.

Indigenous health governance operates at multiple levels, and the forms governance takes are determined by interactions between social, political and cultural elements. At the local level, governance may involve Indigenous communities developing or administering a local health service. At the regional and national levels, Indigenous health governance may include consultation processes, the involvement of Indigenous organisations and communities in shaping policy or legislation, or the formation of networks between Indigenous and non-Indigenous service providers.

This chapter addresses the second research aim in describing the Indigenous health governance structures developed in order to navigate the interface between the political and legislative environment that is the subject of the previous chapter and the social world of the Boroa Filulawen and Makewe communities explored in Chapter 4. These governance mechanisms are heavily shaped by the relationships between the health centres and their communities, presented in the following chapter.

6.1 Governance at the local level

Under Law 16.880 of 1968, the Chilean government recognises two types of community organisations: territorial and functional. Territorial organisations are described as consisting of neighbours who come together to advocate on their own behalf and collaborate with government entities. Functional organisations, such as cultural and artistic centres, youth groups and sports organisations, are not for profit and are formed with the goal of bringing together individuals who have shared interests or characteristics, in order to promote specific values. Similarly to the Indigenous communities inscribed under the CONADI system, the law establishes that these organisations must be assigned a *personalidad jurídica* and registered in a public, national database in order to be recognised as legal entities, receive funds and interact with the government. In order to be registered as a *personalidad jurídica*, an organisation must comply with various requirements, including the election of internal positions including an organisation president, vice president, secretary and treasurer, each of which have specified roles.[311,312]

The Mapuche Health Association of Makewe-Pelale, as an organisation, needs to both represent the interests of the relevant community and administer the Hospital, which includes negotiation with the State, receiving and dispensing of funds and developing and implementing relevant programs. These activities required the Association to establish a *personalidad jurídica* in order to be 'visible' to the State. However, while the Association has a formal structure that is dictated by the State, it is also governed by Mapuche cultural ties and traditions. The below quote illustrates how the traditional and functional are intertwined in how the Association is organised and operates.

De la asociación, bueno, eso está normado por ley, aunque parezca irrisorio un poco porque es contradictorio, ellos al momento de hacerse la asociación indígena ellos establecen estatutos que era uno de los requisitos básicos para poder establecer una PJ, una personalidad jurídica .... Entonces los estatutos definen la forma en que serán dirigidos los presidentes, los vice presidentes, tesoreros y secretarios, como toda organización indígena. .... Ahora si	About the Association, well, the norms are established by law, but it seems a bit laughable because it's contradictory, at the time of creating the Indigenous Association they established statutes which was one of the basic requirements to establish a PJ, a *personalidad jurídica* …So the statutes define the way the presidents, vice presidents, treasurers and secretaries will be managed, all as an Indigenous organisation. ….Now, even though the statutes are

bien tiene estatutos que están regidos por esa ley igual la forma interna es muy mapuche, ¿ya?, es muy mapuche porque en cierta medida tiene que ver con las características de la persona, el tuwun*, que es la descendencia, de donde viene, de qué territorio representa, tiene que ver con esas cosas y aunque cualquiera pudiera esperar, participar o postularse a presidente influyen mucho las características mapuches o culturales de la forma de elección, ¿ya?*	demanded by law the internal process is very Mapuche, right? It's very Mapuche because to a certain extent it has to do with the characteristics of the person, the *tuwun*, which is the ancestry, where they're from, what territory they represent, it has to do with these things and although anyone can hope, participate or apply to be president, the election is influenced a lot by Mapuche characteristics and culture, right? (Makewe staff member, Mapuche)

The governance structure of Boroa Filulawen Intercultural Health Centre stems from the way the territory as a whole organises itself. Within Boroa Filulawen territory, the Territorial Organisation (TO) is the main way that territorial issues are communicated, raised, discussed, and resolved. TO meetings are held on the first Wednesday of every month in the *ruka* (traditional building) of BFIHC. The TO has four main 'themes,' each of which has its own Committee; however, any topic of interest may be raised at the meetings. The main themes are:

- Agricultural productivity
- Health
- Education
- Environment

There are often visitors to the meetings, including representatives from various State institutions, who come to speak on a variety of subjects of interest to the territory. Representatives from BFIHC regularly attended these meetings and present, when necessary, on issues involving the Centre.

The TO is closely tied to the CONADI system of recognition of Mapuche communities referenced in Section 2.3.1.2. It is these State-recognised community representatives, in addition to other community leaders, who form the TO. The TO itself also has a *personalidad jurídica* and is chaired by the TO president.

Porque ellos tienen una directiva que se compone de presidente, vice-presidente, secretaria, tesorero; eso es lo que le exige el Estado a uno, porque todas las comunidades tienen personalidades jurídicas, y el Estado le exige que para poder representar, para poder conseguir proyectos, tiene que estar en esa manera.	Because they have a directorate made up of the president, vice-president, secretary, treasurer; that's what the State demands of each, because all the communities have *personalidades jurídicas,* and the State demands that in order to be represented, to be able to receive projects, they have to have this. (Boroa staff member, Mapuche)

There is an expectation that those who attend the meetings, mainly the community presidents, bring forth any issues or concerns raised by their communities and report back to their communities regarding the discussions held and any resolutions made.

Y cuando se forma un territorio acá en Boroa, están reunidos todos los presidentes de cada comunidad, porque es difícil que vengan todos de cada comunidad…. Y ellos llevan toda una información a sus comunidades. Pero es el que manda en su comunidad, es representante....Por eso vienen ellos a participar en las reuniones, y a presentar alguna propuesta, algunas cositas que hay que hacer…. Por eso vienen los presidentes, porque si él tiene alguna necesidad en su comunidad, lo plantea en la reunión territorial que se hacen todos los meses, y de ahí nosotros negociamos, y de ahí tengo que ir a hablar con la autoridad que nos pueda solucionar el problema. Pero eso – ellos son los encargados de traer esos problemas a la reunión general.	And when a territory is formed here in Boroa, all the presidents of each community meet, because it's difficult for everyone from each community to come…. And they bring information to their communities. But it's the one who is in charge in the community, who's the representative…That's why they come to participate in the meetings, to present a proposal, some things that have to be done… That's why the presidents come, because if he has some need in his community, he can bring it up in the territorial meeting that's held every month, and from there we negotiate and from there I have to go to talk with the authority that can help us solve the problem. But that—they're the ones in charge of bringing those problems to the general meeting. (Boroa staff member, Mapuche)

It was made clear by the Organisation president that there remains a distinction between the Territorial Organisation and the traditional authorities. However, this was seen as a strength—that there was a clarity of roles.

Pero cada uno tiene su especialidad. Los longkos *se dedican todo lo que es cultural. Yo como presidente, me dedico todo lo que es organizacional. Hay tantas cosas que hacer dentro del territorio. Me han dado los caminos, el sistema productivo, el medio ambiente .... [los* longkos*] tienen que ver en todo lo que es cultural, todo lo que es la cultura mapuche; esa es su misión del* longko. *Nosotros somos funcionarios, somos dirigentes que hacemos de todo, y apoyamos; todas las comunidades que están organizadas es que se apoyan. Igual las* machi*, y los* longkos *dicen – son uno solo allí, está todo metido en todo el tema cultural, el tema mapuche.*	But each one has their specialty. The *longkos* dedicate themselves to that which is cultural. Myself as president, I'm dedicated to the parts that are organisational. There are a lot of things to be done within the territory. I've been given the roads, the production system, the environment….[the *longkos*] have to do everything that is cultural, that has to do with Mapuche culture; that is the *longko*'s mission. We're functionaries, we're community leaders that do everything, and we provide support; we support all the communities that are organised. Same with the *machi*, and the *longkos* say—there's just one there, he's involved in everything to do with culture, with the Mapuche. (Boroa staff member, Mapuche)

However, tied up within State-imposed community structures is an underlying purpose behind the TO, which is based firmly in Mapuche concepts of territory.

Esto es un territorio donde están todas las comunidades aquí unidas, juntas; y en estas reuniones territoriales vienen los presidentes de cada comunidad a hacer sus propuestas y qué es lo que quieren, qué vamos a hacer; eso, eso es un territorio.	This is a territory where all the communities are here united, together; and in these territorial meetings the presidents of each community come to put forth their proposals and what they want, what we're going to do; that, that's a territory. (Boroa staff member, Mapuche)

Boroa Filulawen interviewees were conscious of the issue of representativity and aware that the structure of the TO has in the past been interpreted to represent only the views of the attending members—the presidents and community leaders—rather than a true reflection of the needs of the community as a whole. However, this community leader asserts that past evidence has shown that the TO is an accurate representation of the wider communities and that the leaders are careful to listen to the opinions expressed by the people.

Y yo creo que cuando una organización hace bien las cosas y las comunidades lo respaldan por medio de toda su gente de base, yo creo que las cosas se dan; el Estado siempre ve si esa organización o esas comunidades están en todo de acuerdo y trabajan para todo para el mismo objetivo y entonces yo creo que ahí empiezan a creer de que sí esto va a dar resultado y que no es cosa de los puros dirigentes, porque anteriormente también se decía que, 'No, si son opiniones de los dirigentes. No, si los dirigentes son los que dicen pero la opinión de las bases son otras. No dicen lo mismo.' Incluso han llegado a las comunidades y de repente por ahí hacen algunas encuestas preguntando a la gente si están de acuerdo con lo que se está haciendo, lo que está planteando el dirigente, si son palabras del dirigente o son de la base. Y en eso hemos tenido mucho cuidado igual porque igual también hay gente que de repente en las comunidades también capaz por no explicar bien las cosas se puede contradecir y aparece después como si las comunidades no tienen la necesidad y que son gente de algunas personas nada más que opinan y que	And I believe that when an organisation does well and the communities support it through all the people at the base, I think that these things are given; the State always sees if this organisation or these communities are all in agreement and work towards the same objective and I think that there they're beginning to believe that yes, this is going to be successful and that it's not just something for the community leaders, because before they would say, 'No, if this is the community leaders' opinions. No, if the community leaders are the ones that speak but the people have different opinions. They don't say the same thing.' They've even come into the communities and do surveys asking the people if they agree with what they're doing, with what the community leader is proposing, if the words of the community leaders are that of the base. And we're also been careful as well because at the same time there are also people in the communities who aren't able to explain things well and they can contradict themselves and it seems afterwards as if the communities don't have this need and it's only some people that have this opinion. And so we're always listening,

tienen esa propia opinión. Y eso lo estamos escuchando nosotros, siempre hemos escuchado eso.	we've always been listening. (Boroa staff member, Mapuche)

The Intercultural Health Committee of Boroa Filulawen was inscribed as a functional organisation with its own *personalidad jurídica* in 2001. Due to the lack of any official recognition of traditional community structure, a separate organisation needed to be formed to interact with the State. In speaking with the current directors of the Centre, it was made clear that there is a strong distinction between the Committee and the wider Territorial Organisation. The Committee is a small entity formed solely in order to interact with and receive funds from the State and manage the Centre and has no ancestral basis. For this reason, the Directors indicated that the Committee is the 'least participatory' part of the organisational structure and that furthermore, the people of the territory know little of the Committee and speak specifically about the Organisation.

While it was unclear how the Committee members and directors of the Centre were selected, multiple BFIHC interviewees indicated that having directors that came from the community and had support from the wider community lent the Committee validity in terms of their ability to accurately represent and respond to local needs.

Que son las comunidades que tienen sus representantes, sus dirigentes trabajando en las mesas en las reuniones, y que le dan validez a los, a los administradores del centro de salud. O sea, ellos están ahí, porque la comunidad los puso ahí. No es porque ellos hayan sido, y ellos hayan hecho campaña, se hayan postulado, no. La misma comuni… Salieron de la misma comunidad, y esa misma comunidad es la que le da el respaldo.	It's that the communities that have their representatives, their leaders at the roundtable meetings, that gives validity to the administrators of the health centre. It's that they're there, because the community put them there. Not because they've done it, that they've launched a campaign, they've applied, no. The community itself…they came from the same community, and it's the same community that gives them support. (Boroa staff member, non-Mapuche)

The intertwinement of Mapuche and Western ways of governing was also apparent in the internal operation of Makewe Hospital. In the next quote, the Medical Director of the Hospital,

who is not Mapuche, describes this role in the organisation as an advisor on technical matters, while the Association has final say. This limits the decision-making powers that the Medical Director position would hold in another institution in favour of the Mapuche administrators within the Hospital.

Un servicio de salud en hospital o consultorio en cualquier otro lugar, el director tiene más potestades, más facultades para hacer más cosas….. El organigrama, eso está en todas las instituciones, en todas. Y en el nuestro, la asociación mapuche está en la parte superior del organigrama. Eso da a entender que ellos están en – son finalmente los que deciden de cierto, nosotros después baja la dirección médica o técnica… si bien es cierto tienen el título de dirección, pero es más bien un asesor en salud más que todo eso.	A health service in a hospital or clinic anywhere else, the director has more power, more capacity to do more things….the organisational diagram, it's in all institutions, all of them. And in ours, the Mapuche Association is in the top part of the diagram. So in this way we understand that they are—in the end, they're the ones that make the final decision, those of us under in medical or technical director roles….although true, they have the director title, but it's more like a health consultant than anything else. (Makewe staff member, non-Mapuche)

Another participant, a member of the Association, indicates that the Association is seen as the political authority, whose role it is to form links to external bodies or entities, but internal technical decisions are made jointly with the relevant directors.

Nosotros generalmente tomamos más … las decisiones políticas, tanto del hospital, del rol y del funcionamiento y cómo se relaciona con la autoridad. Y la parte técnica, bueno, eso lo ven los técnicos nada más, que en conjunto nos reunimos y ahí tomamos decisiones, referente a la parte técnica.	We generally make more…the political decisions, as far as the hospital, the role and its function and how it relates to State authorities. And the technical parts, well, that has just to do with the technical staff, we meet together with them and there we make decisions with regards to the technical part. (Makewe staff member, Member of the Association, Mapuche)

The Medical Director goes on to speak about the ways that Mapuche cultural norms influence decision-making processes.

Ahora, ellos internamente como organización tienen sus códigos y su manera de entenderse, que en esa parte yo no tengo o no me meto por cierto. Yo como dije hace un rato, soy respetuoso de los procesos que ellos viven porque ellos usan una lógica cultural que no es la mía. Entonces en ese contexto yo puedo estar de acuerdo o en desacuerdo pero yo ahí no tengo opinión. Pero sí puedo decir lo que he visto en estas dos décadas, puedo decir que esa es la manera como ellos han funcionado, en muchas cosas les ha dado resultado y han salido exitosos en cosas importantes…	Now, internally as an organisation they have their norms and their way of understanding each other, in that part I definitely don't get involved. As I said before, I'm respectful towards the processes that they live because they use a cultural logic that isn't the same as mine. So in that context I can agree or disagree but there I don't have an opinion. But I can say that I've seen in these two decades, I can say that in that way that they work, a lot of things have come to fruition and have been successful in important ways … (Makewe staff member, non-Mapuche)

Each of these elements, from the selection of Association members to the way internal affairs are conducted, illustrates the multiple roles of the organisation. Staff interviewees saw the Association as the pathway by which community interests and needs are represented within the Hospital while fulfilling its basic duty to comply with the technical and service functions outlined in its contracts with the Health Department. In the course of undertaking these obligations, the Association was, at the same time, held up as a way of strengthening the standing of the Mapuche people in terms of political power more generally, as reflected in the following quote.

…Creo que de la forma en que el pueblo Mapuche pueda salir adelante y pueda tener una representatividad es creando instituciones que puedan decidir dentro de su territorio y eso es lo que está haciendo la asociación Mapuche….	…I believe that the way the Mapuche people can move forward and have representation is through creating institutions that can decide within their territory and that's what the Mapuche

	Association is doing… (Makewe staff member, Mapuche)

From the point of view of some interviewees from MINSAL, the disjuncture in the way the State conceptualises Mapuche communities and the way communities organise themselves in reality has profound implications for relationships between Mapuche communities and the State and hence for Mapuche community participation in health. As the State can only officially recognise and interact with organisations that fit into quite narrow and restrictive forms, there is limited latitude for communities to be recognised as complex social entities, or for the reflection of traditional social structures. Multiple MINSAL interviewees spoke about how these restrictions led to the construction of organisations that fit into the requirements of the occidental system while subsuming the underpinning traditional social structures.

Lo que pasa es que a veces el sector occidental, o el mundo occidental no la ve, e impone su propia estructura, y la estructura que pone el mundo occidental es funcional a su sistema. Entonces dice: 'En esta comunidad vamos a trabajar y nos vamos a constituir con presidente, secretario y tesorero,' ¿por qué? Porque el presidente va a llevar la interlocución para el sistema de ellos; el secretario le va a tomar los registros, se los va a mostrar; y el tesorero va a llevar todo el tema administrativo; pero de alguna manera invisibiliza a esta otra gran estructura organizacional que tiene para distintas instancias en la comunidad. Pero donde uno vaya, la estructura tradicional mapuche está; solo hay que mirarla, hay que reconocerla, hay que valorarla.	What happens is that in the Western sector, or in the Western world they don't see, and they impose their own structure, and the structure that the Western world puts is a function of its system. So they say: 'We're going to work in this community and we're going to bring together a president, secretary and treasurer.' Why? Because the president carries out the speaking for their system; the secretary will take the registration to be able to show it; and the treasurer will carry out all the administrative tasks. But in this way they render invisible this other huge organisational structure that they have for different procedures in the community. But wherever one goes, the traditional Mapuche system is there; one only has to look for it, to recognise it, to valorise it. (MINSAL staff member 2, Mapuche)

Es decir, nosotros pueblo – el Estado es el que dijo que esta es la forma, esta es la forma de que usted puede acceder o no acceder a ciertos recursos o a ciertos beneficios; entonces, la tabla rasa la está dando es del Estado. Entonces, ¿cómo hacen las organizaciones para estar en los asuntos del Estado? ...Hoy día los indígenas son expertos en burocracia, el elemento burocrático que nosotros inventamos como Estado, pero no son la burocracia propia de los pueblos.	That is to say, us as people—it's the State that says this is the form, this is the form by which you can access or not access certain resources or certain benefits; so, the blank slate that's given is the State's. So, what do the organisations do in order to be involved in the matters of the State? …Today, Indigenous people are experts in bureaucracy, the bureaucratic element that we invent as a State, but it's not the bureaucracy of the people. (MINSAL staff member 5, Mapuche)

One interviewee stated that the imposition of bureaucratic and hierarchical structures denied the way Mapuche communities organised and governed themselves, rejected strengths and capabilities originating from the community, and made it impossible to negotiate ways of working and making decisions that was in line with Mapuche culture.

Entonces, lo que está pasando ahora es que el sistema invade y pone la jerarquía. Entonces, yo jefe ordeno, yo jefe decido; pero es una actitud meramente occidental; entonces, no reconozco al otro que también tiene capacidad, que también tiene oportunidad, y no lo dejo ser; y nuestra esencia como mapuche es formarnos como personas; mientras más sabemos, más humilde. Y este otro sistema como que tienta, porque lo tienta económicamente, lo tienta en el poder, le pone muchos cebos que lo atraen, ¿no?	So what's happening now is that the system invades and imposes its hierarchy. So I as the boss order, I as the boss decide; but it's simply a Western attitude; So I don't recognise that the other also has capacity, that the other also has opportunity, and I don't allow them to be; and our essence as Mapuche is to create ourselves as people; as we know more, we become more humble. And this other system it tempts, because it tempts economically, it tempts in terms of power, it puts out a lot of attractive bait, right? (MINSAL staff member 2, Mapuche)

6.2 Interorganisational governance

In the previous chapter, a Makewe Hospital administrator recounts the experience of joining with other Mapuche health providers to advocate with the Ministry of Health regarding the requirement for a financial guarantee. The same staff member explains:

Y en ese tiempo los pude reunir a los directivos de Boroa Filulawen…de Newentuleaiñ de Nueva Imperial y vinieron gente de Araucanía Norte también que se unieron al problema que estaba pasando, …y hicimos…una reunión al estilo mapuche en la ruka*, donde se analizó la problemática. Producto de la analysis, se acordó de poder ir a Santiago …a demandar esto…*	And in that time I was able to bring together the directors of Boroa Filulawen, of Newentuleaiñ from Nueva Imperial, and people from Araucanía Norte that were brought together by the problem that was happening…and we made…a meeting in the Mapuche style in the *ruka*, where we analysed the problem. As a result of the analysis, it was decided to go to Santiago…to demand that… (Makewe staff member, Member of the Association, Mapuche)

Here it can be seen that governance took place not only at the level of individual centres, but also between centres, in order to address issues of relevance to all Mapuche health centres in the region. Governance at this level was tied to attempts to form a stronger coalition between Mapuche health service providers through the Autonomous Mapuche Health Roundtable, whose members included representatives from Mapuche health centres across Araucanía Sur. Interviewees from Makewe Hospital and MINSAL saw the Roundtable as an important tool in raising the visibility of Mapuche organisations, and membership continues to expand with the number of intercultural health centres being developed. However, Makewe Hospital interviewees indicated that while the Roundtable continues to be active, it is mainly reactive, rather than proactive, coming together in response to a threat or a problem that needs to be solved.

…también con autocrítica, que la mesa ha sido muy reaccionaria, o sea, solamente cuando ha habido un problema reaccionan….	…also to self-criticise, the Roundtable has been very reactive, that is, only when there's been a problem they react…. (Makewe staff member, Member of the Association, Mapuche)
Por otro lado nosotros desde el punto de vista de organizaciones paralelas, o sea otras instituciones de salud del pueblo Mapuche sí hemos tenido alianzas pero alianzas igual así como esporádicas porque igual hay una mesa de auto convocado, autónoma de salud pero que siempre reaccionamos cuando estamos en peligro, o sea no hay una cosa sistemática, no hay una cosa pautada en cual se pueda decir 'nosotros estamos trabajando sobre este tema en particular.'	On the other hand from the point of view of parallel organisations, or other Mapuche health institutions, yes, we've had alliances but alliances that have been sporadic because while there's a Roundtable that we've convened, Health Autonomy, but it's that we always react when we're in danger, that is to say there's not a systematic thing, there's no guide within which one can say 'We're going to work on this topic in particular.' (Makewe staff member, Member of the Association, Mapuche)

Participants did not speak directly about the reasons the Roundtable has tended to be more reactive than proactive. However, it seems likely to relate to the pressures alluded to in Section 5.5.1, as meeting basic contractual obligations while facing ongoing financial insecurity and unpredictability imposed severe constraints on the ability of Makewe staff to plan strategically and proactively.

The reactive nature of the Roundtable may also be related to the strongly autonomous and independent nature of each of the territories, which was mentioned by several interviewees. As covered in Section 2.3.1.1, historically, Mapuche territories each have their own way of managing their affairs and do not interfere with the internal affairs of other territories. This may imply some level of difficulty in forming a coherent and collaborative partnership across multiple Mapuche territories.

Y por otro lado está el pueblo Mapuche, somos nosotros y en definitiva nuestra historia siempre ha dicho que somos independientes, autónomos , incluso de nosotros mismos, o sea por ejemplo, como te decía anteriormente, nosotros no tenemos una estructura piramidal, o sea una estructura donde haya un longko *mayor así que establece que ese es el que manda más y que después viene otro y que manda así en su territorio y después que viene otro y que manda una población o una comunidad, sino que más bien somos de carácter horizontal, o sea cada territorio tiene su propia forma de vida y formas de salud, formas de economía y eso es lo que nos hace particulares…..*	And on the other hand is the Mapuche people, we are and definitely our history has always said that we're independent, autonomous, even within ourselves, that is to say for example, as I told you before, we don't have a pyramidal structure, or a structure where there's a head that establishes that he's in charge of everything and after comes another that's in charge of his territory and after comes another that's in charge of a population or community, instead we have a more horizontal structure, that is each territory has its own way of living and forms of health, forms of economy and that's what makes us particular….. (Makewe staff member, Mapuche)
….nosotros antes tenemos dirigentes de comunidades, cada cual tiene su estructura y la comunidad tiene una estructura de cuatro o cinco dirigentes y son autónomos, todas las comunidades son autónomas, ninguna la dirige la otra…. Todas las instituciones Mapuche son autónomas, su territorio. Un ejemplo, yo no puedo darle orden a Boroa como territorio, y si lo hago me recriminan. Ellos tampoco a nosotros, Imperial lo mismo, y las comunidades es exactamente igual, ninguna comunidad le da orden a la otra comunidad, hay respeto. Todas son autónomas, así funciona.	….before we had our community leaders, each one has its structure and the community has a structure of four or five leaders and they're autonomous, all the communities are autonomous, none commands the other…All the Mapuche institutions are autonomous, their territory. One example, I can't go give orders to Boroa as a territory, and if I do they'll denounce me. They can't do it to us either, Imperial the same, and the communities are exactly the same, no community can command another community, there's respect. They're all autonomous, that's how it works. (Makewe staff member, Member of the Association, Mapuche)

Multiple MINSAL interviewees mentioned the importance of having structured spaces that allowed for discussion, planning and evaluation across different organisations involved in Mapuche health. In particular, interviewees identified the Mapuche Health Network as being key for developing dialogue and functioning working relationships between the Mapuche health organisations and State institutions that were each members.

Nosotros, desde la Seremi Salud, tenemos una participación permanente ya desde el 2000, lleva 15 años, una mesa de salud intercultural. ¿Quién incorpora esa mesa? Todas las organizaciones que trabajan en salud, y ahí está Makewe y Boroa digamos, representado en esta mesa; Imperial, está Saavedra, y también de Malleco; y esa mesa, de alguna manera, recoge como las necesidades anuales para ejecutar su trabajo. Entonces, nosotros hacemos una planificación anual para irle dando curso durante ese tiempo. Y finalmente, también hacemos una evaluación para ver qué se cumplió, qué no, y por qué no se cumplió.	From the SEREMI of Health (Secretarías Regionales Ministeriales de Salud, Regional Secretaries of the Health Ministry), we have had a permanent seat since 2000, 15 years now, on an intercultural health roundtable. Who makes up this roundtable? All the organisations that work in health, and there's Makewe and Boroa represented on the roundtable; Imperial, there's Saavedra, and Malleco as well; and that roundtable, in some way, brings together all the annual necessities to carry out its work. So we create an annual plan to provide a guide for this time. And finally, we also undertake an evaluation to see what was accomplished, what wasn't, and why not. (MINSAL staff member 2, Mapuche)
Yo diría la Red de Salud Mapuche. Que es un espacio, digamos, que ha logrado irse validando cada vez más, hacia el Estado, en relación a una articulación. Entre distintos territorios y distintas dependencias de diálogo, y de participación en el Estado, digamos, o con el Estado, de diálogo político, de cómo creer, de cómo hay que ir orientando, ¿no es cierto?	I would say the Mapuche Health Network, which is a space that has managed to be increasingly validated by the State in terms of articulation. Between different territories and different branches of dialogue, and participation in the State, or with the State, political dialogue, how to believe, how it should be oriented, right? (MINSAL staff member 4, non-Mapuche)

At the same time, however, this same interviewee goes on to indicate that as important as it is, there have been few concrete outcomes from this network.

Hay experiencias insipientes, que están desarrollándose y que están en proceso. Pero, yo creo que esa te… Esa, esa forma de articulación es una – un ejemplo, un claro ejemplo, cómo puede incidir ante el estado… Esta red de experiencia, qué bueno, es que, digamos, creo que esa es un poco … el camino.	They're incipient experiences, which are being developed and they're in progress. But I believe that that…that form of articulation is a—a good example, a clear example, how to be able to influence the State…This network of experience, it's good, it's let's say, I believe that that is a bit…it's the way forward. (MINSAL staff member 4, non-Mapuche)

The health centres were also active in building networks with entities outside the health sector, including governmental and non-governmental and Mapuche and non-Mapuche organisations. The membership of the Mapuche Children's Roundtable (*Mesa por la Infancia Mapuche*) consists of the Human Rights Institute (*Instituto de Derechos Humanos*, INDH), Makewe Hospital, the Indigenous Institute Foundation (*Fundación Instituto Indígena*, FII), the National Service of Minors Araucanía (*Servicio Nacional de Menores*, SENAME) and the Regional Public Criminal Defense (*Defensoría Penal Pública Regional*) with technical assistance from the United Nations Children's Fund (UNICEF). The Roundtable aims to protect the rights of Mapuche children and adolescents through intersectoral and institutional collaboration.[313,314] Makewe Hospital's role in the Roundtable was particularly critical given the intersection between children's rights and vulnerabilities and the process of land recuperation and struggle for autonomy that is being undertaken within the surrounding communities and territories. For example, the State militarisation of Mapuche communities who are seeking to reclaim their land (mentioned previously in Section 2.3.2) has been noted as having a severe impact on the physical and mental health of children and young people as they are caught in the conflict.[315] As a member of the Mapuche Children's Roundtable, Makewe Hospital was seen to some extent as a representative on behalf of the community. The role of the Hospital as a member of the Roundtable therefore also demonstrates one of the ways the Hospital strives to be responsive to those issues impacting on health that originate outside of the health sector.

Y también la asociación tiene un rol externo que tiene que ver en primer lugar con el desarrollo de todo el territorio de Makewe y que se escapa inclusive a las áreas netamente de salud—aunque para el mapuche todo es salud.	And the Association also has an external role that has to do with in the first place, the development of the whole territory of Makewe and that falls outside the purely health field—although for the Mapuche everything is health. (Makewe staff member, Mapuche)

6.3 Discussion

Apart from underpinning Indigenous self-determination and autonomy, effective Indigenous governance has been tied to improved health and wellbeing outcomes for Indigenous communities. Chandler and Lalonde's work has demonstrated the connection between 'cultural continuity' and reduced risk of suicide in Canada's First Nations communities, with cultural continuity being underpinned in part by self-governance at the community level and community control in areas such as health and educational services. Among the factors studied, self-government was shown to have the strongest protective effect against youth suicide.[24] In Australia, Kelaher *et al* (2014) illustrate the importance of equitable governance in achieving equitable Aboriginal health outcomes. Incorporated into this concept of Aboriginal health governance are ties between Aboriginal organisations as well as between Aboriginal and mainstream organisations.[316]

6.3.1 Balancing Indigenous and western governance

6.3.1.1 **Cultural match**

The ties between cultural dimensions of organisational structures and successful Indigenous governance is a key theme in The Harvard Project on American Indian Economic Development (hereafter the Harvard Project). The Harvard Project was initiated in 1987 in order to examine the social and economic development of American Indian reservations and has been running for over two decades.[317] Key findings include the importance of tribal *sovereignty*, *institutions*, *culture*, and *leadership* regarding economic development.[317] However, among the earliest findings of the project was that while self-governance and sovereignty are essential elements for tribal economic development, they were not sufficient.[318] Rather, a key component was the measure of alignment between the expectations and requirements of formal institutions and the tribe's own understandings and beliefs about how authority should be organised and utilised.

The Harvard Project found that this *cultural match* was necessary for governance institutions to be viable—they would need to be legitimate for community members, by adhering to traditional practices and expression of authority, as well as for the formal systems, in order to work effectively with governmental and other organisations.[318] In the case of Chile and elsewhere, issues of cultural match arise due to the underlying task in Indigenous governance: to create a system where decision-making processes are undertaken in ways that are compliant with both Western and Indigenous understandings of power and authority. Interviewees from both health centres as well as MINSAL highlighted that Mapuche ways of doing were packaged into structures that complied with regulations established by the Chilean State as a way to demonstrate legitimacy. Interviewees indicated that Mapuche cultural norms continued to be expressed through these structures in various ways—through the ways members were selected, for example, as well as through conflict resolution and decision-making processes.

Section 4.2.3 touches on Potvin's model of community participation in health promotion,[106] envisaging individual Mapuche communities and the State each engaging in their own first-level translation, as well as secondary translation with each other. Against this model, governance structures can be seen as the mechanisms by which this translation is accomplished and *cultural match* may be a measure of how well they are able to communicate. There are indications that the health centres have been successful in achieving cultural match in their governance approaches. Legitimacy with regards to the State has been demonstrated in the further development of both Centres in recent times—both Makewe Hospital and BFIHC have been granted funding to expand and establish new facilities. The relationships between the health centres and their communities is explored in depth in the next chapter, but the continued support from community leaders indicates satisfaction with current governance processes. Moreover, the findings from the Harvard Project indicate that a high level of cultural match in governance mechanisms facilitates community development, as communities are able to successfully ascertain their own needs and translate this into the acquisition of appropriate resources. The Mapuche territory of Boroa Filulawen is recognised as being particularly strong in terms of advocacy, negotiation with the State and organisation. This has manifested in the development of the area on a number of fronts, including improvements in water supply,[319] improvements in the quality of the roads[320] and funding for a larger and upgraded health centre. Drawing from the findings of the Harvard Project, the coherence between the Territorial Organisation, as a form of governance developed by the community itself and the governance

of BFIHC may be a contributing factor to the high level of development achieved in the Boroa Filulawen territory.

Pacheco's model of Mapuche traditional structures (see Section 2.3.1.2) provides a complementary perspective on cultural match in Indigenous governance.[163] Pacheco describes transitional structures as those that have been created with the purpose of negotiating the spaces between the dominant and dominated societies. The need for Indigenous communities to interact and negotiate with the State through official channels obligates the creation of organisations with highly constrained formal structures that are able to be officially recognised in accordance with Chilean law. This leads to the repackaging of traditional Mapuche social structure into forms that align with the demands of the dominant culture.[163] The formation of the Mapuche Health Association of Makewe-Pelale represents an attempt to incorporate culturally relevant ways of interacting and constructing a Mapuche community into a functional organisation recognised as a political entity by the government. As such, the structure of the organisation adheres to the bureaucratic requirements laid out by the State, but internal mechanisms such as decision-making processes, leadership and membership are strongly influenced by Mapuche social norms. Similarly, the organisations involved in the participatory processes of BFIHC, the Territorial Organisation and the Intercultural Health Committee of Boroa Filulawen, are characterised by a blend of traditional and state-imposed structures. While the nature of the Territorial Organisation itself is influenced by the State requirements to recognise a Mapuche community, the Organisation has strong legitimacy within the communities and is rooted in a Mapuche concept of territory. Pacheco asserts that the development of such structures is a demonstration of adaptability in the face of imposed cultural changes; moreover, they illustrate resistance against State dominance by allowing for the maintenance of identity and traditional social norms as well as providing a way to consolidate and actualise Mapuche political power.[163]

Within the governance model of Boroa Filulawen Intercultural Health Centre, the lines of decision-making are relatively explicit, with close ties evident between the administering Intercultural Health Committee of Boroa Filulawen and the Territorial Organisation, and from there to the wider communities. For the Mapuche Health Association of Makewe-Pelale, the adherence to traditional ways of asserting authority and leadership, alongside a Hospital organisational structure that privileges Mapuche decision-making processes is central to maintaining legitimacy as a Mapuche community organisation. In these ways, the Mapuche Health Association of Makewe-Pelale and the Boroa Filulawen Health Committee illustrate the

use of Pacheco's transitional structures to strengthen the cultural match between cultural understandings of how power should operate and adherence to formal institutional requirements.

6.3.1.2 **Recognition of Indigenous organisational values**

While interviewees were clear that the structure of the TO was based in State requirements, with the direct participation of community presidents, rather than traditional authorities, they also felt that this separation between the functional and traditional was appropriate. The two spheres—the functional and traditional—interacted but each had a separate role to play. The functional organisations and their authorities were created for advocacy purposes and to interact directly with the State, whereas the traditional authorities maintained cultural aspects of life in the territory. Nevertheless, comments from the directors regarding the Committee being the 'least participatory' part of the structure indicated that the lack of cohesion between the functional and traditional could, in some instances, undermine the full expression of community participation.

This position reflects themes that also arose in interviews with MINSAL staff members. In speaking with people from various State health institutions, several participants highlighted the lack of State recognition of traditional Mapuche social structures and authority as hampering processes of true community participation and preventing communities from making decisions in a way that aligned with cultural norms. From the point of view of these MINSAL interviewees, the validation and incorporation of traditional roles was seen as a way of improving participatory processes by improving the distribution of decision-making power.[321] These interviewees highlighted difficulties in bridging the divide between State reliance on narrow, geographically-based definitions of Mapuche communities and the realities of community traditional roles, social structures, fluidity and heterogeneity. This gap in understanding how Mapuche communities function limits the scope for genuine engagement. MINSAL interviewees indicated that Mapuche community participation is complicated by a disjuncture between different ways of working, conflicts over timelines and limited scope to acknowledge and accommodate local variation. Concern was also expressed regarding the risk that State rejection of the complex nature of Mapuche communities may further entrench existing power differentials as Mapuche culture and ways of working are overwhelmed by those of the State.[230] Overall, the contrast between the complex, fluid and changing ways in which Mapuche communities organise themselves and the rigidity of the limited avenues for

interaction accorded by the State imply that strong restrictions persist in how community participation in health is able to be operationalised.

These tensions expressed by interviewees regarding the balance between Indigenous forms of governance and fitting with Western institutional structures are also found elsewhere in the literature. Lemchuk and Jock (2004) draw on nine case studies of Canadian Aboriginal health systems to illustrate that productive relationships between Aboriginal communities and government entities necessitate an understanding of both Aboriginal and governmental cultures and ways of working. However, they also note the long timelines necessary for this exchange and understanding to occur.[118] In the evaluation report of the Akeyulerre Healing Centre in Alice Springs, Australia, the centering of Aboriginal ways of governance is described as underlying the requirements for incorporated bodies.[322] The governance mechanisms based on Elder leadership and kinship and family ties are highlighted as a strength of the organisation, promoting cultural retention and valorisation which contributed to healing at the community level.[322] At the same time, persistent tensions between Centre processes and those of funding bodies and other mainstream and government entities are noted.

Blagg (2008) speaks about the tensions inherent in spaces that exist between wholly Aboriginal and wholly non-Aboriginal domains,[323] such as in the governance of Aboriginal community-controlled organisations. The continuum between the two represents dynamic, shifting mechanisms that allow new types of interaction between the domains, which are neither traditional structures nor attempt to colonise Aboriginal culture.[323] In this way, Aboriginal communities and organisations negotiate a balance between Aboriginal cultural understandings of authority and governance and the organisational and bureaucratic requirements of the broader formal system. Figure 16 illustrates some of the governance mechanisms utilised in Mapuche health to navigate between the Indigenous and non-Indigenous domains.

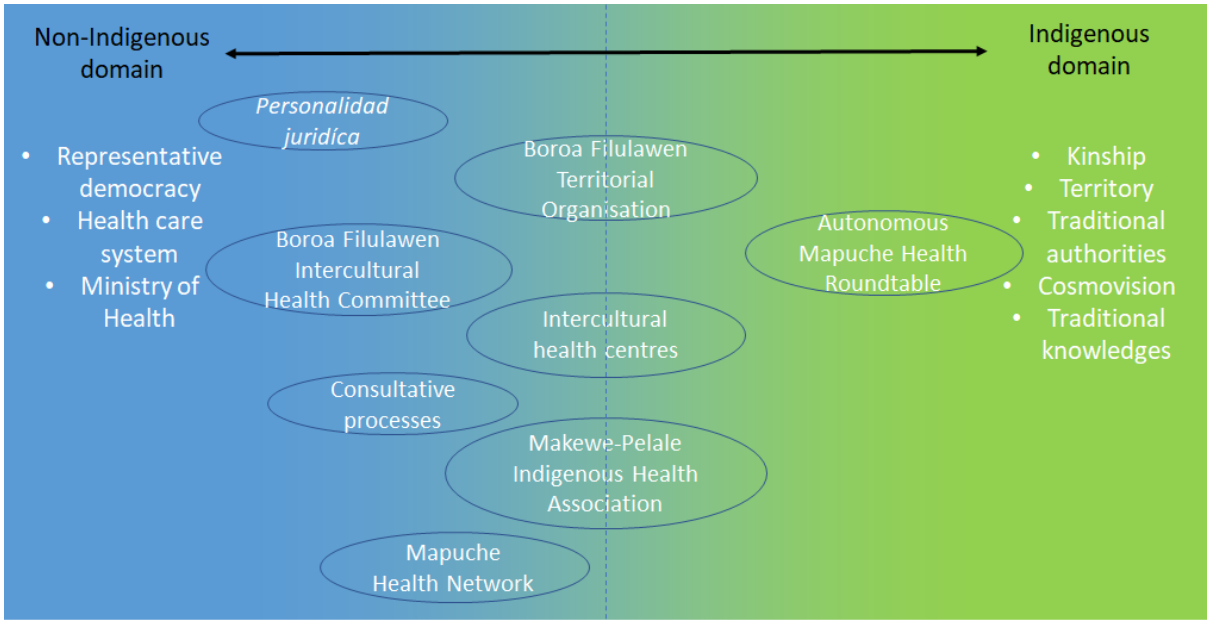

Figure 16. Governance mechanisms in Mapuche health. Adapted from Blagg (2008)[323]

'Hybrid' organisational structures are those that sit in the centre of the continuum. In considering their operation, it may sometimes be difficult to see and easy to ignore the underlying and internal cultural frameworks when the 'public' face is that of a functional, western entity.[322] However, as illustrated by multiple interviewees, understanding and respecting the cultural influences on the structural organisation is crucial to effective partnerships and optimising the strengths that communities bring in the management of their own affairs. Without this recognition, community-controlled organisations risk becoming 'bureaucratic extensions of the mainstream system.'[324]

The findings of the Harvard Project imply that a degree of flexibility in Indigenous governance structures is beneficial in allowing Indigenous communities to develop systems that are in alignment with their understanding of authority and legitimate decision-making in order to maximise cultural match.[318,325] In presenting findings from the Harvard Project, Begay and Cornell speak about two pairs of American Indian nations: The first pair have very similar governing institutions but markedly different outcomes, as the governing structure aligns with one nation's traditional models of governance (although not completely) while being substantially different from the other's. The second pair of nations have very different governing institutions but both have had successful outcomes, as the governance structures have been developed by the nations themselves. While the particular structure may vary widely from traditional governance, the manner in which it has been created supports its legitimacy.[325]

Flexibility is therefore needed on both sides of the equation: Indigenous communities may need to develop or adopt governance elements that are not part of their traditional norms, while the State needs to have a degree of openness to variations in Indigenous governance structures and institutions.[325] As it now stands, the Mapuche cultural norms that underlie governance structures are not 'visible' to the State. State recognition of the cultural aspects of Mapuche governance could increase flexibility on the side of the State, allowing Mapuche organisations to then develop governance structures that are more appropriate to their needs and cultural contexts. One fairly straightforward option may be to introduce more flexibility regarding the requirements for Mapuche organisations to be recognised with a *personalidad jurídica*. This approach could allow for Mapuche organisations to structure themselves in ways that are more aligned with cultural understandings of authority and participation, make these cultural elements more apparent and increase transparency in participation processes for all parties.

6.3.1.3 **Representativity and accountability to the community**

The United Nations Commission on Human Rights identifies the key elements of good governance as:

- Transparency
- Responsibility
- Accountability
- Participation
- Responsiveness (to the needs of the people).[308]

The principles of *responsibility*, *accountability*, *participation* and *responsiveness* arose throughout interviews,[308] particularly in BFIHC, although they were not necessarily framed in those terms. As highlighted, Committee members were seen as having legitimacy in the community because they were selected by the community itself—that is, they were *accountable* to the community, who had the power to remove them from their position if they did not fulfil their commitments. This was seen as being tied up with the principle of *participation*, as interviewees reflected on Committee members as representing the will of the community as a whole; although the principle of participation was also complicated by conflict between Indigenous and western ideas of what this should look like. Because they were part of the community, Committee members were seen as being well-placed to ensure *responsiveness* to community needs.

The principle of *transparency*, however, was relatively absent from interviews with staff members from the health centres. Questions about how precisely Committee and Association members and Centre directors were selected tended to be turned aside, or relatively superficial answers were given—for example, that people from the community voted for them, with no specifics supplied. This may relate to the cultural elements that guided selection of authorities, as touched on in the quote beginning on page 133, which were not seen as an appropriate topic. This raises the question of who, in particular, the process of participation should be transparent to—it seems likely that the selection of leaders may be relatively transparent for those members of the community that are involved, while remaining hidden from an outside perspective.

Interviewees indicated that in the past, questions had been raised regarding the extent to which the administrating bodies of the health centres truly represented the will of the wider community. Tensions between processes of community participation and democratic values are not limited to Indigenous contexts. In examining the evaluation of community participation initiatives, Butterfoss (2006) found that most collaborations and partnerships were not reflective of the wider community demographics as they tended to leave out sections of the community, including marginalised groups.[108] These conflicts may be particularly salient in the case of Indigenous community participation, since upholding traditional norms, including in the selection of local leaders and representatives, is often an underlying aim of such initiatives. However, Indigenous mechanisms for selecting leaders and making decisions often do not align with the principles of representative democracy—that is, an expectation that members will cast their vote for individuals to govern and represent their interests—which is largely a Western concept. As indicated in the quote on page 133, Indigenous leaders may come to power for reasons of family standing or lineage, territorial ties or spiritual qualities.

Moreover, traditional Indigenous forms of governance do not necessarily imply a broad form of community participation. The state of Oaxaca, Mexico implemented reforms in 1995 that formally recognised Indigenous customary law in the selection of local leaders.[326] While Hiskey and Goodman (2011) could not provide conclusive results regarding how customary law in the selection of local leaders impacted citizen participation at the local level, observation suggested some divergent outcomes.[327] The authors report that in some municipalities, the traditional systems operated such that all adult citizens gathered to discuss the selection, requiring an almost unanimous decision to be made. On the other hand, however, some municipalities adopted restrictive practices regarding who could participate, with an estimated 18 percent of municipalities operating under customary law excluding women from the

selection process. Still other municipalities were reported to be controlled by political bosses, prohibiting citizen participation.[327] Ultimately, the authors conclude that instituting Indigenous forms of decision-making may decrease the breadth of citizen participation in these processes.[327]

This concerns the distinction between *direct* and *social* participation (as introduced in Section 2.2.2.1)—considering community participation with regards to the number of people involved in the process as opposed to consideration of the social groups, particularly ones that are marginalised, that are enabled to provide input. The value of ensuring equitable community participation—that is, the inclusion of all social groups within the community—and the expression of traditional Indigenous social and cultural norms may therefore be in conflict. Butterfoss suggests that supporting participation measures that place emphasis on accountability of leaders to community members, rather than focusing on mechanisms that aim to adhere to community demographics but incorporate little accountability may be a way to balance community self-governance with ensuring that community needs are being expressed.[108] This position is coherent with viewpoints expressed by interviewees from the health centres. As illustrated by the quotes in Section 6.1, interviewees from BFIHC perceived the issues of representativity, legitimacy and accountability as being intertwined. These interviewees indicated that community leaders and the Directors of the Centre are *legitimate* because they accurately *represent* the community's interests, as evidenced by the fact that they are selected by and are therefore *accountable* to the community, who otherwise would not allow them to remain in their positions.

6.3.2 Interorganisational and regional governance

Within Chile, the main approaches to Indigenous participation in policy-making are consultation processes and the establishment of roundtables between government agencies and Mapuche service providers. The first characteristic of Pacheco's structures of transition is their capacity to facilitate relationships and negotiation between the dominant and dominated societies.[163] Governance mechanisms play a central role in this process as they form the basis of accepted patterns of interaction between the two. As such, in the cases of Boroa Filulawen Intercultural Health Centre and Makewe Hospital, governance structures that operate between the State and the centres demonstrate tensions inherent in establishing legitimacy and equitable allocation of responsibility within an inequitable system.

Interviews with MINSAL and Makewe Hospital staff touched on the importance of various roundtables that have enabled discussion and shared plans for action. However, interviewees also consistently indicated that the effectiveness of these roundtables and other forms of dialogue were curtailed. This was due both to the overarching rigidity of the health care system, which resisted any type of external input into decision-making processes and the reactive nature of the roundtables, which limited long-term planning. The difficulties apparent in forming avenues for community participation that uphold community independence and autonomy is the underlying issue that the theory of governmentality grapples with. As introduced in Chapter 5 and elaborated on in this chapter, even as policy, legislative and governance structures are set in place to allow communities greater control over their health care and foster dialogue with the formal health system, there are strong restrictions in place that prevent deeper change from occurring. Under such a framework, community participation and control in health may serve only to shift the task of ensuring bureaucratic regulation of Indigenous communities to communities themselves.[328]

This is not a situation unique to Chile—Indigenous health governance mechanisms that truly engage with and address power differentials between Indigenous communities and the State and enable power-sharing are relatively rare. For example, in Canada, the systemic lack of effective governance structures in Indigenous health has been tied to health inequities due to unequal power relations between Canadian governments and First Nations communities, the exclusion of First Nations from policy-making and a lack of government accountability.[126] The reform and decentralisation of the Brazilian health care system in the late 1980s saw the installation of Indigenous participatory structures across jurisdictional levels[135]—however, the system has been heavily and consistently criticised for a lack of accountability to and representativity of the Indigenous communities, as well as failing to ensure that decisions made through such processes are implemented.

Nevertheless, there are examples internationally of governance structures that reimagine the balance of power between the State and Indigenous communities. The British Columbia Tripartite Framework Agreement (see Section 2.2.3.1) was established, in part, to address and resolve some of these tensions. A key pillar of the Agreement is the concept of *reciprocal accountability*, that is, shared responsibility between First Nations and governments for achieving First Nations health goals.[125,329] The principle of reciprocal accountability addresses the imbalance of responsibility and control through the clear delineation of roles, performance expectations and mechanisms for review and adjustment for all involved parties at various

levels.[125] Under the Tripartite Agreement, the Canadian federal government continues to fund health services. However, the Agreement established the First Nations Health Authority (FNHA) as the entity responsible for planning, designing and implementing First Nations' health programs as well as being central to research and policy development in the field.[125]

In Australia, the *2017 Aboriginal governance and accountability framework* of the Victorian Department of Health and Human Services positions Aboriginal governance as being guided by the principle of self-determination, as supported by the UN DRIP.[330] As such, the Framework aims to embed Aboriginal leadership and decision-making at all levels within the health department of the state of Victoria.[330] It does so through the formulation of various governance mechanisms, at three levels, including:

- Local area Aboriginal Governance Committees
- Divisional Aboriginal Governance Committees
- An Aboriginal Strategic Governance Forum (statewide)

This is in conjunction with other strategies such as biannual 'community conversations' to identify community health needs and feedback progress and the creation of an Aboriginal Evaluation and Research committee to oversee progress on and evaluation of the state Aboriginal health, wellbeing and safety evaluation plan.[330]

In some ways, the Victorian framework is a more structured and embedded form of the steps towards Indigenous governance being undertaken in Araucanía Sur. As such, it may provide some instruction on how to continue to build on the work already being done. The codification of mechanisms for Indigenous governance in policy may support the formation of more established, proactive and therefore effective processes to promote shared decision-making. Having such structures in place may also lead to increased coherence within the sector as a whole as collaborative ways of working become more entrenched.

6.4 Conclusions

As the processes by which decisions are made, governance affects Indigenous health outcomes in a number of ways. Indigenous health governance refers to the processes by which authority is wielded in allocating resources, setting health priorities and designing, developing and implementing Indigenous health policy and programs. As such, governance is the means by which individuals, communities and organisations are allowed or inhibited in having a say over

how their health is addressed. In Indigenous health, governance encompasses both the ways that Indigenous communities and organisations navigate their interactions and relationships with the State and the internal governance of Indigenous organisations.

Makewe Hospital and Boroa Filulawen Intercultural Health Centre represent the intersection between their communities and the wider health system. As such, governance at the level of individual Mapuche health organisations demonstrates various ways of balancing Indigenous understandings of authority and decision-making with presenting as a legitimate organisation within the wider health care system. This encompasses considerations of who has the authority to represent the community in participatory processes and measures of accountability to the community by selected representatives. However, official 'blindness' to the Mapuche ways of governing that underpin Western organisational structures was identified by interviewees in the health care centres as well as MINSAL staff as an ongoing barrier to supporting community participation in its entirety. Recognition of the complexities inherent in navigating this space could allow for the construction of more appropriate and effective ways of working between Mapuche and non-Mapuche organisations and improve processes of Mapuche community participation.

The effectiveness of governance at the organisational level is strongly dependent on having sufficient mechanisms for Indigenous governance at higher levels, as national health policy will either support or curtail the autonomy and capacity of Indigenous organisations to respond to their local contexts. As explored in the last chapter, within Chile, despite a legislative framework that sets out obligations for the government to consult and engage with Indigenous peoples, this occurs to a minimal extent. This chapter has followed on by considering the interface between these legislative and policy frameworks and Mapuche ways of understanding authority and undertaking decision-making processes. After this examination of the interaction between the policy context and Mapuche health centres, the next chapter looks at the relationships between the centres and their communities.

Chapter 7. Relationships between the Centres and their communities

For Indigenous peoples, the quality and strength of community connections form part of a holistic understanding of health.[12,17] Indigenous health centres therefore strive to incorporate this understanding of health into the way they work. Central to the functioning of Indigenous health centres are the relationships between the centres and the communities they aim to serve. Apart from the provision of clinical services, Indigenous health centres tend to utilise mechanisms to build connections with their communities and strengthen and support cultural knowledge, including the incorporation of traditional social structures into the way they function. On the whole, Indigenous health centres are committed to localised decision-making processes, which depend on being able to integrate an understanding of community norms, values and priorities into program development and implementation.[118]

Where the previous chapter is primarily concerned with how the centres interact with State agencies and other organisations, this chapter examines the other half of the equation. Here, the relationships the two health centres have with their respective communities is considered. In particular, this chapter is concerned with the third research aim, describing the ways in which Boroa Filulawen Intercultural Health Centre and Makewe Hospital maintain and navigate their positions with respect to community hierarchies and social structures, and the resulting impact on how the centres operate. As such, this chapter draws from Makewe Hospital patient interviews alongside those of health centre staff members.

7.1 The health centres and their communities

For Makewe Hospital and Boroa Filulawen Intercultural Health Centre, being situated within the communities' social structures was central to the way they operated. Relationships between the centres and the local traditional authorities, such as the *longko* and *machi*, among others, were built into decision-making processes and underpinned efforts to improve health at the family and community level. The centres themselves were embedded in the community social structure in a variety of ways—through employing local people, including community leaders; through governance structures that overlapped with wider community governance mechanisms; and through outreach work that depended on having intimate knowledge of community politics and social norms.

This staff member describes the relationship between Makewe Hospital and the community authorities as being mutually beneficial in the sense that the local traditional authorities were strengthened and more respected by having a hospital that valued and validated the importance of these social structures. At the same time, the Association relied on the support of local communities to maintain their position.

...hemos tratado de mantener el hospital obviamente, los longkos *de las comunidades tienen la, los lazos con Makewe porque consideran que Makewe es un centro de salud, un hospital que, que por estar en la comunidad y estar administrado por una asociación mapuche tiene más pertinencia con su, le da más sentido al, al, a la cosmovisión mapuche ¿ya? ellos se sienten acá escuchados, se sienten respetados y por tal motivo ellos siempre están en contacto con Makewe para entregar el apoyo y, y, y que este tema perdure, este, este modelo de atención acá en Makewe ¿ya? por ahí se ve, se ve, se visualiza más el apoyo mutuo. También el hospital necesita de las comunidades porque el hospital si no tuviera el apoyo de las comunidades, de los* longkos, *de los* kimches, *tampoco, estaría todavía administrando este hospital.*	…We've tried to maintain the hospital obviously, the *longko* of the communities have the, the ties with Makewe because they believe that Makewe is a health centre, a hospital that, as it's in the community and administered by a Mapuche Association has more relevance with their, fits better with the, the Mapuche worldview, yeah? They feel listened to, they feel respected and for this reason they're always in contact with Makewe to give support and, and, and that this lives on, this, this model of care here in Makewe, right? For that reason, it's seen as, visualised more as mutual support. The Hospital also needs the communities because if the Hospital didn't have the support of the communities, of the *longko*, of the *kimche*, they wouldn't be administering this hospital any more either. (Makewe staff member, Mapuche)

Similarly, in BFIHC, this interviewee describes the organisational and cultural structures of the territory of Boroa Filulawen as being interconnected and mutually supportive, with the *longko* and *machi* supporting the work of the health centre and vice versa. In this instance, the mutual support between the health centre and the traditional authorities is explicitly linked to the concept of a single, united territory.

Claro. Nunca hemos tenido problema porque los longkos *hacen su trabajo, la organización hace su trabajo, los chicos del centro también hacen su trabajo; pero siempre estamos todos unidos en contacto. Cuando se hacen* Nguillatún *o* We Tripantü*, todo el tema de cultura mapuche, nosotros apoyamos todo; y ellos después cuando la organización tiene que hacer algo, también ellos apoyan. Entonces, el territorio Boroa Filulawen – es uno solo.*	Of course. We've never had a problem because the *longko* do their job, the [Territorial] Organisation does its job, the boys in the Centre do their job as well; but we're always together and in contact. When there's the *Nguillatún* or *We Tripantü*, everything to do with Mapuche culture, we all support everything; and they afterwards when the Organisation has to do something, they also support it. So, the territory of Boroa Filulawen—it's all one. (Boroa staff member, Mapuche)

The next sections explore the centres' relationships from two perspectives: first, how the surrounding communities are made visible and present in the centres themselves; then, the roles the centres play in the wider communities.

7.1.1 The communities in the Centres

In both BFIHC and Makewe Hospital, a high proportion of staff came from the surrounding areas, with the exceptions to this rule consisting of those professional roles that could not be filled by local people due to barriers in educational attainment. The following quote illustrates that the relationship between Makewe Hospital and the surrounding community, including familial ties, was central to the way the Hospital functioned. These ties consisted of formal links, such as employment, influenced by traditional Mapuche norms.

A ver, mira, yo tengo cincuenta y ocho trabajadores acá, quizás los únicos que no son parte de la comunidad son los profesionales por un tema de que el acceso a la educación de las comunidades… pero muchas de las personas que trabajan acá, que son técnicos paramédicos, paramédicos formados en la época de los anglicanos	Let's see, look, I have 58 workers here, maybe the only ones that aren't part of the community are the professionals because of the issue of educational access in the communities…but many of the people that work here, that are paramedic technicians, paramedics trained in the time of the Anglicans, belong to the community, they're

pertenecen a la comunidad, son de la comunidad y el sistema de relaciones de filiación de la comunidad está establecido por un sistema que se llama un sistema de patrilinaje *entonces muchas de las persona tienen, a diferencia de lo que es la cultura occidental, familia se considera todo…y las familias son grandes entonces en cierta medida también hay una relación familiar entre muchas personas que trabajan, no directa pero sí familia en el contexto cultural Mapuche….*	from the community and the system of filial relationships in the community is established by a system that's called a system of *patrilineage* so many of the people have, as opposed to the Western culture, family is considered everything…and the families are big so to a certain extent there's also a familial relationship between many people that work, not directly but still family in the Mapuche cultural context…(Makewe staff member, Mapuche)
La mayoría de ellos (de mi comunidad) son usuarios acá, pacientes acá pero si hay que defender el hospital para que siga la comunidad está ahí, está ahí, un tiempo se pidió apoyo y la comunidad está ahí, estaba presente. Hay, valoran, la comunidad de por acá por ejemplo, yo soy de la comunidad de acá cerca acá, esta cerquita del hospital, valora mucho al hospital, incluso yo nací aquí, mi mamá me tuvo acá en este hospital.	The majority of them (from my community) are users here, patients here but if there's a need to defend the hospital so that the hospital continues the community is there, it's there, once the community was asked for support and the community's there, it was present. There's, they appreciate, the community here for example, I'm from the community here, close to the hospital, they really value the hospital, even I was born here, my mother had me here in this hospital. (Makewe staff member, Member of the Association, Mapuche)

The following quote demonstrates the ways that interactions between community members and Makewe Hospital are located not only in a provider-user relationship, but are also influenced by cultural norms around how Mapuche communities operate. This illustrates the nature of the familial and community ties that exist between the Hospital and the surrounding territory as reinforcing traditional and cultural ways of communicating and interacting.

Entonces, eso prácticamente, la, hoy en día se da la participación, si efectivamente pero no constantemente de las bases hacia esta 'organización que representa a la comunidad' entre comillas y que está a cargo de la administración del hospital, pero eso también hay que entenderlo en términos culturales, quizás en la forma de organizar, cómo se organiza la comunidad indígena, ¿ya?, por territorio y por comunidades; pero cualquier cosa que suceda directamente vienen los representantes de comunidad y de presidente a presidente y de longko *a presidente se establecen diálogos, entonces cuando hay problemas por familia o etcétera son ellos los que resuelven, son presidentes,* longkos.	So that, essentially, now today participation takes place, effectively but not constantly from the people in the community towards the, quote 'organisation that represents the community,' unquote, and that's in charge of the Hospital's administration, that that also has to be understood in cultural terms, maybe in the way of organising, how the Indigenous community is organised, right? By territory and by communities; but anything that happens the community representatives come directly and from president to president and from *longko* to president dialogues are established, so when there are family problems and so on they're the ones that resolve it, the presidents, *longko*. (Makewe staff member, Mapuche)

As alluded to in the quote above, the majority of Makewe Hospital patient interviewees said that they did not participate in Hospital community meetings or cultural events directly, but they were more likely to say that the community leaders participated in this way, which was seen as evidence of a positive relationship. This is tied to the idea that the role of community leaders was to represent the individual communities, and that this way of communicating between the community and the Hospital was more appropriate than individuals being directly involved with issues concerning the Hospital.

….en esas reuniones no he participado yo porque a esas reuniones se invitan a los presidentes de las comunidades… solamente los presidentes, los, los del directorio de ahí de las comunidades vienen acá a participar…. Y después ellos les dan	….I haven't participated in these meetings because they invite the community presidents…just the presidents, the, the people of the directorate from there the communities come to participate…And afterwards they give the information to the

la información a los socios de cada comunidad.	people of each community. (Patient 5, Man, 45)
Sí, en varias veces, en varias oportunidades [gente de la comunidad] han sido invitados al We Tripantü*, bueno ya que se acerca el veinticuatro de Junio….Siempre invitan a los dirigentes de la comunidad, sí.*	Yes, sometimes, in some opportunities [people from the community] have been invited to *We Tripantü*, which is coming up on the 24th of June…They always invite the leaders of the community, yeah. (Patient 21, Woman, 36)

Patient interviewees felt that the more direct involvement of community leaders was appropriate, as these people would be able to bring information back to the communities.

…yo creo que, la comunidad ha participado en esto, siempre hay cómo, hay dirigentes que representan a organizaciones y yo creo que está bien, está bien. (Usuario 8, Hombre, 60)	…I think that the community has participated in that, there's always like, there's leaders that represent organisations and I think that's good, it's good. (Patient 8, Man, 60)

Apart from these methods of communication between the Hospital and the surrounding communities, many staff and patient interviewees' comments regarding the current state of community participation at Makewe Hospital centred around the consultative processes that were undertaken during the planning phases in constructing the new hospital. A series of community meetings were held in the years preceding construction of the new hospital in order to advise members about the progress and allow them to have input into the design. These meetings took place both at the Hospital and within the communities themselves throughout the planning and design phases.

Ahora estamos trabajando para el hospital nuevo… que es decirle 'Bueno, usted me mandó a hacer un hospital nuevo, estamos empezando a hacerlo' y ahí decir '¿Y ahora qué vamos a hacer?, ¿Qué le vamos a meter a ese hospital nuevo?¿Qué quiere usted en	Now we're working for the new hospital…that is, to tell them, 'Well, you told me to build a new hospital, we're starting to do it,' and from there to say, 'And now what do we do? What are we going to put in that new hospital? What do

ese hospital nuevo?'....Y ahí hay participación de la comunidad, ahí dicen. ¿y nosotros qué es lo que hicimos? 'Bueno' dijimos 'Bueno, si usted no está conforme con la que estamos mostrando se la cambio, ¿Qué problema hay?, no hay problema, usted está diciendo, la cambiamos'. Se cambió en el diseño, ¿me entendís o no? Entonces ahí hay participación, no es una cuestión que nosotros llegamos y decimos 'Se hace', nosotros mostramos 'Esto se puede hacer, aquí está', 'Sí pero esa no me gusta, esa ruka *no me gusta, hágalo de otra manera' y hay que hacerlo.....*	you want in that new hospital?'….And there you have participation from the community, there they tell you. And what do we do? 'Well,' we say, 'Well, if you're not comfortable with what we're showing, we'll change it. Where's the problem? There's no problem, you're telling us, we'll change it.' And the design gets changed, you see? So there we have participation, it's not that they come to us and we say, 'It's already done,' We're showing, 'This can be done, here it is,' 'Yeah, but I don't like this, I don't like this *ruka*, make it a different way,' and it has to be done… (Director of Makewe Hospital, President of the Association, Mapuche)
Bueno, cada vez que ha habido reunión para, por ejemplo ahora están en proceso de, de gestionar nuevo, nuevo hospital, me han invitado a reunión y también he participado apoyando a la directiva, que se cumplan los periodos, los compromisos que hay de trabajo que tiene para construir el nuevo hospital.	Well, every time there's been a meeting for, for example now they're in the process of building a new, a new hospital, they invited me to the meeting and I've participated as well supporting the directorate, that they achieve the timelines, the work commitments that they have to be able to construct the new hospital. (Patient 8, Man, 60)

In both Makewe Hospital and BFIHC there was an expectation that as the members of the respective administering structures were part of the communities, they were aware of issues affecting and arising from the community. For example, interviewees indicated that as the Directors of the BFIHC were situated within the territory, they would likely already know the necessities of the community and be able to incorporate this knowledge into the development of appropriate programs to address community needs. For these reasons, the existence of these links between the community and the organisations were seen to constitute a form of

community participation in and of themselves. Below, a similar perspective is espoused by a Makewe Hospital staff member.

Lo que pasa es que cuando una organización, se supone que prepara un proyecto y dentro de ese proyecto ya las necesidades están ya, ya se viene sabiendo cuáles son las necesidades que van a tener las comunidades. Entonces eso lo aborda el dirigente, en este caso del centro salud o el dirigente territorial, porque ya las cosas están dadas, ya se conocen las diferentes inquietudes que hay con el tema de salud por ejemplo, ya se viene sabiendo ya.	What happens is that when an organisation, one supposes that they prepare a project and within this project the needs are already there, that they come knowing what community's needs are. So the community leader approaches this, in this case from the health centre or the territory leader, because the things are already given, they already know the different worries that are there with respect to health for example, they come already knowing. (Boroa staff member, Mapuche)

As outlined in the previous chapter, in the case of BFIHC, the Territorial Organisation structure serves as the primary method for formal identification of local health needs at the community and territory level. The ties between BFIHC and the TO enables a fairly constant stream of communication between the leaders of the communities and the Centre. Major changes to the Centre, including progress on the current process of constructing a new facility for the Centre, were also discussed and finalised at TO meetings, indicating a high level of community input over Centre operations.

Bueno, aquí se realizan reuniones periódicas de todas las comunidades, que en realidad son las que forjaron y solicitaron desde un comienzo de este proyecto que es el centro de salud intercultural Boroa Filulawen. Bueno, entonces se van comentando dentro de esa reuniones como todas las opiniones de todos los presidentes de las comunidades, se va opinando sobre la evolución que va teniendo	Well, here we have regular meetings with all of the communities, in reality it's the communities that forged and petitioned from the beginning of this project of the Boroa Filulawen Intercultural Health Centre. Well, so they come speaking in these meetings about all the opinions of all the community presidents, they come talking about the evolution of the health centre, what they

el centro de salud, ellos dicen qué es lo que más necesitan….	most need…. (Boroa staff member, Mapuche)

BFIHC clinicians also indicated that it was usual for individuals attending the Centre to raise concerns regarding issues such as accessibility of health care during their consultations, and cited this as a key way that community health needs were articulated.

En la, en la consulta normal.….Cuando uno le dice: '¿Sabe qué? Va a tener que ir a ver el especialista a Temuco'. '¿A Temuco? Pero, ¿por qué? ¿Por qué no acá en Imperial, que me queda más cerca? O, yo no me manejo en Temuco, yo no conozco Temuco….¿Por qué tengo que desplazarme?' 'Porque el sistema es así'. 'Pero, ¿por qué no se puede traer un especialista a acá?' Y de hecho, cuando se traen…se llena. Siempre tienen pacientes para atender.	In the normal consultation….When one says: 'You know what? You have to go see the specialist in Temuco.' 'In Temuco? But why? Why not here in Imperial, which is closer? I don't know anything about Temuco, I don't know Temuco….Why do I have to uproot myself?' 'Because that's how the system is.' 'But why can't they bring a specialist here?' And, in fact, when we do bring a specialist….it fills up. There are always patients to attend to. (Boroa staff member, non-Mapuche)

While there were many avenues of communication between Makewe Hospital and the surrounding territory, various staff interviewees indicated that in its current form, community participation was generally limited to consultation processes or information provision, rather than rising to the level of community co-governance. This interviewee in particular draws parallels between the forms of community participation at the policy and community levels, indicating that both are primarily concerned with consultation.

Eso sería una parte de participación, una parte que tiene que ver de la participación en relación al estado y la otra parte de la participación tiene que ver con la comunidad en sí misma con la administración del hospital, son dos niveles,	That would be one part of participation, one part that has to do with participation in relation to the State and the other part of participation has to do with the community itself with the administration of the Hospital, they're two levels, one at the level

uno a nivel de las bases y la cogestión dentro del centro de salud o hospital y el otro a nivel de la organización y su representatividad de las comunidades con el estado, ¿ya?, en ambas se da a nivel consultivo, más que eso no veo una participación mucho mayor.	of the people of the community and co-management within the health centre or hospital and the other level relating to the organisation and its representativeness of the communities with the State, right? In both it occurs at the level of consultation, more than that I don't see much in the way of participation. (Makewe staff member, Mapuche)

Similarly to the way the functioning of the Autonomous Mapuche Health Roundtable (see Section 6.2) was described, within Makewe Hospital, participatory processes at the community level were also seen to be particularly activated during times of change, or in response to a situation that needed to be resolved, rather than a constant feature.

No es todo el tiempo, se da en determinados momentos, por ejemplo con la construcción del nuevo hospital, ¿ya?, el apoyo a la construcción del nuevo hospital se busca el máximo de comunidades representativas dentro, dentro de que asistan y que conversen en conjunto con la asociación con los personeros representantes de la política de gobierno, estamos hablando del Servicio de Salud Araucanía Sur, ministerio de salud, el gobierno regional, etcétera pero son etapas, cómo te digo frente a hechos puntuales; normalización del nuevo hospital, alguna amenaza que pueda venir, cómo el cierre de hospitalizados y transformar esto en Cesfam (Centro de salud familiar), entonces ahí la comunidad	It's not all the time, it happens at specific moments, for example in the construction of the new hospital, right? In support of the construction of the new hospital the maximum number of representative communities are sought within, within so they can attend and can discuss together with the Association with the government representatives, we're talking about the Health Department, the Ministry of Health, the regional government and so on, but there are stages, as I said, in relation to specific steps, planning the new hospital, some threat that may arise, such as closing the inpatient ward and turning it into a Cesfam (*Centro de salud familiar*, family health centre), so there the community participates much more actively and defends

participa mucho más activa y defiende ese hospital, defiende su hospital…	this hospital, defends their hospital… (Makewe staff member, Mapuche)
Ahora últimamente no se ha dado mucho el tema de la participación ¿ya? no se ha, no se han hecho grandes trawun, *reunión con el territorio para hablar de un modelo de atención que, que, que obviamente va cambiando con el tiempo ¿ya? pero sí se ha dado en el tema de, del diseño de este nuevo hospital que se está haciendo ahora en Makewe, la construcción de, de un edificio nuevo, ahí se dio harto el tema de participación porque igual se trabajó con la autoridad tradicionales, se trabajó con los líderes de comunidades, con longkos, presidentes de comunidad y en ese sentido podemos rescatar que se ha mantenido, se ha hecho el tema de participación ¿ya?…*	Now lately there hasn't been much about the theme of participation, yeah? There haven't, haven't been big *trawun*, meeting with the territory to talk about a model of care that, that that obviously changes over time, right? But yes, there's been this issue of the, the design of this new hospital that's being built now in Makewe, the construction, of, of a new building, there the idea of participation was really realised because at the same time they worked with the traditional authorities, they worked with the community leaders, with *longko*, community presidents and in that sense we can save what's been maintained, what's been done in the area of participation, right? (Makewe staff member, Mapuche)

Nevertheless, the processes of communication, consultation and information provision were seen as essential to the appropriate functioning of the Hospital within its context and its capacity to resolve problems when they arose, particularly when reinforced with adherence to and strengthening of cultural norms.

No obstante los procesos participativos a nivel informativo, a nivel consultivo se da tratando de alcanzar un máximo de representatividad a nivel de territorio, territorio indígena en donde, por ejemplo para temas claves se organizan salidas a la comunidad, respetando también sus protocolos, sus normas y se tratan de	Although the participatory processes are at the informative, the consultative level they've tried to reach a maximum representativeness at the territory level, Indigenous territory where, for example in key terms they organise trips out to the community, respecting the community's protocols and norms and try to resolve that

resolver eso con la opinión de la comunidad...a nivel de gestión interna no hay una mayor incidencia, sino que la relación a través de su representante directo en el cual ellos tienen que informar cada cierto tiempo por estatuto los avances, los retrocesos o las problemáticas que están afectando en ese momento, ¿ya?	with the community's opinion...At the level of internal management there's not much impact but in the relationship via their direct representative, in that way they can be informed every once in a while regarding the advances, the delays or the problems that are happening in that moment, right? (Makewe staff member, Mapuche)

7.1.2 The Centres in their communities

Both BFIHC and Makewe Hospital maintain ongoing and constant presences in the surrounding territory through a variety of ways. In BFIHC, the *ruka* and auditorium of the Centre were central places for community meetings, from the monthly TO meetings to meetings called for specific purposes—to discuss the municipal project to bring potable water to the communities[319] or the progress being made to maintain and improve the local roads—allowing representatives from BFIHC to be a regular presence. During these meetings, attendees had the opportunity to ask questions and voice their concerns regarding the issues being discussed. In addition to increasing the engagement of BFIHC in daily community life, the themes of these meetings sometimes overlapped directly with Centre affairs, such as during a community meeting regarding paving local roads—which are generally gravel and in very poor condition—when the Regional Government publicly committed to pave the roads leading to the Centre in order to increase accessibility.[320]

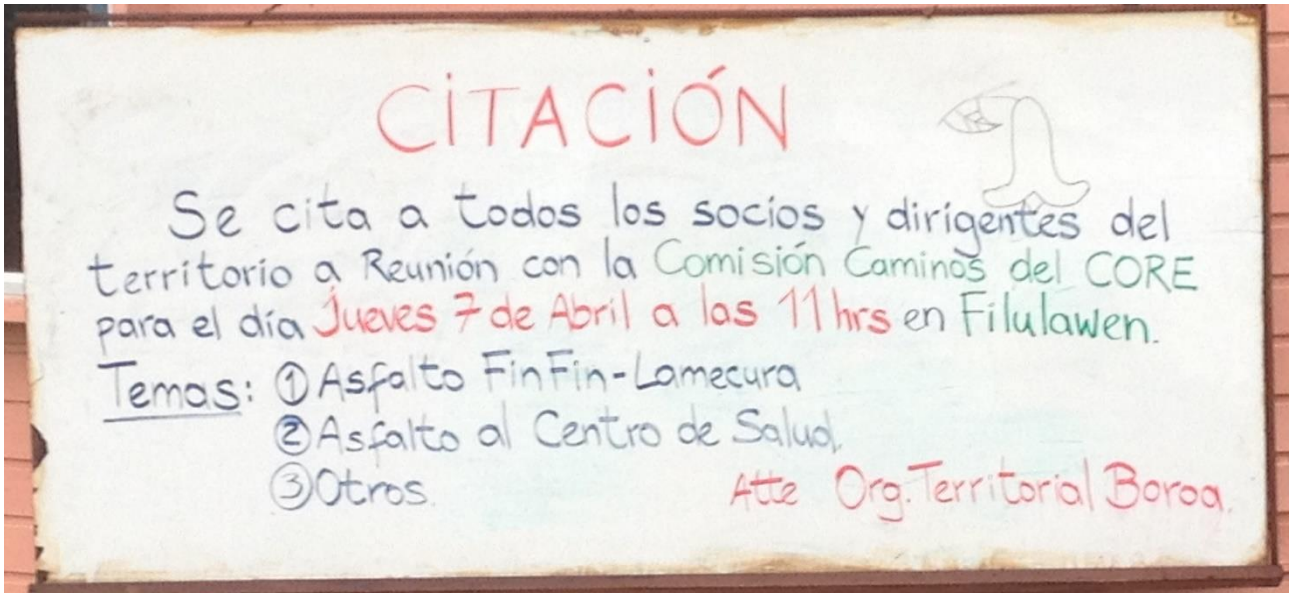

Figure 17. Invitation posted at BFIHC informing community members of an upcoming meeting to be held at the Centre regarding paving local roads. At this meeting, the Regional Government announced its commitment to pave the roads leading to BFIHC

In addition to its role in providing medical services, Makewe Hospital staff were frequently requested to intervene in community situations where there was an element of vulnerability or risk of harm. In such cases, Hospital staff such as the director, mental health team and others as necessary would meet with the relevant community authorities such as *longko* and *machi* in order to decide the appropriate course of action. In this way, the presence of the Hospital supported community affairs being handled in a way that was seen as appropriate within the cultural context and facilitated outcomes that were acceptable to those involved as far as possible. The quote below illustrates how instrumental the consideration of the family role is when discussing health issues in the community. An intimate understanding of and connection to the community as a whole are therefore necessary for the Hospital to fulfil this type of mediating role.

También hay problemáticas que tienen que ver con lo individual, generalmente en el mundo mapuche no hablan mucho de lo individual, siempre afecta familia, ¿ya?, generalmente no es cómo en la sociedad chilena que tú tienes un problema, lo	There are also problems that have to do with the individual, generally in the Mapuche world they don't talk much about the individual, it always affects the family, right? Generally it's not like in Chilean society where you have a problem, you resolve it in

resuelves de manera individual y el problema se responde individualmente, acá generalmente cuando hay una problemática …está asociada a una familia, entonces la negociación es familiar…	an individual way and the problem is responded to individually, here generally when there's a problem…it's also associated with a family, so the negotiation is familial…. (Makewe staff member, Mapuche)

As an extension of this role, the Hospital also acted as a bridge between community members affected by vulnerability and risk of harm and State authorities. This facilitative role was carried out in individual cases of mediation as well as by means of established institutional structures such as the Hospital's role in the Mapuche Children's Roundtable (see Section 6.2).

As part of its regular work, BFIHC undertakes various forms of outreach, supporting people in the territory to form Elders' groups and Women's groups, for example, focused on supporting the group members to articulate their own aims and move forward in achieving them. While Makewe Hospital had previously undertaken similar work, funding cuts had lessened the capacity to provide such extensive outreach services.

Medical professionals such as nurses, midwives, kinesiologists and doctors would make house visits (*visitas domiciliarias*) to those people that could not come into the centres for treatment and simultaneously made use of the opportunity to enquire about any unmet need in that or neighbouring households. These routine home visits were utilised in both Makewe Hospital and BFIHC to maintain communication between community households and the health centres, and were seen as an important way of keeping abreast of the needs of particularly vulnerable community members who were either house-bound or very isolated.

Eso se hace a través de la visita domiciliaria que se está haciendo ahora, porque ahora todos los profesionales prácticamente del hospital están saliendo a visita…. se va con, con médicos, con enfermera, con kinesióloga, con la matrona, con todos los profesionales, se va a hacer visita domiciliaria y se va pesquisando las necesidades que tiene la comunidad ¿ya? ya	That's done via the home visit that's being done now because now practically all the Hospital professionals are going out for visits…they go with doctors, with nurses, with a kinesiologist, the midwife, with all the professionals, they go for home visits and they go investigating the needs that the community has, right? Since this recurring visit is for disabled people for example,

sea esta visita recurrente que son de los discapacitados por ejemplo, de los postrados…pero eso también da de, da la posibilidad de que uno se tope con otras cosas, con otra necesidades que habían a lo mejor en el vecino al lado…y la asociación de esa forma se va enterando y se va incorporando más gente a solucionar los problemas de salud, esa es la forma de trabajar que tiene acá Makewe, a través de la visita domiciliaria …	people who are house-bound…but that also allows for the possibility to run across other things, other needs that maybe the next door neighbour has… and in that way the association goes finding out and goes involving more people to solve their health problems, that's the way of working here in Makewe, through the home visit… (Makewe staff member, Member of the Association, Mapuche)

However, the need for home visits far outstripped the capacity of Makewe Hospital to undertake them. With a relatively high amount of disability in the territory, a rising number of elderly individuals living alone and the issue of geographic access, there was a strong demand for these services. The poor quality of the vehicle used by the Hospital severely limited the number of visits that could be scheduled and had been an ongoing topic of negotiation with the Health Department.

Y ayer mismo tuvimos una reunión con gente de movilización del servicio salud demandando que tenemos vehículos en muy malas condiciones y que también necesitamos renovación de vehículos y más vehículos para poder cubrir esa necesidad…estamos preocupados de eso obviamente.	And just yesterday we had a meeting with people in mobilisation in the Health Department demanding, because we have vehicles in very poor condition and we also need the vehicles to be repaired and more vehicles to be able to cover that necessity… we're worried because of that obviously. (Makewe staff member, Member of the Association, Mapuche)

The closeness of the relationship between the Hospital and individual communities varied significantly by the intervening distance. Makewe and Pelale are quite large territories traversed mainly by gravel roads that are normally in poor condition and may be impassable for part of the year due to flooding. There are therefore substantial geographical barriers to

accessing the Hospital, which in turn limits the amount of contact between the Hospital and communities at the further ends of its catchment area.

Periodic assessments of community needs were undertaken by the director of Makewe Hospital and entailed taking time to go into the communities to consult directly regarding improvements to service provision. While this was an important way to understand the needs of the community as a whole, the geography and reach of the region, combined with poor road quality, meant the use of this strategy was a highly time-intensive process.

Bueno, yo recorrí un mes más o menos la comunidad mapuche de Makewe y ahí la gente empezaba a hablar y decir que 'se necesitan estas cosas' por ejemplo, decían que no es bueno que haya un matrón haciendo labores de enfermería, que debiera haber una enfermera….	Well, I toured about the Mapuche community of Makewe for about a month, more or less and there the people started to speak and say 'These things are needed,' for example, they said that it's not good that there's a midwife doing a nurse's work, that there should be a nurse…. (Director of Makewe Hospital, President of the Association, Mapuche)

In addition to providing biomedical services, Makewe Hospital contributed to strengthening local control of health care through the development of health services in smaller and more remote communities within the Makewe and Pelale territories. The Hospital was instrumental in the development of a small rural health centre (*posta*) managed by the Mapuche community in Colpanao, within Makewe territory. As the following quote demonstrates, in addition to support in the design and implementation phases, Makewe Hospital continues to lend material support through the provision of medical personnel attending at the Colpanao *posta*.

Por ejemplo el centro de salud Colpanao nos solicita a nosotros que lo apoyemos en la gestión de su posta rural, lograron construir una posta, un centro médico rural, está catorce o veinte comunidades asociadas en este centro de salud cultural y en donde el hospital establece el compromiso a través de su asociación de asistirlos una vez a la	For example, the Colpanao Health centre asked that we support them in the development of their rural *posta*, they were able to construct a *posta*, a rural medical centre, it's fourteen or twenty communities associated with this cultural health centre and where the hospital established an agreement via the Association to attend once a week

semana con médico, enfermero, odontólogo, matrona, paramédico … así se han definido los acuerdos entre ellos, entre la asociación y la otra organización y ambos tienen representatividad de comunidades entonces se, la solución es interna entre ellos, de gestión, ¿ya?, ahí si tienen una mayor incidencia.	with a medic, nurse, dentist, midwife, paramedic … that's the agreement they have between them, between the Association and the other organisation and they both have community representativity, so the solution is internal between them, the governance, right? There they have more influence. (Makewe staff member, Mapuche)

In Boroa Filulawen, the engagement of the TO with a variety of issues was central to the way interviewees conceptualised participation in health, even when these issues did not relate directly to health care. Recognition of the intertwinement between health and contextual factors underpinned the way the TO operated. While the majority of its focus was outside the health sector, the following quote highlights the importance of the TO in the participatory processes of identifying and meeting the health needs of the local population in a way that is holistic and multifaceted, as an interviewee reflects on participation in health:

Es que en el tema de salud no sé cómo explicarle porque yo creo que la participación es hacia la Organización [Territorial], no a la salud; porque por ejemplo, la participación en lo que convoca la organización, por ejemplo para algunos eventos, para alguna – cuando se hace el acto por ejemplo culturales y la participación es venir, que toda la comunidad puede concurrir a los diferentes eventos sociales.	It's that on the topic of health, I don't know how to explain it to you because I believe that participation is towards the [Territorial] Organisation, not health; for example, the participation that the Organisation brings together; for example for some events, for some—when for example some cultural acts take place, participation is attending, that the whole community can come together to attend different social events. (Boroa staff member, Mapuche)

The issue of having sufficient water is a recurring theme in Boroa Filulawen, and indeed in Mapuche communities throughout central southern Chile. The high acreage of pine and eucalyptus plantations on and bordering Mapuche territories have led to severe water shortages for local communities, with insufficient levels of water for growing the subsistence crops and

raising animals that these communities depend on.[169] Moreover, many in the community do not have access to potable water, and the region is currently implementing a project to bring potable water to rural communities. During the period of data collection, there were multiple community meetings regarding the process of bringing potable water to Boroa, and these were always strongly attended, with up to 160 people packed into an auditorium with standing room only.

Estamos pensando en el tema de agua, yo creo que esa es una parte muy fundamental porque las comunidades yo creo que tienen una gran necesidad de agua, en este momento el agua es tan – nosotros tenemos muy poquita agua, bien están los ríos y están los esteros pero esos esteros y esos ríos están vendidos a empresas trasnacionales y nosotros no tenemos para regar, para los animales e incluso para el consumo humano lo trae la municipalidad.…Y las comunidades por medio de su dirigente hacen un listado y quiénes son la gente que más necesidad de agua tiene y llega el agua potable….	We're thinking about the theme of water, I think that that's a very fundamental part because the communities I think have a great need of water, in this moment the water is so—we have very little water, well there's the rivers and the estuaries but those estuaries and those rivers are sold to transnational companies and we don't have any to irrigate, for the animals or even for human consumption the municipality brings it….And the communities via their leaders made a list of who were the people who most needed water and they brought potable water…. (Boroa staff member, Mapuche)

Of course insufficient water provision has an impact on health in a variety of ways, including leading to inadequate sanitation and increasing the spread of infectious disease, disease from contaminants or pollutants, dehydration and malnutrition due to inadequate crop production.

The scarcity of water also has an impact on the medical care received by the community. The following quote illustrates that insufficient water has led to the loss of *lawen*, plants used by traditional Mapuche herbalists. The TO is currently in the process of trying to halt this damage through its advocacy work in the agriculture and environmental sectors, although this community leader saw progress as being slow.

Pero en la parte de agricultura yo creo que estamos un poco débiles, en la parte de medio ambiente…Y que sin la – el territorio	But in terms of agriculture I think we're a bit weak, in terms of the environment…if the forestry companies don't stop deforesting the

si no dejan deforestar la empresa forestal, igual no vamos a tener agua, vamos a perder casas, vamos a tener menos, el lawen se va ir perdiendo, se van a ir secando por no tener agua.	territory, we won't have water, we'll lose houses, we're going to have less, the *lawen* will be lost, everything will be dry because there will be no water. (Boroa staff member, Mapuche)

7.2 Discussion

7.2.1 Cultural norms and avenues for participation

The 'bridging' role Makewe Hospital and Boroa Filulawen Intercultural Health Centre play between their communities and the State can be seen as a junction between multiple layers of socio-technical networks in Potvin's model of community participation (see Section 2.2.2).[106] Using this model, one network level would be operating within each Centre, as internal decision-making processes and negotiations are taking place. A second level is located between the Centres and the State and a third between the Centres and their communities.

Where the process of translation between the health centres and State agencies was largely structured by governmental requirements, in both Makewe Hospital and BFIHC, the influence of cultural and social norms on the relationship between the Centre and the surrounding territory was of central importance. The Makewe-Pelale and Boroa Filulawen territories are separated by only approximately 30km, with similar demographics. In addition, the establishment of BFIHC borrowed heavily from the example set by the Mapuche Health Association of Makewe-Pelale taking over administration of Makewe Hospital. Despite this, Makewe Hospital and Boroa Filulawen Intercultural Health Centre have evolved very differently, including utilisation of very different governance structures, service provision models and various participatory elements. The contrasts between the two cases highlight the relevance of local cultural and political contexts in shaping participatory processes.

The Association was developed specifically in order to administer the Hospital following the withdrawal of the founding Anglican missionaries; in contrast, BFIHC was established through a more organic process, developing out of ongoing discussions by the Territorial Organisation regarding community development. Therefore, referring to the socio-technical network model, from the initial stages of the Centres, the processes of *problematisation* (establishing the need

for a health centre and the nature of such), *interest* (identification of community members who could meaningfully contribute to the establishment and/or administration of the centre) and *enrolment* (successful engagement with these community members) have been shaped by their individual history.[106]

Although both Centres are now firmly established, participatory processes are ongoing in response to issues, threats and problems that arise, as well as advocacy that the Centres undertake. The processes of problematisation, interest and enrolment therefore involve continuous engagement with community members, in particular community leaders and authorities. Particularly in the example of BFIHC, the three processes were tightly interconnected, with issues being raised within the Territorial Organisation, and selection and engagement of those community members best placed to address the issue being undertaken by way of the TO. Problematisation also occurred as part of the intersection between the Centre and the surrounding community—for example, through the outreach undertaken by BFIHC staff members and outpatient visits.

In shifting from Potvin's socio-technical network to Rifkin's model for assessing community participation, participation is considered to be 'broad' or 'narrow' along each axis in relation to direct participation. *Direct participation* refers to the proportion of the community in question that is participating, without considering the question of *social participation*, that is, whether the community members participating belong to marginalised or dominant gender, class or social roles.[102] It is important to note that the majority of the community may not have had the opportunity or capability to participate directly in the identification and assessment of community needs. Some of these barriers may be pragmatic ones—issues of geographical access, for example. Others are cultural.

Both staff members and patient interviewees at Makewe Hospital spoke about the ways that cultural and social norms shaped the range of acceptable participatory processes and the avenues by which community members could provide input into the ways the health centres were run. Interviewees explained that the pathways that enable communication between community members and the Association were shaped by the organisation of the community itself, including the elected community presidents, family ties and traditional authorities. Similarly, on the whole, patient interviews indicated that the majority of community members do not participate directly with regards to the Hospital, whether this is taken to mean giving input or feedback regarding the administration or running of the Hospital or participating in events or ceremonies hosted by the Hospital. Rather, patients shared the implicit points

expressed by staff, that such direct participation was properly the responsibility of the community leaders and authorities. While Centre directors are available to the community for feedback, there are also hierarchies in place that needed to be respected. Patient interviewees as well as Makewe Hospital staff members indicated that it was not necessarily appropriate for community members generally to voice concerns directly to the Director. There were specific channels that were available for communication—community members may make their concerns known to their community leaders, such as the community president or *longko*, who would then follow the appropriate protocol and negotiate to resolve the issue. Both patient interviewees and staff members felt that this approach was in line with cultural norms. While the processes for selection of Centre administrators were not clear in either Centre, it was evident that the selection process was not through purely democratic means and was mediated by cultural norms. This form of community representation is in contrast to (usually Western) expectations that representation should be equitable and democratic. However, the adherence to cultural norms is an important part of the ways the Centres interact with and support their communities. These relational aspects strengthen the notion that participation is 'constructed,' not just 'practiced,' as it is continuously developed through the incorporation of established social norms into shared action for change. The mediation of participation by cultural norms is a key component of the context-specific nature of such initiatives.[101]

The question of 'narrow' or 'broad' participation is therefore somewhat complicated in that while in theory, community members as a whole have a variety of ways to make their concerns known, participation for a large proportion of the community is mediated by cultural norms and communication pathways. This is not an issue particular to this context—as covered in Section 2.2.2.1, the question 'Who participates?' is central to nearly all experiences of community participation, where participation is governed by social standing and access to those who are seen to 'represent' the community.[72] Communities' internal power dynamics and their influence on processes of participation—and equity in participation—has been explored from a number of perspectives.[72,111,331,332] In response to complexities around equitable representation in community participation, Morgan (2001) highlights the viewpoints of pragmatists, who tend towards utilitarian action, even if this means accepting that participation is not fully democratic; and activists, who push for a sustained commitment to social justice and enhancing participation and empowerment for marginalised groups within communities.[72]

In interviews with staff from both Boroa Filulawen Intercultural Health Centre and Makewe Hospital, emphasis was placed on the idea that the Centre administrators would not be in place

without the support of the wider community and the traditional authorities, indicating a high level of accountability between Centre administrators and the community. This, in addition to the level of acceptance and support for culturally-mediated forms of participation indicates that in this case, appropriate assessment of participatory processes should incorporate measures of accountability of leaders to community members. This is in contrast to measures that aim to evaluate democratic processes in participation or representativity based on reproducing community demographics.[108]

7.2.2 Strengthening traditional knowledge and social structures

Pacheco (2012) identifies the loss of *longko*'s political power as one of the aspects of Mapuche culture that has been most strongly affected by the process of colonisation.[163] The political power and authority held by *longko* were replaced by the power of the Chilean State, which imposed new social structures as Mapuche sovereignty was diminished. Under this new social system, the family structures and position of the *longko* could no longer fulfil their traditional roles.[163] Pacheco characterises *structures of transition* as mechanisms that serve, in part, to resist Mapuche assimilationism to dominant Chilean societal norms by strengthening the traditional internal structures of Mapuche communities.[163] While the intercultural health centres and their administering organisations, the Mapuche Health Association of Makewe-Pelale and Intercultural Health Committee of Boroa Filulawen, are the public-facing expressions of this effort, examination of the relationships between the health centres and their communities illustrate how this cultural affirmation is realised.

Under Pacheco's structures of transition model, one of Makewe Hospital's roles within the community is to provide a 'space of refuge' within which traditional social structures can be stabilised and sustained. Interviews from Makewe Hospital staff members affirm this, strongly highlighting the ways that the community's traditional authorities and the health centre reinforce each other and are interconnected. Moreover, the incorporation of *patrilinaje* and *parentesco* in the Hospital's decision-making processes and in hiring community members creates a system that valorises the role of the extended family within a traditional *lof*.[163]

The incorporation of familial and community ties within Makewe Hospital's structure, such as through employment, meant that these cultural relationships became part of the way the hospital operated. This intimate connection with the community allowed Makewe Hospital to function within a framework that saw violence and conflict as involving the entire family or community, rather than the individual. Resolving such issues thus necessitated ongoing

dialogue between the Hospital and traditional authorities such as the *longko*. This way of working promoted respect for the position of traditional authorities in the community and helped to reinforce the validity of following cultural norms in resolving community conflicts. As such, the mutually reinforcing relationship between Makewe-Pelale's traditional authorities and Makewe Hospital are a key aspect of the Association's understanding of its role and is positioned in relation (and in resistance) to the dominant Chilean society. The Hospital's political role in defending, translating and mediating community processes to State institutions is a significant part of what allows the internal community structures to flourish.[163]

While not explored specifically in interviews, the desire to preserve and validate traditional and cultural ways of doing things were expressed in informal conversations with the Director of Makewe Hospital with regards to traditional Mapuche health care. This desire underpinned a central principle of the Hospital—to provide only biomedical health care on-site. By working alongside and respecting the role of the *machi* and other traditional healers in the territory, the Hospital's provision of biomedical care served to complement the traditional system, rather than attempting to co-opt or supplant it. That is, because community members could access biomedical care, the *machi* and other traditional healers could focus their attention on those matters that were rightfully within their sphere, rather than inappropriately attempting to attend to problems that were outside their expertise. In these ways, the Association's close work with the communities and the traditional authorities (first-level translation, in the parlance of Potvin's participatory framework[106]) and subsequent realisation of community interests through negotiation with the wider health system (secondary-level translation) represents the use of traditional structures in establishing ongoing resistance against assimilation through the preservation of traditional cultural values and norms.

As covered in the previous chapter, the public form of the administering institutions of the intercultural health centres is wholly removed from cultural understandings of authority and appropriate decision-making processes. However, the quotes from BFIHC and Makewe Hospital staff members at the beginning of Section 7.1 emphasise the mutual support that exists between the health centres and the traditional authorities. Patient interviews also provide evidence that the engagement of the Association with community leaders was seen as an appropriate way to manage authority and decision-making processes. This indicates that the work undertaken by the administering organisations in establishing ongoing relationships and consultation with community members and traditional authorities has been essential to their

viability and resulted in increased cultural match between community-based and State-based governance structures.

7.2.3 Community participation and holistic health

In both BFIHC and Makewe Hospital, the closeness of the relationships between the Centres and their communities, and in particular, the presence of directors and senior staff members who were themselves from the communities, were highlighted as being instrumental in identifying community health needs. This occurred in three primary ways: Firstly, there was the presumption expressed by staff in both centres that by living in the community, the directors had first-hand knowledge of existing community needs. Secondly, community members could express themselves either directly to Centre staff or to the community leaders, who would take their concerns to Centre administrators. Finally, BFIHC staff indicated that participants were empowered to speak to clinical staff during their visits regarding necessary improvements in care. The Needs Assessment criteria of Rifkin's spidergram model of measuring participation in health programs ranges from a 'narrow' ranking where the identification of needs is imposed from the outside, to a 'wide' ranking where community members are involved in needs assessment.[102] The multiple ways existing to make the health needs of the territory known to the Centre identified by interviewees would indicate a 'wide' process, particularly in the case of BFIHC.

However, given that BFIHC is reliant on State funding, the processes by which the State determines and allocates resources also needs to be taken into account and balanced against the expressed needs of community members. This is also the case in Makewe Hospital, where the programs and services offered by the Hospital are tightly constrained by their obligations to and dependence on the State. The centralised nature of health priority-setting in Chile therefore undermines the effects of Mapuche governance and community participation at the local level and the capacity to deliver holistic care. This is the effect of having little to no avenue for Mapuche input into decision-making in health at higher levels funding arrangements organised in accordance with priorities that are determined at a national level.

At the same time, the intertwined relationship between the health centres and the surrounding communities allowed the organisations to fulfil a role that went beyond the provision of health services. BFIHC staff felt that the TO constituted a form of participation in health in itself, as it brought the territorial communities of Boroa Filulawen together to address a wide variety of concerns that impacted on health, despite being based outside of the health sector. This

approach incorporated an intertwinement of such elements as the environment, social and cultural connections and available infrastructure.[119] It offers an extremely pragmatic and practical view of health—as can be seen in the example of water availability, if the issues brought before the TO are not addressed, the health of the population is threatened on a number of fronts. The ways in which the health centre was involved in the economic, environmental and social aims of the community was only possible due to the close ties between the Centre, the community and the Territorial Organisation, all of which operated in conjunction to unify and achieve development across Boroa Filulawen territory.

The aspects of the centres that strengthen Mapuche identity and cultural continuity may also be protective of community members' health beyond the effects of health service provision. The experience of structural violence, ongoing practices of discrimination and colonisation and the resulting intercultural and historical trauma are common themes across Indigenous peoples worldwide, including the Mapuche.[29] The establishment of initiatives that take community-level approaches informed by an understanding of these collective experiences may serve to build community resilience by promoting community cohesion and Indigenous identity.[333,334]

The holistic approach that forms the basis of Indigenous health care worldwide incorporates an understanding of individual, familial and community wellbeing as being interconnected.[12] The need for a community-level approach to health is reinforced by an understanding of structural violence as experienced by Indigenous peoples, which manifests as intergenerational trauma and can contribute to increased levels of violence, substance abuse and other health issues.[335] Moreover, health care as driven by Indigenous communities is underpinned by principles of cultural retention, strengthening Indigenous identity and Indigenous autonomy, which in themselves are determinants of Indigenous wellbeing.[24,336] This may involve the incorporation of Indigenous languages, practice of traditional ceremonies and/or an explicit focus on traditional cultural expressions.[298,322,337]

For these reasons, Indigenous health centres often utilise strategies that aim to address health issues through working with the community as a whole and necessitating an understanding of local contexts, including relevant cultural norms, local priorities and politics and demographic and epidemiological trends.[118] A localised approach therefore serves to recognise and validate the unique nature of Indigenous communities and the high level of variability in terms of community structures and hierarchies. Ensuring a strong relationship between health care providers and the community they serve is therefore critical. BFIHC and Makewe Hospital exhibited differences in how they interacted with their territories, but both centres strongly

valued their relationships with traditional authorities and saw part of their role as contributing to the community's ability to continue maintaining their cultural distinctiveness. This approach was seen as part and parcel of how they delivered health services to their communities.

7.3 Conclusions

The connections between the health centres and their respective communities formed an intrinsic dimension of their functioning. In addition to strengthening Mapuche social structures, including the roles of traditional authorities, the relationships with the community leaders increased the perceived validity of the administrating organisations. In this way, the administering organisations had increased legitimacy from the community in their negotiations with the wider health care system. As such, the relationship between the centres and their communities as seen as mutually beneficial.

Communication between Makewe Hospital and surrounding communities was conducted in accordance with cultural protocols, with traditional authorities being heavily involved in relaying information between the community and the Hospital. These ties with traditional authorities allowed the Hospital to intervene in community health issues through dialogue and negotiation with all involved parties. In Boroa Filulawen, the ways in which the health centre and the wider community were intertwined enhanced a unified territorial identity, with all actors working together to ensure that health issues were addressed from both within and without the health sector. In both centres, integration with the community was part of the operationalisation of a holistic understanding of health incorporating individual, family, community and environmental health.

The next chapter continues to focus on the communities surrounding Makewe Hospital and Boroa Filulawen Intercultural Health Centre. Here, the viewpoints of patients regarding the quality of care provided and their perceived benefit from having access to Mapuche-administered health care are explored.

Chapter 8. What matters to patients

Potential benefit from community participation has variously been cited as the development of health programs that more directly correspond with local needs and are therefore more relevant and acceptable to the target population; services that reflect the values and cultural norms of patients and are therefore welcoming places to attend; and increased community ownership over health services leading to positive feelings towards the health services provided and therefore increased utilisation (see Figure 3).[78,338] In order to explore the validity of these assumptions, hearing from patients and community members about what they value and how they make decisions regarding their health care is essential.

Previous chapters have detailed how Makewe Hospital and Boroa Filulawen Intercultural Health Centre operate in relation to their communities, the broader health system and the policy environment. In this way, the forms community participation takes in both centres have been examined. This chapter corresponds with research question number 4 in going on to explore how these experiences of community participation accord with patient expectations of their health service and what they value about the care provided. In order to address this question, interviews were undertaken with Makewe Hospital patients. While patient interviews were not done in BFIHC, interviews with health centre staff members and service providers help to provide some insight into the patient perspective.

8.1 Users selecting health care services

In order to gauge what qualities were most important in selecting a health care service, patients were asked why they chose to attend Makewe Hospital, rather than another health centre. If they had previously attended other health centres, they were asked why they changed to Makewe Hospital and if they felt there was a difference in the quality of care. The most frequently cited reasons for choosing Makewe Hospital were short wait times, geographical accessibility, and availability of clinicians.

…anteriormente me atendía en Quepe pero mucho mejor acá la atención….En que hay médico, hay tres, cuatro médicos, a diferencia de allá que uno tiene que levantarse a las cinco de la mañana para alcanzar un cupo, quedan solamente diez cupos.	…before I attended at Quepe but the care is much better here…In that there's the doctor, there's three, four doctors, as opposed to there where one has to get up at five in the morning to get a space, there's only ten spaces. (Patient 1, Woman, 28)

Porque es el más cercano, más cercano y menos trámite, menos espera….Es más, es más rápida la atención, sí, por ese tema…. Es igual que en todos los otros hospitales pero es más, es más rápido…..Sí, no se espera mucho para, para que sea atendido por médico.	Because it's closer, closer and less bureaucracy, less wait time…It's more, the care is faster, yeah, for that reason…It's the same as in other hospitals, but it's faster…Yeah, one doesn't wait too long to be seen by the doctor. (Patient 5, Man, 45)
En que aquí, no sé si es por las enfermeras, es más rápido la atención, por ir a Miraflores por ejemplo, puede estar dos horas uno esperando, o más…hay que estar el día entero pero aquí no, aquí lo derivan a uno a cualquier centro cuando está muy grave la persona...	In that here, I don't know if it's because of the nurses, the care is faster, I went to Miraflores for example, you can be there two hours waiting, or more…you have to be there the entire day but not here, here they take you to another centre when the person's really sick… (Patient 6, Man, 56)

A few patient interviewees specifically mentioned the nature of Makewe Hospital as a reason for choosing to attend. Most patients who had presented at other centres said that the care provided at Makewe Hospital was similar (see second quote above), although some felt that at Makewe there was less chance of being discriminated against. These interviewees indicated that having a high proportion of Mapuche staff meant that there was less discrimination and more access to quality services, as well as staff that were more available and responsive. In the quote below, the patient voices her perception that she is less likely to experience discrimination at Makewe Hospital than other health care centres; however, she also highlights geographical access as an important factor.

Por el acceso, me queda más cerca, la atención es buena, las personas igual parte de las que trabajan aquí igual son Mapuches entonces no hay una discriminación con la, con el mismo género por lo menos en este hospital. La experiencia que me he llevado en otro hospital es que sí discriminan a los Mapuches…	Because of the access, I'm closer, the care is good, the people as well some of whom work here are also Mapuche so there's no discrimination with the same type at least in this hospital. The experience that I've had in other hospitals is that they do discriminate against the Mapuche… (Patient 14, Woman, 24)

8.2 Patient perspectives on Mapuche hospital administration

While it was generally not a primary factor in their decision to attend, patient interviewees did indicate that they valued the cultural aspects of Makewe Hospital and those elements that made it recognisably 'Mapuche.' Patients were asked whether they viewed Makewe Hospital as being part of the Mapuche community and the reasons for their answer. All patient interviewees agreed that the Hospital was part of the Mapuche community, and the majority cited its physical location and the high proportion of Mapuche staff as evidence of this.

Porque es parte del sector, lo más cercano, mucha gente mapuche que trabaja también aquí en el hospital.	Because it's part of the sector, the closest one, there's a lot of Mapuche people that also work here in the Hospital. (Patient 21, Woman, 36)
Es que desde que se fundó acá se remitían mapuches, claro que estuvieron los ingleses un tiempo a cargo del, del hospital pero después ya empezaron a tomar los, los mapuches los cargos y ahora se quedaron los mapuches.	It's that since it was established here Mapuche were sent, of course the English were in charge of the Hospital for a while but after the Mapuche started to take charge and now the Mapuche stayed here. (Patient 25, Woman, 51)

In interviews with patients, the importance of having a good relationship between the Hospital and the surrounding communities, particularly the leaders of the communities, was asserted.

Es que es necesario tener una buena relación de parte de los funcionarios cómo de la gente de la comunidad, estar siempre en contacto, estar informados.	It's necessary to have a good relationship between the administration and the people of the community, to be always in touch, to be informed. (Patient 21, Woman, 36)

In the following quote, the speaker ties together the importance of mutual support between the community and the Hospital, the Hospital's involvement in cultural and spiritual ceremonies such as *machitún* (a ceremony undertaken by a *machi* to cure illness), and Mapuche identity.

Porque para apoyar el hospital, para apoyarlo, porque siempre esté, que esté con la comunidad unido así…. Aquí hay machitún*…. Tiene que ser así porque la cuestión, esta es la comunidad Mapuche entonces tiene que ser Mapuche, tiene que apoyar a los demás.*	In order to support the Hospital, to support it, because it's always there, always united with the community….Here there's *machitún*…It has to be that way because the thing is, this is the Mapuche community so it has to be Mapuche, they have to be supported. (Patient 26, Woman, 50)

As highlighted in Chapter 7, for the most part, patients did not participate directly in community meetings or cultural events held by the Hospital. Rather, it was expected that community leaders, particularly the community presidents, would act as intermediaries between the Hospital and the wider community. Patients saw this participation on the part of community leaders as evidence of a positive relationship between the Hospital and the community.

The majority of patient interviewees had little understanding of how the Hospital functioned and was administered. Few of the patient interviewees had knowledge of or understanding of the Association, although some knew the Association Director.

Yo conozco al presidente de la asociación, Francisco Chureo no más pero…No sé quién más son directorio….Ellos buscan recursos a lo mejor, no sé, para, para el hospital yo creo, ese es el tema.	I know the president of the Association, Francisco Chureo but not the others, but…I don't know who else is in the directorate…They look for funding maybe, I don't know, for the Hospital I think, that's the thing. (Patient 5, Man, 45)

Nevertheless, there were some that had quite detailed knowledge of how the Hospital functioned.

Bueno, este hospital está dirigida por una organización indígena de la asociación Makewe y a pesar que de repente hay falencias económicas pero ahí vamos, han salido airosos en las gestiones, todo ha costado, no es fácil y este hospital, teniendo	Well, this Hospital is directed by an Indigenous organisation of the Mapuche association and although maybe there are some economic needs but we're going, they've been successful in the management, everything's been difficult, it's not easy and

un hospital nuevo aquí vamos a estar súper bien.	this hospital, having a new hospital here it's going to be really good. (Patient 8, Man, 60)

Regardless of whether they knew about the Association or not, patients were asked whether they thought it was important that a Mapuche organisation administered the Hospital, as opposed to a non-Mapuche organisation. Responses to this question were mixed. Overall, there was a more prominent tendency to speak positively of the high proportion of Mapuche staff at the Hospital, rather than expressing an emphasis on the administration. A few patients thought that having Mapuche administer the Hospital was important, and supported this viewpoint with a variety of reasons—in the quote below, the respondent indicates that having a Mapuche organisation meant that there was more opportunity for community members to have direct input into Hospital workings.

Hasta ahora funciona la, están ofreciendo bien la, cómo está, entre los mismos Mapuches, están ofreciendo bien…. Yo creo que en eso no, no hay mucho, mucho que decir, está, hasta el momento está bien, está mejor cómo Mapuche. Él, él, la persona que está a cargo del hospital, que es Mapuche, uno conversa con él, lo ve a diario… por ejemplo los chilenos, no tiene karma, no está al alcance para hablar con él porque no vive aquí y a lo lejos andaría y si viene que escondería en una oficina arriba, en cambio el otro no, el otro anda, generalmente anda por aquí, vive por aquí cerca y nos puede, muchas veces hemos tenido problemas con hospitalizar gente y el caballero cómo sabemos dónde vive hemos ido a su casa nosotros, nos vamos a hablar a su casa y muchas veces y el sábado que a él no le corresponde estar aquí nosotros	Up to now it's worked well, they're providing well, it's like, between Mapuche themselves, they're providing well…I think in that there's not much, much to say, it's, up to this time it's good, it's better as Mapuche. The, the person that's in charge of the Hospital, who's Mapuche, one talks with him, you see him daily…for example, the Chileans, they don't have karma, they're not within reach to speak to because they don't live here and they come from far away and if they come they hide in their office upstairs, on the other hand the other's not like that, the other comes around, they generally come around here, they live close by here and one can, many times we've had problems with hospitalising people and the gentleman as we know where he lives we've gone to his house, we go to speak at his house and many times on Saturdays when

vamos allá y él nos atiende y él da la solución al problema, esa es la parte buena. En cambio si estuviera por un winka, *adonde la ha visto, no se puede.*	he's not here we go there and he speaks to us and gives us a solution to the problem, that's the good thing. On the other hand, if a *winka* (non-Mapuche) were here, to go to be seen, it wouldn't be possible. (Patient 7, Woman, 55)
Sí, mejor Mapuche…Nos entiende a la persona que está acá en el sector y la enfermedad igual.	Yeah, Mapuche is better…They understand us as people that are here in the sector and the illness as well. (Patient 38, Man, 43)

The following patient interviewee connects having a Mapuche administrator, reduced discrimination in care and community development in the form of improved employment opportunities for future medical personnel from the community:

Claro, puede ser, mejor sería…..Porque así entre los mapuches se entienden más porque a veces los chilenos discriminan a los mapuches, por ejemplo la gente a veces algunos no saben hablar en castellano, siempre a veces los discriminan, entonces mejor que hayan, aquí necesitamos un doctor bilingüe igual, puede haber un doctor mapuche porque yo sé que hay doctor mapuche…igual estudian los jóvenes ahora. Por ejemplo nosotros, yo no tengo estudios pero los jóvenes, mis hijos tienen estudios y algunos jóvenes mapuches estudian enfermería, pueden estudiar, algunos se van a otros países a estudiar y esos después aquí en Chile no los validan porque son mapuches. Después esos deberían atender acá, aquí en su comunidad.	Of course, it could be that, it would be better…Because here, between Mapuche it's understood better because sometimes Chileans discriminate against Mapuche, for example the people sometimes some don't know how to speak Spanish, always sometimes they discriminate, so it's better that there's, here we need a bilingual doctor as well, there could be a Mapuche doctor because I know that there are Mapuche doctors…and the young people are studying now. For example us, I don't have education, but the young people, my children are educated and some young Mapuche study nursing, they can study, some go to other countries to study and after here in Chile they're not validated because they're Mapuche. After they could work here, here, in their community. (Patient 26, Woman, 50)

In the context of the Hospital being under threat due to lack of funds (see Section 5.5.1) and previously being on the verge of closure before the Association took over administration in 1998, the following patient ties Mapuche administration to increased future security. This support was also related to the patient's perception of the Hospital as being part of the territorial identity of Makewe-Pelale.

No, yo creo que está bien que lo administre una persona Mapuche. Porque quizás el no Mapuche tendría otros intereses, quizás el Mapuche está a favor de nosotros, del pueblo y siempre soy partidaria de que lo siga administrando una persona Mapuche, sí porque en realidad el occidental piensa de una manera distinta a nosotros, por ejemplo puede venir un médico, no sé, de, de Temuco pero puede tener otra, otra visión sobre las atenciones y hasta puede pensar 'hay muy poca gente' y se puede cerrar el hospital, en cambio una persona Mapuche que sea de la comunidad yo creo que siempre lo va a defender porque es parte de la cultura, es parte de acá, del territorio porque es una identidad territorial, hay una identidad, un compromiso con nuestra gente.	No, I think it's good that a Mapuche person administer it. Because maybe the non-Mapuche would have other interests, maybe the Mapuche will favour us, the people and I'm always supportive of the Hospital continuing to be administered by a Mapuche person, yes, because in reality the Western person thinks in a different way from us, for example a doctor could come from, I don't know, from Temuco but maybe that have another vision about care and they might even think, 'Oh, there's not many people here,' and they could close the hospital, on the other hand a Mapuche person who's from the community I believe is always going to defend because it's part of the culture here, of the territory, because it's a territorial identity, there's an identity, a commitment to our people. (Patient 32, Woman, 33)

At the same time, however, the majority of respondents either thought that having a non-Mapuche administrator would also be acceptable or thought that having a combination of Mapuche and non-Mapuche administrators would be beneficial. For many of these patients, the core question was the quality of the administration, including transparency and accountability, rather than whether the administrators were Mapuche or not.

Es que, mira, si, si el Mapuche es transparente para dirigir un hospital que lo haga y si viene otro que es trasparente y lo va a hacer bien también tiene la posibilidad de hacerlo, ambos, lo que viene aquí, lo que pasa es que uno tiene que ser trasparente en todo. Ahora, cómo Mapuche, cómo yo soy Mapuche me gustaría que lo dirigiera un Mapuche pero no para que se llene los bolsillos de plata de los Mapuches, sino que para que tengamos una mejor atención para todos, a eso, a eso voy yo.	It's that, look, if, if the Mapuche is transparent in directing the Hospital, let them do it, and if another comes that's transparent and they're going to do it well there's also the possibility that they do it, both, whoever comes here, it's that they have to be transparent in everything. Now, as a Mapuche, since I'm Mapuche I'd like for a Mapuche to direct it but not to fill Mapuche wallets with money, rather so that we have better care for everyone, there, that's what I have to say. (Patient 35, Woman, 43)
Buen, por lo que he visto hasta ahora la administración ha estado bien….Yo creo que la administración hasta ahora creo yo lo ha hecho bien, no, no estoy discriminando, si estuvieran no Mapuches estaría mala, sino que yo creo que hasta ahora ha estado bien, nadie se ha quejado de lo contrario.	Well, from what I've seen up to now the administration has been good…I think that the administration up to now I think they've done well, no, I'm not discriminating—as if non-Mapuche were here it'd be bad—rather that I think that up to now it's gone well, no-one's complained otherwise. (Patient 36, Man, 28)

A few thought that there should be co-operation between Mapuche and non-Mapuche in administering the Hospital and that having both would bring complementary strengths.

Yo creo que tiene que haber un balance en ese sentido, pienso que puede haber tanto Mapuche como no Mapuche…porque nuestra visión cómo Mapuche siempre ha sido un equilibrio y de respetarnos porque siempre tenemos que basarnos en todas las opiniones, nunca es bueno tener solo una parte porque cuando uno se contrapesa	I think that there has to be a balance in that sense, I think that there could be Mapuche as well as non-Mapuche…because our vision as Mapuche has always been to be in balance and to respect because we have to be grounded in all opinions, it's never good to have just one part because when there's a counterweight just on one side it always

para un solo lado siempre cómo que trae problemas pienso.	brings problems I think. (Patient 30, Man, 36)
No porque las, las dos cosas es importante, tampoco no puede uno solamente ver lo Mapuche porque también siempre está acompañado de otra persona porque es bueno para trabajar en compañía porque uno solo no puede, poco.	No because the, both things are important, at the same time you can't just see the Mapuche side of things because it's also always accompanied by the other person because it's good to work together because one alone can't, just a little. (Patient 34, Woman, 40)

8.3 The influence of community participation on care

As can be seen in quotes from the previous two sections, a number of patients felt that there was a correlation between having a high proportion of Mapuche staff members in the Hospital and lower levels of racism and discrimination towards Mapuche patients at the individual level. In addition, a few patient interviewees drew a connection between having a Mapuche administrator and improved access and quality of care, although this was much rarer.

No, yo creo que en el hospital indígena es menos feo que el hospital no indígena, feo porque yo cacho que hay poca, poca experiencia, poca confianza se tiene entre, entre Mapuches y no, y lo bueno que hay en este hospital buena, buena profesional, buena.	No, I think that in an Indigenous hospital it's less ugly than a non-Indigenous hospital, ugly because I see that there's little, little experience, little trust between Mapuche and non-Mapuche, and the good thing is that in this Hospital they have really, really good professionals. Really good. (Patient 20, Man, 30)

The quotes on pages 191 and 192 demonstrate some of the ways patients conceptualised having a Mapuche hospital administrator could lead to improved care at the organisational and system level. The quote on page 191 draws a connection between having Mapuche administration and strengthening the Mapuche health workforce through increased employment and training opportunities for Mapuche health workers. On page 192, the patient felt that a Mapuche administrator was more likely than a non-Mapuche organisation to fight to ensure that the

Hospital remained open and available to provide accessible services and to defend community interests. In the case of BFIHC, the Centre was established through the advocacy and organisation of the community, and Makewe Hospital remained in operation due to the Association taking up administration. In both cases, therefore, direct community action has been the driving force behind the availability of health services in close proximity.

In addition to the establishment and continuation of the centres, input by community members also led to services being expanded to accommodate expressed patient needs, as described by staff members. BFIHC staff indicated that the need to have comprehensive care close to home was frequently articulated by patients. The Director of Makewe Hospital expressed similar viewpoints and indicated that community consultation processes played a key role in deciding which health professionals to contract (see quote on page 175). The growth in the number and variety of health care professionals BFIHC contracted—in both the biomedical and traditional teams—as well as the increasing complexity in the care provided was attributed to the demands of the community. These needs were driven by the extreme physical, emotional and financial hardship imposed by travelling to urban centres for complex care.

No, es un choque tan, tan fuerte para ellos, culturalmente hablando. Dejar su hogar, dejar su animal, en dejar su familia, dejar su cultivo, para estar en un hospital. Nunca es fácil.	No, it's a really big shock to them, culturally speaking. To leave their house, their animal, leave their family, leave their crops, to be in a hospital. It's never easy. (Boroa staff member, non-Mapuche)

In this way, BFIHC staff interviewees noted that the articulated demands of the community as well as an increase in presentations at BFIHC have led to changes not only in the quality of care provided, but in the extent and complexity of the services offered by the Centre. The next quote, a continuation from that in the middle of page 168, explicitly ties the demands of the community as articulated through the TO to increases in professional attending hours. The quote following illustrates a similar point from the perspective of a community leader.

.... ahí yo creo que se generó también el hecho de que ahí tengamos a otros médicos, de que se amplíen las jornadas de todos los otros profesionales también, yo este año cumplí 8 años trabajando acá y cuando yo	….there I think that has also generated the fact that here we have other medics, that the days have been extended for all the professionals as well, this year I celebrated 8 years working here and when I arrived here I

llegué acá yo por ejemplo venía solo los lunes y los miércoles y médico había solo los lunes y los miércoles. Entonces ha ido creciendo, obviamente por las necesidades que nos expresa nuestra población.	only came for example Mondays and Wednesdays and the medic was only Mondays and Wednesdays. So that's increased, obviously because of the needs expressed by our population. (Boroa staff member, non-Mapuche)
Por ejemplo, se hace en catastro y cada comunidad pone un planteamiento y dice cuál es mi necesidad de la comunidad, qué es lo que necesita, cómo estamos y quién le gustaría que el centro de salud tuviera a su disposición. Por ejemplo en esto de pedir la hora, de venir a hacer y para venir al médico, por ejemplo, que nadie se vaya sin atenderse, por ejemplo, el dentista que atienda la semana corrida para que pueda atender a una comunidad completa, a un cierto número de personas, que nadie se quede sin atenderse.	For example, a registry is made and each community makes a plan and says what is it that my community needs, what is it that it needs, how we are and who would you like the health centre to have available. For example in this to request an appointment, to come to do and so the doctor comes, for example, that nobody goes away without being seen, for example, that the dentist attends during the week so that the entire community can be seen, a certain number of people, that nobody's there who hasn't been attended to. (Boroa staff member, Mapuche)

Due to the difficulties in accessing health care in urban areas, the presence of the Centre in the rurality of the Boroa territory was seen as a necessary progression from the system of *postas* (see Sections 2.3.3.1 and 7.1.2). The below quote indicates the belief from one staff interviewee that the model represented by Boroa, in bringing more complete care to rural areas, represents the direction that needs to be taken in rural health care.

Porque el, el sistema que actualmente existe para la población rural, es el tema de postas y estaciones médico rurales, que fue creado en los años 60, y que fue para traer a los profesionales de la ciudad al campo, pero, una vez al mes. Lo cual es totalme… Al tiempo de hoy en día, es totalmente	Because the, the system that currently exists for the rural population, it's the idea of *postas* and medical stations, which was created in the 60s, and which bring professionals from the city to the country, but one time a month. Which is totally….At this time, today, it's totally inadequate, because

insuficiente, porque la gente no puede esperar a la ronda para enfermarse. La gente se enferma hoy día, se enfermará mañana, pasado. Entonces, ¿por qué los profesionales tienen que estar tan centralizados?….Y, lo que necesitamos hoy en día, que sí ya es difícil conseguir profesionales para la ciudad, va a ser mucho más difícil conseguir profesionales para el campo. Pero, no por ello la población rural es menos importante que la población urbana.	the people can't wait for the rounds to get sick. The people get sick today, they'll get sick tomorrow, the day after tomorrow. So why do the professionals have to be so centralised?...And what we need today, which yes, it's already difficult to get professionals in the city, it's going to be much more difficult to get professionals in the country. But for all that the rural population is not less important than the urban population. (Boroa staff member, non-Mapuche)

Autonomy was a particularly strong theme for both Makewe Hospital and BFIHC staff members in speaking about the way the way participatory processes influenced the work of the health centres. At the level of the Centre, a level of autonomy was seen as a necessary component of community participation, being crucial to the ability of the Centre to fulfil those health needs expressed or identified by participatory processes.

The autonomy of individual patients was characterised somewhat as a positive-feedback cycle by BFIHC, with patients being empowered through the more equitable power relations exhibited by Centre staff to further demand improvements in the care delivered. The provision of both traditional and biomedical care on site was seen as crucial to this autonomy, both being a manifestation of the territory's will as expressed by the TO's initial proposal and an opportunity for individual patients to freely choose and have access to the type of care that best suited them. Members of the health team also saw respecting this choice as promoting patient autonomy.

Esa es una, una gran diferencia. Y, lo otro es el tema de poder elegir. O sea, si alguien se va a ver con la machi, *yo no le voy a decir nada, porque fue su elección. Yo no lo obligué, ni la* machi *lo obligó. Y, gente que a mí me dice: 'Doctora, yo me vi con la* machi,	That is a, a big difference. And the other is the idea of being able to decide. If someone goes to see the *machi*, I'm not going to say anything to them, because it was their decision. I didn't force them and the *machi* didn't force them. And people say to me,

discúlpeme'. Y, yo le digo: 'Pero, ¿por qué?' 'Ah, porque pensé se, se vería mal que yo me atienda con ella y con usted'. 'No, porque eso es parte de su autonomía, y eso hay que respetarlo'.	'Doctor, I went to see the *machi*, I'm sorry.' And I tell them, 'But why?' 'Oh, because I thought it would be seen badly if I come to see her and you as well.' 'No, because it's part of your autonomy, and one has to respect that.' (Boroa staff member, non-Mapuche)

8.4 Discussion

Patients' perspectives differed substantially from both those of MINSAL and service provider interviewees in that they were strongly utilitarian—that is, above all else, patients were most concerned with whether they felt they were receiving accessible and appropriate health care service. In contrast to interviewees from MINSAL or centre staff members, patients did not, on the whole, voice concerns about political power, Mapuche autonomy or the incorporation of Mapuche perspectives in public health policy. These differences had profound implications for how patients and providers viewed various elements of Makewe Hospital and its administration—while patients for the most part appreciated the cultural and community-oriented aspects of the Hospital, including its administration by a Mapuche provider, they did not consider these to be a core aspect of their decision to attend.

8.4.1 Patient perspectives in the assessment of quality primary health care provision

Development of indicators of quality primary health care provision has been undertaken in many contexts to support and evaluate the efficiency, efficacy and transparency of health care systems.[339,340] While there exists no universal definition of quality in health care, the WHO (2006) defines quality health care as occurring in six areas:

- Effective: Developed from an evidence base, delivers improved health outcomes for individuals and communities and is based in need;
- Efficient: Maximises the use of resources and minimises waste;
- Accessible: Delivers timely health care in a geographically appropriate setting and is supported by skills and resources that match the level of need;
- Acceptable/patient-centred: Aligned with the preferences, cultures and aspirations of service users and their communities;

- Equitable: Personal characteristics including gender, ethnicity, age, race, socioeconomic status and geographical location do not impact on the quality of care received; and
- Safe: Minimises risks and harm to service users.[339]

However, the concept of acceptable/patient-centred care may not fit in easily with other aspects of quality health care. Patient satisfaction as a concept is not clearly defined, and while patient satisfaction surveys are widely agreed to be an important tool in health care planning and quality control, the impact of patient feedback on improvement initiatives varies widely.[341] The Aboriginal Health & Medical Research Council (AH&MRC) Continuous Quality Improvement (CQI) Support Program was undertaken in order to develop practical tools that could be used to by ACCHOs to increase their capacity to undertake quality improvement initiatives.[342] As part of the program, an international review was conducted to examine the development and use of indicators of quality provision in primary health care.[342] The review found that while being patient-centred is a key component of quality primary health care,[70,339,343] the development of robust and meaningful indicators to assess the patient experience and patient satisfaction has proven challenging.[344-346] Moreover, the review indicated that patient involvement in the creation of quality indictors is rare.[347,348]

In Chile, health care indicators are largely concerned with clinical practice, efficient operation of the health centre and the mitigation of patient risks, with minimal focus on the patient experience or patient-centred aspects of care. Article 4, Section 11 of the 2005 MINSAL law DFL N°1[349] states that MINSAL has the authority to establish minimum standards for health service providers. The nine standards that service providers must comply with are:

- Dignity of the patient: Visibly display the Citizen Rights notice, be registered with an Information, Complaints and Suggestions Office, have patient informed consent forms available before high risk procedures are undertaken;
- Quality control: Be in compliance with defined quality control policies;
- Clinical control: Application of a program to evaluate and improve relevant clinical practices;
- Access, opportunity and continuity of attention (AOC): Explicit processes to provide immediate attention to patients in emergency situations with risks to life, as well as a triage system and risk notification systems;

- Appropriate human resources: Ensuring that clinical staff and other professionals are certified for their duties and undertake only those duties for which they are qualified;
- Records: Established processes to avoid lost files and maintain appropriate recordkeeping and confidentiality;
- Equipment safety: Undertaking appropriate measures to replace and repair equipment as necessary for patient safety;
- Infrastructure safety: Periodical review of threats to safety such as fire risks and procedures to mitigate them; and
- Diagnostic and therapeutic support services: Undertaking appropriate measures to ensure that diagnostic and pathology services are trustworthy and secure.[349]

Of these, only the 'Dignity of the patient' criterion focuses on how patients experience their health care. However, even this criterion is primarily concerned with the provision of patient information and ensuring that patients have the opportunity to have their complaints and suggestions heard, rather than incorporating indications related to patient satisfaction or experiences. Law 20.584, *The rights and responsibilities of the patient in relation to health care*, covered previously in Sections 2.3.3.1 and 5.3, establishes the patient rights that each health centre must respect. As covered previously, this law also establishes the right of Indigenous peoples to receive medical attention that is culturally appropriate in areas with high Indigenous populations.[228] These patient rights are covered in the Citizen Rights notice referred to in the 2005 MINSAL law and include:

- Have timely and understandable information about their health;
- Receive dignified care that respects their privacy;
- Be called by their name and attended with care;
- Right to information;
- Review of information contained in their clinical file;
- Free will;
- Autonomy to participate in scientific research;
- Rights of patients with mental or intellectual disability;

- Patient rights to participate; and
- Medications and consumables.[228]

Issues of patient dissatisfaction are a constant theme within the Chilean health care system.[350,351] A review of patient satisfaction was undertaken in 2013 as a result of the reported dissatisfaction with quality of care received in San Juan de Dios Hospital in Santiago. Within this study, nine criteria were evaluated:

- Wait times;
- Physical infrastructure;
- Personal care;
- Pharmacy services;
- Provision of information;
- Patient security;
- User satisfaction;
- Hospital accreditation; and
- Attention received.[350]

However, there is no indication that the selection of these criteria was developed through consultation with patients, or that these reflect what patients themselves prioritise in their care.

A qualitative 2013 study undertaken in the Metropolitan Region of Chile was the only one found that derived elements of perceived quality of health care from patients themselves. In patient focus groups the researchers found four principal themes that defined patient satisfaction:

- Warm personnel;
- Clear information provided in 'non-medial' terminology;
- Physical and psychological support; and
- Short wait times.[351]

The study also highlighted that the perceptions of patients and providers regarding the elements that defined quality provision of health care provided differed quite dramatically; they found only a 55.3% correlation in the ranking of quality indicators.[351]

8.4.2 Makewe Hospital patient perspectives

While elements of the patient experience must be weighed against measures of effectiveness and efficiency, patient satisfaction and comfort are also necessary to ensure that patients are able to access necessary care. Moreover, in the case of Indigenous health care in Chile, culturally appropriate care is a right enshrined in international and national law.[2,228]

The administrators of Makewe Hospital make a considerable effort to speak to community members, foster close connections to community leaders and ensure that the community is represented within the Hospital to the extent possible. In these ways, Makewe Hospital strives to more directly incorporate patient perspectives and concerns and orient its care towards a patient-centred perspective. At the same time, these are also factors that support the accountability of Makewe Hospital to the community, illustrating the entwinement of accountability and patient-centred care.

Makewe Hospital followed the general trend observed in the literature, where service providers and patients often have quite different views regarding what is important in health care provision and in determining quality health care. However, patient and staff interviews particularly illustrated this disjuncture in relation to political, rather than clinical elements. While Makewe Hospital staff made clear connections between Mapuche hospital administration and quality health care provision, they were also strongly concerned with the fulfilment of such values as Mapuche autonomy, political power and self-determination. Staff members stressed the importance of the space created by the Hospital for increased Mapuche representativeness and active engagement within the State. Within a framework of health that centred the importance of culture, human rights and Indigenous self-determination, staff indicated that these functions of the Hospital were valued as much as factors affecting the biomedical care provided. Patients, on the other hand, showed more ambivalence regarding the political and cultural nature of the Hospital.

Indigenous health policy in Chile is largely framed around the concept of 'intercultural health,' with a focus on the articulation between traditional and biomedical approaches to health and health care (Section 2.3.3.1). In practice within mainstream centres, this often means the use of intercultural facilitators and the use of Mapudungun in signage, which is more symbolic than

practical as the vast majority of Mapuche speak Spanish and those that do not are likely to be illiterate.[154] Although it offers only biomedical care, Makewe Hospital is recognised as an 'intercultural' hospital (the only one in Chile), with its administration by a Mapuche organisation a key part of its 'intercultural' nature, combined with the high proportion of Mapuche staff.

Patients did not speak directly about the concept of intercultural health. However, their emphasis on the dimensions of health care that related most closely to biomedical care provision and the relatively low priority given to cultural and political elements of the Centre may indicate that they do not see 'intercultural health,' at least as it is normally defined in Chile, as being immediately relevant to them. Rather, where patients appreciated the Mapuche nature of the Hospital was in the reported lower experiences of racial discrimination compared to other health centres, as well as the feeling that with the majority of staff being from the surrounding community, they were more likely to be understood. This may indicate two things: first, as Makewe Hospital offers only biomedical services and the *machi* and other traditional health agents were accessible in the community, 'intercultural health' is not a concern, since patients are able to access both systems in their appropriate and distinct contexts as needed. Relatedly, the reasons behind patient decisions to attend Makewe Hospital indicate the importance they placed on pragmatic elements such as elimination of racism and discrimination in biomedical care, geographical accessibility and reduced waiting times, rather than the 'intercultural' nature of the Hospital.

8.4.3 Patient choice and autonomy

In examining patient perspectives on primary health care in rural Canadian communities, Wong and Regan (2009) identified three main themes that influenced patients' health care seeking behaviour and their assessment of the quality of care provided.[352] *Making tradeoffs* entailed balancing their health needs with the financial costs and time and safety considerations of having those needs met. Geographic accessibility of services featured heavily within this theme, as the practicalities of travelling to regional or urban areas limited their capacity to utilise tertiary or specialist services. *Continuity of care* encompassed having an ongoing relationship between individual patients and their health care provider, which was important in building and maintaining trust; the continuity of information necessary for both providers and patients in order to manage chronic conditions effectively; and a coherent approach to the management of health care services. These last two dimensions, information and management

continuity, were also related to the theme of *Efficiency*, or having a well-organised system that minimised wasted resources.[352]

Interviews with Makewe Hospital patients and BFIHC staff members touched on each of these themes in various ways. Makewe Hospital patients repeatedly cited the physical proximity and the reduced wait time of the Hospital as a key feature in their decision to attend, and the perceived efficiency of management was central to patients' support of a Mapuche administering organisation. In BFIHC, the staff member's comments regarding the need for a move away from the *postas* system towards increased complexity of care provided within the community was tied to the themes of *Making tradeoffs* as well as *Continuity of care*. The high financial, time and emotional costs for patients who needed to travel to regional and urban areas for health care was a driving factor in the push for providing increased services in the community, as was the recognition that intermittent and disjointed access to medical personnel was insufficient for the health needs of the community.

Wong and Regan also note that people living in rural areas are more able to affect their health care in direct ways than people in urban areas, including through engagement regarding resource allocation and medical treatment.[352] This was reflected particularly in interviewees with BFIHC staff. With these interviewees, autonomy at the level of both the individual patient and the Centre was a key theme in relation to community participation—that is, the capacity of users to shape health care provision in order to ensure that it conforms to their needs. The question of autonomy is central to the theme of community participation—as explored earlier (see Sections 5.5.1 and 5.5.2), the extent to which Indigenous health services have operational autonomy is a reflection of the power communities hold to ensure health services conform to their needs and priorities. For BFIHC, this manifested as the capacity to provide increasingly comprehensive and complex care to their rural population, in recognition of the geographic, economic and cultural impediments that prevented community members from accessing appropriate care in urban areas. Moreover, the successes of the community as they were able to bring about change was then taken as evidence that further change was possible. Community empowerment and autonomy are commonly expressed as both a necessary condition for and an outcome of effective community participation, as the basis of the *empowerment* model.[71,72,78] This cycle of community participation, positive outcomes, empowerment and further community engagement is clearly evident in quotes from BFIHC staff.

8.4.4 Patient perspectives towards Mapuche health care administration

Overall, Makewe Hospital patients expressed values that reflected a 'utilitarian' approach to community participation.[62,63] That is, patients were mostly outcome-oriented, and supported Mapuche administration of the Hospital insofar as it furthered the goals of efficient, effective and high-quality health care, such as through reducing discrimination and ensuring continuation of access to services. In contrast, the democratic model of community participation was, for the most part, absent. Patients did not strongly indicate that they saw Mapuche administration of the Hospital as a vehicle for political power, except as it related to adequate health care funding or ensuing that the Hospital stayed open. These viewpoints are in line with the wider literature, which illustrates that patients tend to see the value of community participation in health through a utilitarian lens.[72,107] This may indicate that the health care decisions made by patients of Makewe Hospital are more strongly influenced by rurality, rather than Indigeneity. Studies also indicate that identity based on community or ethnicity may be relevant and 'practiced' in some facets of life, but not factor into others, including selection of and participation in health services.[353] Given the high costs in terms of both time and money to attend a service other than Makewe, it makes sense that these pragmatic considerations are at the forefront of the decision-making process.

The participation of the Hospital in Mapuche celebrations and ceremonies such as *We Tripantü* and *Nguillatún* was highlighted as being an essential part of the Hospital's role in the community by both staff and patients. Patients also highly valued the relationship between the Hospital and the community, which was assessed as being positive due to the participation of community leaders in such celebrations as well as community meetings. Patients spoke positively of the Association as a whole and expressed their belief that the Association would work on behalf of the community and ensure that health care continued to be accessible. This included providing work and training opportunities for community members and therefore more appropriate health care in the long term. This is tied to patients' approval of having a high proportion of Mapuche staff—patients associated this with less discrimination in care and recognised that this may not be the case under a non-Mapuche administration. Patients felt that as Association members were part of the community, they were more accessible and accountable.

However, there was some disjunction between the support of the Association and the value perceived by patients in having the Hospital administered by a Mapuche organisation. Several patients indicated that they were less concerned with having a Mapuche administering

organisation than they were with the quality of the biomedical care provided. This may indicate that patients see the role of the Hospital within the community and its role as biomedical service provider as being somewhat distinct. As the Hospital operates without direct connection to traditional Indigenous health care, patients may primarily value dimensions associated with biomedical care and see cultural and community issues as secondary considerations. Therefore, it could be that, as these patients attend the Hospital for biomedical services, they see the administrators' belonging to the Mapuche community to be largely immaterial to the care provided. As it was not possible to interview patients of BFIHC, where traditional health care is offered on site, it is difficult to assess whether this aspect of care affects the importance patients place on the incorporation of cultural values in the operation of the health centre.

The relative distance between the majority of patients and the non-clinical aspects of the Hospital may also affect their views of the Association. As previously stated, most patients are not involved with the Hospital outside of receiving health care. For the most part, it is the community leaders who take part in community-focused and cultural events (meetings, ceremonies, etc.). Patients' overall understanding and interest in this aspect of Makewe Hospital's operation may therefore be lower than it would otherwise be. Patients' ambiguity towards the benefit of Mapuche hospital administration is also likely to be in part related to not having a clear understanding of the role of the Association or health care administration in general—a position which would be common to many patients across health care settings. In Rodríguez and Caballero's 2013 review of patient satisfaction with care provided in a Santiago hospital, 85% of patients surveyed indicted that they did not know what the hospital accreditation process consisted of.[350] In the study, patients were also asked whether they knew the Rights and Responsibilities of Patients protocols established by Law 20.584,[228] which 73% did not. When asked why they did not know about these protocols, the highest proportion, nearly one third (32%) responded that they did not know about them because they were not interested.[350] These items may indicate a lack of knowledge and/or interest in the general Chilean public with regards to hospital administration, processes and operations that are not visible to patients or directly impact their experiences. In this case, the perspectives of the interviewed Makewe Hospital patients would be in line with this trend.

8.5 Conclusions

The current study was not designed to test whether community participation has led to increased service usage, better quality health care provision or improved health outcomes for Mapuche patients. Rather, patient interviews were conducted with the aim of understanding

how patients perceived and understood the relationship between the Hospital and the surrounding community as well as their perspective of the influence of this relationship on health care provision. The interview data suggest that for Makewe Hospital patients, participatory elements mattered less than pragmatic factors in assessing health care quality. Patients indicated that they did value the cultural and community-oriented aspects of the organisation, such as involvement in cultural and spiritual ceremonies and community meetings. They also spoke positively of the high proportion of Mapuche staff—associating this with less discrimination in care. However, these factors were not identified as primary reasons for deciding to attend at Makewe Hospital as opposed to another service. Rather, this choice of service providers was made primarily on the basis of factors such as geographic proximity, reduced wait times and higher availability of clinicians. Some did cite the availability of transport to other centres when necessary—a service not provided at other centres—as an additional factor.

There was a high amount of ambiguity about whether it was of particular benefit to have a Mapuche organisation administering the Hospital, as opposed to a non-Mapuche administration. While no patients were against the idea of having a Mapuche organisation administering the Hospital, the majority of patient interviewees were more concerned with the quality of administration, rather than whether the administrators were Mapuche or not. These seemingly contradictory points may indicate that while patients do value the cultural role the Hospital plays in the community, they primarily see the Hospital as a biomedical facility and its capacity to fulfil this role appropriately is a foremost consideration, even if this weakens the cultural and community aspects.

Chapter 9. Indigenous community participation in health: The case of Chile

This is the first of two discussion chapters which consider the Chilean case in light of international experiences in facilitating Indigenous participation in health. To support this discussion, the following model demonstrates the connections between themes explored throughout the thesis. The overarching impact of international and national legislation and policy on the available avenues for community participation is shown. The hierarchical relationship between national and jurisdictional health agencies is indicated through differences in the thickness of the arrows. Indigenous health centres form the interface between communities and State elements. Advocacy on the part of the health centres to be involved in decision-making and priority-setting is a key dimension of their interactions with State agencies. However, the use of uneven arrows shows the unequal nature of this relationship as well. Governance structures between individual Indigenous health centres, as well as between the health centres and non-governmental agencies are represented, as are the relationships between each of the health centres and the communities they serve. The 'Community' domain represents elements such as the traditional health system, cultural norms and traditional social structures as well as the health care needs of the community and perceptions regarding how well these needs are provided for (Figure 18).

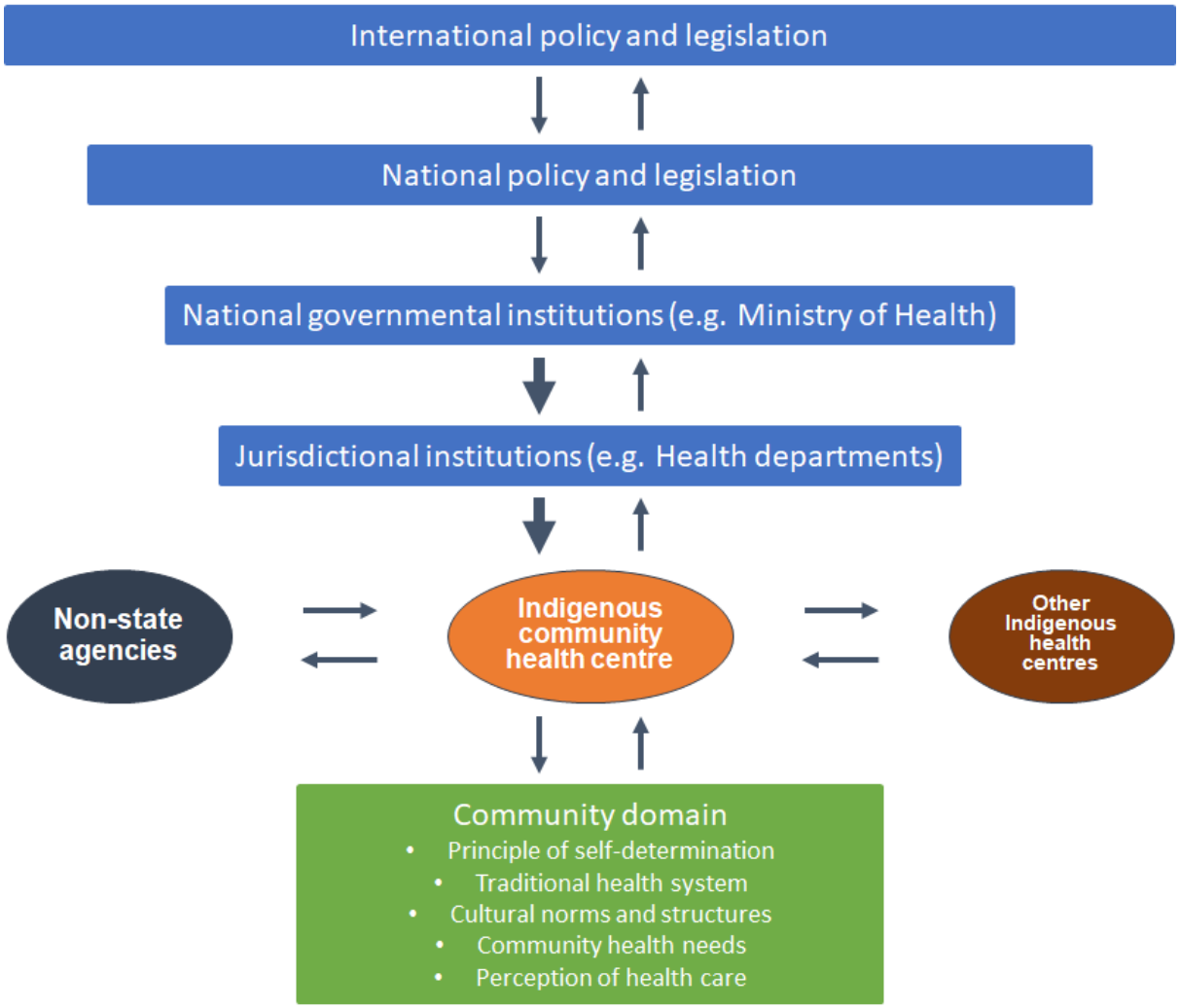

Figure 18. Indigenous community health centres and their interactions with community and state and non-state actors

The first section of the chapter outlines international approaches to the implementation of ILO 169; reciprocal accountability; Indigenous health governance and facilitating Indigenous control of health services. Drawing on Chilean and international experiences, recommendations for strengthening Indigenous community participation and supporting its efficacy in Chile are then presented in the second section.

9.1 Contextualising the Chilean experience

As illustrated in the above model and discussed throughout the thesis, mechanisms to enable Indigenous participation can be operationalised at multiple levels. The socio-technical network model helps to demonstrate the importance of having shared principles and understanding

across levels in order to facilitate effective participation.[106] Where a socio-technical network is unresponsive to the translation processes engaged in by other network actors, the interconnected and dynamic nature of the system is undermined and essential elements of governance such as participation, accountability and responsiveness are highly restricted.

The following sections therefore outline international approaches to Indigenous community participation which are situated at different levels. While international policy exists in the form of ILO 169, the UN DRIP and other instruments, the relevant principles and obligations hold limited force if they are not reflected in domestic frameworks. In addition to coherence between international and domestic legal frameworks, internal coherence with respect to policy and practice in community participation should also be considered. Reciprocal accountability as a way of detailling the responsibilities of all stakeholders in supporting Indigenous health can be embedded at all levels—from setting national-level policy to establishing funding agreements at the level of individual health services. The principle of reciprocal accountability goes hand-in-hand with enabling Indigenous forms of governance, and ensuring that Indigenous understandings of governance are reflected in governance structures throughout the system. The development of policy that facilitates Indigenous control of health services may be initiated at the national level but will likely be most strongly enacted at local levels.

9.1.1 Aligning international and national policy and legislation

Chile is subject to a number of international frameworks that are relevant to the government's obligations towards Indigenous peoples. However, ILO 169 is the only instrument that is legally binding and has been particularly influential in shaping discourse and expectations regarding Indigenous rights; although as has been seen, the principles laid out in ILO 169 have not been fully operationalised.

In addition to Chile, other Latin American countries have also struggled to ensure that the principles of ILO 169 are supported by and upheld under domestic law. In Colombia, legal decrees intended to provide guidelines around determining the conditions under which the right to previous consultation would apply were ultimately struck down under ILO 169 because they did not follow a consultation process with Indigenous communities. The Constitutional Court has therefore become the responsible body for establishing the regulations around prior consultation.[354] The Court has heard a number of cases in this regard and has released rulings in favour of Indigenous peoples and recognising the importance of maintaining the social, cultural and ethnic integrity of the country's Indigenous peoples. Additionally, the Colombian

government has issued detailed instructions about how to carry out consultations. However, the Constitutional Court rulings in conjunction with government guidelines have not been sufficient to provide a cohesive framework to govern previous consultation with Indigenous peoples.[354]

Examples of difficulties in implementing the principles of the Convention are also seen in Guatemala, where both government and extractive companies have argued against implementation of prior consultation on the grounds of economic and financial concerns. Multiple attempts to pass regulation regarding prior consultation have been struck down, some because the regulations themselves had not involved prior consultation with Indigenous groups. Under this context, there have been contradictory judicial rulings regarding the consultation process, and the Constitutional Court has ruled consultations to be merely informative.[355]

However, there have been countries that have taken measures to align national legislature with the principles of ILO 169. Peru ratified ILO 169 in 1994 and in 1995 the right to previous consultation for Indigenous peoples was enshrined in the Constitution; however, it was not until 2011 that a national law regarding Indigenous rights to previous consultation, *Law of the right to prior consultation for Indigenous and Native peoples* (*Ley del derecho a la consulta previa a los pueblos indígenas u originarios*), was passed. Despite this delay, Peru was the first country in Latin America to incorporate the principles of the Convention into national legislation. Nevertheless, issues of interpretation and identifying who 'counts' as Indigenous and is therefore included under the right to previous consultation continue to cause tension and conflict. Despite this step forward, implementation of the law is threatened by the government's refusal to uphold it: in all cases where mining interests have been at stake, the government has, to date, declined to recognise Indigenous rights to previous consultation. Moreover, there have been attempts by government officials to introduce exceptions for mining projects, or to limit the applicability of ILO 169 to only certain tribes.[356]

Norway was the first country in the world to ratify ILO 169 in 1990, after being a key player in the revision of ILO 107. As in Latin America, the question of land rights was a key concern.[357] However, in contrast with the experiences of most ratifying Latin American countries, Norway underwent a process of considering the alignment between national legislation and the principles of ILO 169 in the early stages, prior to and immediately following ratification. The Sami Parliament noted during consultation that while the Norwegian legislature was likely not in full compliance with the requirements of the Convention, there was ongoing work being undertaken to work towards this goal.[357] Overall, the perspectives of

the various governmental Ministries were congruent with this position, and there was a general consensus that the Convention could be ratified without prior changes to legislature. Moreover, it was held that ratifying the Convention could lead to stronger support for policy and legislation to protect Sami self-determination and land use rights. Vik and Semb (2013) credit this perception of overall congruence between the minimum standards of the Convention and the existing legislative Norwegian framework for the swift passage of the proposal to ratify ILO 169.[357]

An international comparison of legislative approaches to Indigenous health found that Constitutional recognition of Indigenous peoples and their special status helped to form the basis of coherent national Indigenous health legislation in the cases of New Zealand and the United States.[292] This is important in creating congruence both between international and national frameworks and within the country's jurisdictional levels. In particular, New Zealand's Treaty of Waitangi between the Māori and the British Crown has been a powerful influence in establishing the legal recognition of Māori peoples and in delineating Crown obligations with respect to Māori sovereignty. Governmental recognition of the distinct health needs of Māori people is encapsulated in three principles that were derived from the Treaty of Waitangi by the Royal Commission on Social Policy and subsequently used to guide government policy.[19,358] These principles are: *partnership*, or working together with iwi, hapū, whānau and Māori communities; *participation*, the involvement of Māori at all levels of decision-making, planning, development and delivery services; and *protection*, which involves the Government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.[359,360] The New Zealand Public Health and Disability Act 2000 sets out the District Health Boards' (DHBs) objectives around health inequities and Māori participation in health decision-making.[361]

In contrast, the cases of Australia and Canada, which do not have Constitutional recognition, exhibited weaker and more piecemeal legislative structures. In Australia, legal recognition of Indigenous health needs is scant, and where legislation does exist, it tends to outline objectives and principles, without detailing the mechanisms by which they will be accomplished. In Canada, there exists a lack of clarity around responsibilities for Indigenous health at various levels of government and the processes of funding, policy-making and implementation are fragmented and complex.[292] Attempting to address this situation is the basis of reciprocal accountability agreements.

9.1.2 Reciprocal accountability

Community participation has been identified as being necessary for Indigenous self-determination and autonomy—that is, the ability of Indigenous peoples to make decisions on their own behalf, act upon these decisions and have them respected and supported by governmental institutions.[362] However, as discussed previously (see Sections 2.2.2.1, and 5.6.3), community participation has been heavily criticised due to the ways in which the State devolves responsibility to communities for service provision or program implementation while maintaining control over aspects such as resource allocation and priority setting. As a result, communities assume the risks and burdens associated with providing services, often with limited resources, but continue to be restrained in their ability to respond appropriately to local needs and priorities.[111] As can be seen in the interviews with Makewe Hospital staff, community participation provokes tension between aspirations of being able to deliver appropriate and necessary health services to the community and being obliged to comply with the constraints imposed as a condition of legitimacy (Section 5.5.2).

The concept of reciprocal accountability was identified by a MINSAL interviewee as a potential benefit of Indigenous community participation in health. This interviewee expressed the belief that community participation would lead to increased community empowerment and engagement. This in turn would improve the transparency of State systems to communities, hence allowing communities to demand more accountability on the part of the State (Section 5.2.2). To some extent, this has been realised in that both Makewe Hospital and Boroa Filulawen Intercultural Health Centre have been successful in achieving significant advances through means of advocacy and negotiation. At the same time, however, while health providers articulated the view that increased participation enabled State accountability, they nevertheless also felt that the reality often fell short.

Similarly to the perspectives of Makewe Hospital staff, in Canada, the transference of health services to First Nations communities has been criticised as a mechanism by which the government divests itself of responsibility for First Nations health.[126] At the same time, the provision of First Nations health services is characterised by a complex network that has led to confusion over assigned roles as well as gaps in services delivered to communities.[292] The Tripartite Agreement first introduced in Section 2.2.3.1 and also discussed in Section 6.3.2 was primarily conceived as a way of providing clarity around lines of accountability, formalising the responsibilities of all parties and providing a more equitable balance in the responsibilities and obligations of First Nations and the Canadian government at the province level.[125]

The concept of reciprocal accountability has also been recognised as a cornerstone of Indigenous participation, control and engagement in health in Australia.[125,303] This has particularly been the case at the level of individual organisations with regards to financial agreements. As discussed in Section 5.6.3, historically, Indigenous organisations and communities have borne the brunt of accountability in terms of being expected to justify funding received by their respective governments in the form of onerous reporting requirements.[302] Sullivan (2009) highlights the scrutiny and control imposed onto Aboriginal people as a result of strict unidirectional accountability arrangements.[302] Reciprocal accountability is therefore seen as part and parcel of reimagining power relations between Indigenous communities and the State. In contrast to the approach taken by the Tripartite Agreement, where government obligations to their Indigenous peoples are made explicit, Sullivan draws on Edwards' work on accountability in community-public partnerships[363] and Mosse's conceptualisation of planning development as a process.[364] He thus proposes a view of reciprocal accountability that supports trust between governments and Aboriginal organisations and relies on building relationships and framing outputs as improvements in community members' lives as identified by individuals themselves.[302]

In Chile, interviewees identified a number of mechanisms that were valued for facilitating cooperation, planning and dialogue between the health centres and government and non-governmental agencies, such as the Mapuche Health Network (see Section 6.2). These can be seen as an example of Sullivan's view of accountability, focusing on building stable relationships between communities and governmental organisations.[302] Strengthening these platforms could provide additional avenues for transparency and accountability, even against the lack of explicit or formal reciprocal accountability agreements. Part of this process is ensuring that such governance structures not only reflect the culture of government agencies, but also incorporate Indigenous elements. This could also enable two-way learning processes, which create a more equitable relationship by positioning Indigenous peoples as experts on their own communities and health needs.

9.1.3 Enabling Indigenous forms of governance

While roundtables such as the Mapuche Health Network were described by interviewees as important for shared discussion, there was also acknowledgement of their limitations. Interviewees asserted that the effectiveness of regional governance structures depends on the existence of mechanisms to enable joint decision-making at State and regional levels, which is

minimal in all sections of Chilean government. Multiple interviewees indicated that the inability of the Chilean State to acknowledge and incorporate Mapuche ways of working undermined the capacity of communities to have appropriate input into decisions concerning health priorities, funding and resource allocation (Section 6.1).

In theory, intercultural health, which is often used as the framework for Indigenous health in Chile, is relatively 'agnostic' about power relations. That is to say, the aim of bringing together traditional Indigenous and biomedical approaches is removed from consideration of larger systems of domination and repression within which they operate. In practice, however, intercultural health has been characterised as 'ethnogovernmentality'—a process by which Indigenous knowledges, ways of thinking and doing are subsumed into Western bureaucratic processes under the guise of promoting Indigenous values.[301] The quotes provided in Section 6.1 give a sense of this when MINSAL staff indicate that 'in the Western world…they impose their own structure… (MINSAL staff member 2),' this structure being 'the form by which you can access or not access certain resources or certain benefits (MINSAL staff member 5).' At its core, governance (and community participation more broadly) is concerned with allocation of resources, identification of needs and priority-setting through negotiation and conflict mediation. Incorporating Indigenous ways of working helps to even the balance of power by acknowledging the validity of Indigenous perspectives and knowledge within this process.

In contrast to Chile, where Indigenous forms of governance are wholly invisible to the State, other countries incorporated Indigenous forms of governance as part of a larger legislative framework. In a report for the International Union for Conservation of Nature and Natural Resources, Cuskelly (2011) considers the question of state recognition of what she terms 'customary law,' or the 'customary worldviews, principles or values…enforced by community institutions.[365] The author views the tensions between State and customary laws as a question of perceived legitimacy—as the power of customary laws come from the community's acceptance, they are likely to continue to adhere to customary law where possible, even in the face of sanctions or penalties. In this review, 115 of the 190 constitutions were found to have some provision for customary law. Chile was not found to have any such provisions.[366]

If incorporated into the Chilean context, formal recognition of the roles of traditional authorities and the Mapuche worldview has the potential to facilitate cohesion between Mapuche and State conceptualisations of governance and provide stronger legitimisation of Mapuche governance structures. Given that the imposition of bureaucratic State requirements has been found to lessen the participatory dimension of administering Mapuche health care

centres, increased recognition of traditional governance within Mapuche organisations may in turn support wider forms of participation in health care. This recognition could be undertaken in conjunction with the Health Transfer Policy outlined in the next section as part of the process of providing policy and/or legislative provisions for distinctly Indigenous governance and administration structures.

The importance of flexibility in governance arrangements at local levels is highlighted in the findings of the Harvard Project in that maintaining 'cultural fit' necessitates the ability to adapt to local understandings of authority and appropriate organisational processes.[318] The findings of the Harvard Project are also congruous with the viewpoint that effective Indigenous governance draws on the strengths and capabilities that exist within Indigenous communities.[307,367] Dodson and Smith (2003) identified 'a strong cultural fit with the local community'[307] as being a critical element of good Indigenous governance, while the Office of the Registrar of Indigenous Corporations (ORIC) (2003) draws on the Harvard Project to characterise 'cultural fit' as entailing a balance between the standards of organisational governance and community traditions and values.[368] Given that these elements are highly context-dependent, this also supports the conclusion that good Indigenous governance must incorporate some level of flexibility.[367] In the cases of Makewe Hospital and Boroa Filulawen Intercultural Health Centre, the administrative organisations exhibited elements of both traditional Mapuche and State-imposed governance. The organisations fulfilled the requirements of the *personalidad jurídica* but in ways that were informed by traditional understandings of expression of power and authority. However, while the Mapuche organisations demonstrated flexibility in adopting State understandings of governance, there was no similar accommodation from the State.

9.1.4 Facilitating Indigenous control of health services

Worldwide, the expansion of Indigenous community-controlled health services has unfolded in various ways. Since the Mapuche Health Association of Makewe-Pelale took over administration of Makewe Hospital in 1998, there has been a proliferation of health care services administered by Mapuche communities, and the number continues to increase. The majority of Mapuche administered health centres have arisen directly from community demand rather than being transferred to community control. The notable exception to this is Makewe Hospital itself—and even here, the former administrator was the Anglican Church, rather than the State. In New Zealand, Māori health services are specifically developed and delivered by

Māori providers. District Health Boards (DHBs) are often the primary funders of Māori health providers and many Māori health providers are contracted to provide services on behalf of DHBs. Māori health providers are distinguished by support by manawhenua (territorial rights or authority) and/or the local Māori community; and mainly Māori staff members, owners and/or directors.[131,369,370] In the United States, American Indian and Alaska Native (AI/AN) Tribes may exercise community control over health services either by taking over management of existing services from the IHS or by developing such services *de novo*.[132,133,371,372]

Under Canada's 'Health Transfer Policy,' community control of health services is often accomplished through transfer of administrative control. Here, administration of established services that have previously been delivered by the federal government may be transferred to pre-existing First Nations governance structures that also have responsibility for managing other programs. Under this program, differing levels of community control allows flexibility in community management and implementation balanced with financial support from the federal government. A 2013 evaluation of the Health Transfer Policy found that communities experiences positive outcomes, including an increased awareness of health issues, increased culturally appropriate health care strategies in place and higher integration of health care and social services.[126,373]

9.2 Implications for Chilean policy and practice

This section aims to bring together the current situation in Chile with international experiences presented in the previous section and throughout the thesis to present some possible ways forward for Chilean policy and practice.

The following recommendations are presented foremost with a view towards promoting coherence between international and national policy as well as across all levels of domestic policy to strengthen Indigenous participation and governance. In the Chilean case, it can be seen why having a health system with a narrow and hierarchical structure renders it nearly impossible to realise good Indigenous health governance. As explored previously (see Section 2.3 and Chapter 5), within Chile decisions regarding health priorities, resource allocation and health programs are primarily made in Santiago. Using the socio-technical network model as a framework, the intercultural health centres can be seen as situated within at least three levels of networks—the first level occurring within the administrative structures of Boroa Filulawen Intercultural Health Centre and Makewe Hospital, the second being composed of the interactions between the administrators of the health centres and their communities and the

third being positioned between the administrators of the health centres and the State, represented by individual government agencies (see Figure 7). Lower levels of government at the regional and municipal level have limited latitude to take autonomous action in these matters, and are mainly tasked with administering those decisions made in the capital. Therefore, even in the case where community participation operates successfully at lower levels, the lack of good Indigenous health governance at higher levels limits the capacity of individual health centres to successfully mediate between the two. Developing appropriate Indigenous participation is therefore likely to necessitate a whole-of-system approach.

9.2.1 Formal mechanisms to enable adherence to ILO 169

As seen in the previous section, in addition to Chile, the experiences of a number of Latin American countries demonstrate the difficulties that can arise when the obligations of international instruments such as ILO 169 are inadequately supported or even undermined by national legislative frameworks.[173,174,354-356] Without the establishment of appropriate mechanisms to facilitate prior consultation, guidelines to judge whether the consultation undertaken is adequate and legislative pathways to clarify disputes, there is there is the possibility of increasing conflict, rather than resolving it. Specifically in the case of Chile, where national legislation does exist, it contradicts and limits the rights of Indigenous peoples laid out in the Convention and hinders even those government agencies that have the political will to undertake adequate consultation from doing so (see quote on page 107).

In acknowledgement of these issues, in 2014 Michelle Bachelet campaigned on a proposal to review and revise both DS Nº 66 and DS Nº 40 in consultation with Indigenous communities with the goal of creating transparency and accountability in the government's compliance with the standards of ILO 169. This was to include the dedication of financial resources to consultation and monitoring processes.[173,180] However, this did not come to pass. Therefore, an initial step towards bringing Chile's policy and legislative frameworks into line with ILO 169 would be undertaking this proposed review and revision of DS Nº 66 and DS Nº 40.

A review of the application of ILO 169 and the process of prior consultation in a number of Latin American countries found that an important consideration was ensuring cultural suitability. This includes the involvement of the appropriate authorities and institutions as selected by Indigenous peoples and communities and questions of timelines, which should be adequate and flexible enough to accommodate dialogue and negotiation as necessary.[174] Chile was one of the countries particularly identified as having a tendency to impose shortened and

inadequate timelines on consultation processes. Moreover, the language of DS Nº 40 was found to be unclear with regards to the appropriate process. In Chile and other countries, there is ambiguity in who should be involved in the consultation, both with regards to representatives for Indigenous peoples and the appropriate governmental or private bodies.

For these reasons, new legislation regarding consultation processes should be developed in partnership with Indigenous peoples. This approach would establish a common understanding between governmental institutions and Chile's Indigenous peoples regarding the purpose and expectations of consultation, situations under which the obligation to consult is triggered and mechanisms by which it should be realised. This same legislation should also outline grievance processes to resolve disagreements about whether adequate consultation was undertaken.

9.2.2 Enshrining Indigenous recognition and political representation

Chile is the only Latin American country, with the exception of Costa Rica, whose Constitution does not recognise any rights of Indigenous peoples or their right to prior consultation.[174] However, as outlined previously, Constitutional recognition of Indigenous peoples has been identified as a facilitating factor in developing a coherent legislative framework for Indigenous health.[292] The Constitutional recognition of Indigenous peoples and their right to prior consultation would therefore be a key step in establishing congruence between Chile's obligations as set out by international law and its domestic legal framework, as well as providing a strong policy basis for Indigenous participation. The topic of Constitutional recognition of Indigenous peoples has been under discussion in Chile since the return of democracy in 1990.[374] During this time, there have been numerous draft constitutional reform projects, the most recent having been initiated by Michelle Bachelet in the final week of her second term as the culmination of a consultative process first initiated in 2015.[374,375] However, with the subsequent initiation of Piñera's second term, the necessary steps to bring the proposal to fruition were not undertaken.

Section 2.3.2 discusses the current progress towards the establishment of a Ministry of Indigenous Peoples in Chile as well as a National Congress of Indigenous Peoples and associated Congresses of Peoples. This initiative attempts to ensure, through legislation, that each of the Indigenous peoples of Chile have formal mechanisms to contribute to appropriate policy-making. The successful formation of these bodies would enshrine avenues for Indigenous representation, participation and decision-making at the national level. As such, this would represent a historical and important step towards a more open government that

engages with the rights of Indigenous peoples to self-determination and to have a say in those matters that concern them. Importantly, the Congresses of Peoples, each representing one of the Indigenous peoples recognised by law, would be tasked, in part, with working alongside State agencies as well as the National Congress. Such an arrangement would help to support better coordination between Santiago and the regional areas of Chile, thus increasing responsiveness to regional contexts and providing some shift away from governmental centralisation.

The subsequent recommendations in this chapter would each be supported and furthered by the development of the Ministry and associated Congresses. These legislative bodies, if installed, would play a key role in the facilitation and coordination of each of the actions put forth below.

9.2.3 Development of a National Indigenous Health Plan

In research examining Indigenous health policies in Australia, Brazil, Chile and New Zealand, Chile was found to be the only country that did not have a national Indigenous health plan; it was also the country that had the lowest level of national policy relating to Indigenous health.[297] A national Indigenous health plan is valuable in that it allows governments, Indigenous organisations and communities and other stakeholders to come to a shared agreement on Indigenous health priorities and how to address these. The establishment of a national Indigenous health plan creates policy that illustrates government intentions and provides a set of expectations against which progress can be measured. As part of this, a national Indigenous health plan would ideally outline concrete steps to take and would incorporate reciprocal agreement principles in providing guidance regarding stakeholders' responsibilities. In achieving these goals, the national Indigenous health plan could facilitate coordinated action across different sectors in order to address those factors that impact on Indigenous health but lie outside of the health sector—*e.g.* education, environmental factors such as water, land and air quality and employment. The development of a national Indigenous health plan could be undertaken under the guidance of the Ministry of Indigenous Peoples and the National Congress of Indigenous Peoples.

9.2.4 Policy to facilitate Mapuche health care administration

While the development of policy at the national level is crucial, there also needs to be connections between national frameworks and support for Mapuche service providers on the

ground, in ways that contribute to their day-to-day work. This section outlines a number of policy instruments to strengthen and recognise Indigenous health care providers.

A recurring theme in interviews was the precarious position of Mapuche health care providers with regards to both funding and the capacity to exercise autonomy, largely due to a lack of formal recognition of the existence of Indigenous health care providers and the economic and social reality of the contexts they work within. Here, three policy strategies are presented to solidify and expand Mapuche health administration in Chile. The three strategies: 1) formal recognition of Mapuche health care providers, 2) policy enabling the transference of existing health centres to Mapuche administration and 3) the development of reciprocal accountability agreements would ideally be implemented in conjunction. In this case, the strategies are likely to have an additive effect, as they will be mutually reinforcing. However, where this is not possible, or where the strategies are each implemented gradually, the individual strategies by themselves are likely to have positive effects on the positioning of Mapuche health care services and providers and the relationship between them and the State.

9.2.4.1 **Formal recognition of Mapuche providers/administrators and their unique circumstances**

Mapuche health care administrators cited the lack of policy support for their position as one of the main barriers to their work and keeping the health centres operational. As it currently stands, Mapuche health centres are only able to operate under legislation intended for private, for-profit health services and created with the assumption that patients of these services will be able to pay rates high enough to contribute to running costs. This runs counter to the situation in Mapuche communities with high needs and low resources.

The installation of legislation that creates a separate category of providers could allow for the creation of regulatory and resource allocation processes that are more accommodating than those currently in place for private and for-profit service providers. This legislation would not necessarily need to be specific to Indigenous providers. Rather, it could pertain to, for example, non-governmental entities providing health services to disadvantaged or high-needs areas. Under this new category of health care providers, more flexibility in financial arrangements could be introduced, as well as increased clarity around funding mechanisms. This would serve to remove some of the current inappropriate impositions experienced by Mapuche health services, such as the ‘guarantee’ discussed in Section 5.5.1. As part of this, alternate ways to

finance health services for specific populations according to level of need could also be established.

9.2.4.2 **Health transfer policy**

Interviews with Boroa Filulawen Intercultural Health Centre staff highlighted the inadequacy of the *posta* system for meeting the health needs of people in rural communities. For this reason, the establishment of centres such as BFIHC was seen as an important step forward in addressing issues of geographic inaccessibility while providing care that was localised and suited to the needs of the community (see Section 8.3). However, a key barrier to the development of more comprehensive health services in rural areas is the lack of staff available—both as administrators and as clinical personnel. Facilitating Mapuche administration of health centres located within Mapuche communities would be a way of addressing this barrier—however, as discussed above, the current lack of legislative and policy support impedes this step.

In order to expand Indigenous community control, a Health Transfer Policy such as Canada's may be possible in Chile, particularly for health centres placed in Indigenous communities or in areas with a high Indigenous population and possibly extending to *postas*. To some extent, Makewe Hospital itself is a demonstration of the validity of this approach—while the Hospital was never government-operated, the Association initially convened for the purposes of taking over administration from the Anglican missionaries that had established the Centre in order to avoid government control.

As it currently stands, Chile has no legislative or policy provision for the Indigenous administration of health services. Rather, services such as Makewe Hospital are treated as private health care centres, which places them under regulations that do not correspond with their economic reality and causes them to be at continual risk for financial unsustainability and closure (Section 5.5.1). In order for a Health Transfer Policy to be operable in Chile, an initial step would need to be the policy and/or legislative recognition of Indigenous governance and administration structures. This could be beneficial for Indigenous service providers across the country, as such recognition could lead to more explicit policy regarding the roles of Indigenous administrators and how best to support them.

In conjunction with legislation that facilitates Indigenous administration of health services, adopting a version of the Health Transfer Policy based on the Canadian experience could serve to expand Indigenous community control in health and deliver proactive support for Mapuche

communities wanting to deliver their own health care services. As previously indicated, under the Canadian policy, First Nations governments assume administrative control over health programs to the extent outlined by the selected transfer level; however, the federal government continues to supply financial support, determined by historical expenditure.[128]

Canada's Health Transfer Policy has been criticised for not enabling full First Nations control over community health services. Rather, critics point to the policy as extending governmental control over health services through accountability requirements and providing insufficient community capacity-building, thereby undermining Indigenous autonomy.[126,128] At the same time, adoption of this policy in Chile could serve to further establish the validity of Indigenous health service providers and provide a level of financial support that is currently unavailable. Moreover, application of the policy could be strengthened through the establishment of reciprocal accountability agreements.

9.2.4.3 **Reciprocal accountability agreements**

Interviewees identified reciprocal accountability as both a facilitating factor and, ideally, an outcome of Mapuche participation in health. The principle of reciprocal accountability, where all parties have responsibility in ensuring equitable Indigenous health outcomes, has been utilised in both Australia and Canada to reframe the relationship between governments and Indigenous health care providers.[125,302] Reciprocal accountability agreements can be utilised at multiple levels to ensure clarity around stakeholder responsibilities, transparency regarding expectations and a more equitable distribution of power between Indigenous communities and other parties responsible for Indigenous health.

Adoption of an approach similar to British Columbia's Tripartite Framework Agreement[125] at the regional or national level in conjunction with the establishment of a Ministry of Indigenous Peoples in Chile could strengthen the development of Indigenous health programs in a coordinated fashion. With guidance from the Ministry, arrangements could be made for increased consolidation of Indigenous health policy, including both the first national Indigenous health plan and the articulation of the expected contributions of various stakeholders to Indigenous health goals.

The approach to reciprocal accountability in funding mechanisms outlined by Sullivan[302] could hold promise for increased alignment between autonomy on the part of service providers and necessary support structures. At local levels, refinement of accountability mechanisms could include evaluations of performance that incorporate measures such as client satisfaction and

support. The establishment of reciprocal accountability agreements would serve to address the current insecurity in Mapuche health administration by providing clear and explicit guidance regarding the governmental support to be provided. In addition to clarifying financial support, these agreements could also focus on issues of capacity-building for Mapuche administrators or communities that would like to prepare for taking on administrative responsibilities in the future. This would be particularly relevant to the second strategy presented, enabling a smoother transition of health centres and *postas* to Mapuche administration.

Within the Chilean context, there are two key barriers to the implementation of reciprocal accountability measures. First, given the country's high level of centralisation, the development of an Indigenous health sector that facilitates input into decision-making processes at local and regional levels is likely to be a work in progress for some time. Further to this, reciprocal accountability requires the government to recognise specific Indigenous health needs and to acknowledge its own responsibility for addressing them. As it currently stands, Chile has very little legislative and policy infrastructure that supports these actions. However, as previously indicated, with the creation of a Ministry of Indigenous Peoples, there may be increased scope to strengthen this area. Similarly, formal recognition of Mapuche health services could be established through partnership and reciprocal accountability agreements between the services and relevant health departments either in addition to or in the absence of the legislative and policy changes outlined in the above sections.

9.2.5 Strengthening sectoral cohesion

The number of Mapuche health providers continues to grow, and the sector has established various mechanisms that aim facilitate discourse with relevant governmental and non-governmental organisations, such as the Mapuche Children's Roundtable (Section 6.2). Moreover, as detailed, individual providers regularly engage in advocacy at various levels. At the same time, however, the sector continues to be disjointed, which can make advocacy and negotiation less effective.

The historical and cultural tendency for Mapuche communities to be very distinct and autonomous has led to a high level of variation in the forms of governance structures within health centres as well as in the types of services provided (for example, whether traditional Indigenous healing is provided on-site) (Section 6.1). This allows communities to maintain their independence and health services to be conducted in a way that embeds local values and priorities and may support a higher level of community ownership of health services. However,

this high level of independence between health centres may be part of the reason for the low cohesion found across the sector, with individual health centres interacting with each other through loose networks and negotiation with the State being undertaken in an *ad hoc* fashion. Interviewees indicated that while the current measures to support coordination across Mapuche health centres were important, these networks tended to be reactive against threats as they appeared and limited in their capacity to be proactive as a sector. For this reason, instituting mechanisms to strengthen cohesion between Mapuche providers could lead to enhanced policy creation, negotiation and advocacy. Having governance mechanisms in place that would enable Mapuche providers to come together and speak in a unified manner at regional and national levels would provide a more stable platform from which the sector could seek representation.

While increased sector cohesion at higher levels may be beneficial, the strengths of community-based service provision in its strong connection to local community dynamics and needs should also be recognised. Particularly in the case of the Mapuche, the historical and cultural importance of community independence and autonomy is paramount. Local service providers should therefore be enabled to continue operating independently at the community level while contributing to the stability of the sector as a whole.

9.3 Conclusions

The last few decades have seen a rise in international Indigenous networks and the establishment of international frameworks for conceptualising the rights of Indigenous peoples alongside a general increase in the methods by which policies are borrowed, adopted and adapted as countries look outside their own borders to learn about new ways of addressing pressing issues. In the field of Indigenous health, this has been demonstrated in a number of comparative policy studies and reports that reflect on how Indigenous policy has been developed and implemented in a variety of contexts with an eye towards learning from the experiences of others.

The establishment of international Indigenous policy has proven to be a strong factor in shaping policy at the national level. Despite the difficulties in implementing ILO 169 and the limitations of the Convention itself, it has been instrumental in the development of national and international standards in relation to free, prior and informed consent with Indigenous peoples in relation to matters that concern them. Taken in conjunction with the UN DRIP, the two international instruments provide a recognised framework for the conceptualisation of

Indigenous peoples' rights to consultation and engagement within the context of their self-determination and cultural and territorial retention.

As the first of two discussion chapters, this chapter aims to bring together the main themes explored throughout this thesis and locate them within the broader international literature before considering some implications for the improvement of Chilean policy and practice in Indigenous participation in health. In this way, it offers a new contribution to the literature by examining the interconnected role of international, national and local factors in shaping Indigenous community participation and applying the lessons learned to the particular case of Chile.

In considering the Chilean and international experiences, a number of elements to strengthen Indigenous community participation in health are presented. The majority of these lie within the purview of the Chilean government. These include the establishment of governmental bodies to enact Indigenous representation across government, strengthening legislative cohesion regarding Indigenous participation, and the installation of policies to provide more security for Indigenous health providers and enhanced coordination in addressing Indigenous health. Finally, the possible benefits of strengthening cohesion between Mapuche health providers to increase political power are put forward.

The next chapter shifts perspectives—while continuing to reflect on the same themes presented throughout the thesis, its focus moves from the case of Chile to consider their relevance to international policy and practice with regards to Indigenous participation in health.

Chapter 10. Implications for international policy and practice

As previously stated (see Section 2.4), in the field of Indigenous health much of the comparative literature is centred around Australia, Canada, New Zealand and the United States,[127,248,300] as are many of the professional networks.[242,376] This is primarily because these four countries share a dominant language, a history of settler colonialism and other historical similarities. Indigenous populations across these countries also exhibit poorer health outcomes in relation to their non-Indigenous counterparts, leading to governments looking elsewhere for innovative and effective approaches to support improved health outcomes for their Indigenous peoples. Indigenous peoples worldwide share some factors relating to health. These include holistic conceptualisations of health and similar underlying principles, including self-sovereignty, health equity and incorporation of Indigenous knowledges (see Section 2.1). There are also shared challenges across borders: policy failings due to a lack of articulation and difficulties in developing genuinely equitable relationships with State authorities, among others. At the same time, differences in factors such as political and legislative environments and demographic patterns have shaped the ways that Indigenous affairs, including Indigenous health, have been addressed. The four countries therefore exhibit stark differences in Indigenous health policies, strategies and programs.[19,248,297,377]

These differences in approaches and their strengths and weaknesses provide opportunities for learning. There has been little in the way of 'hard' Indigenous health policy transfer between the countries, despite fairly established avenues for evidence and information sharing, with the possible exception of top-down processes, such as the establishment of international agreements. However, within Indigenous health, the shared underlying principles of self-determination and Indigenous sovereignty may mean that this field is more amenable to being shaped by civil society, including Indigenous community organisations both within and outside of the health sector. In this case, the 'soft transfer' of ideas and evidence may have a strong direct influence on how Indigenous health is addressed, rather than primarily through its influence on government policy and legislation.[239]

This chapter builds on the previous, which placed the Chilean experience within an international context, and goes on to consider what implications there may be for the broader field of Indigenous community participation in health. As such, it responds to the fifth and final research aim. The chapter consists of two sections which cover policy and practice. The

first section presents lessons for policy supporting Indigenous community participation and as a practical application attempts to answer the question: What does international experience advise regarding whether Australia should ratify ILO 169 and, in the case of ratification, what supports need to be in place to allow the principles of the Convention to be realised? The second section examines lessons for the development and support of Indigenous community health services as pathways for community participation in health.

10.1 Australia's ratification of ILO 169 as cross-country policy transfer

Lixinski (2017) presents the case that Latin America may provide a particularly rich source of knowledge and experience in engagement with Indigenous peoples, particularly for Australia.[378] Lixinski cites the historical reluctance of Canada, Australia, New Zealand, and the United States to engage with international agreements such as the UN DRIP and ILO 169. This leads to the suggestion that looking towards countries that are more willing to do so, such as in Latin America, may provide relevant lessons. The relative ease and frequency with which countries in the region exchange ideas, policy and best practice regarding Indigenous issues also speaks to the possibility of opening this network to English-speaking countries.[378]

As reviewed in Section 2.4, Mossberger and Wolman's (2003) *prospective policy evaluation* framework aims to assess those elements that will contribute to successful cross-country policy transfer.[250] This is in contrast to the majority of policy transfer frameworks, which tend to adopt a retrospective approach. Here, Australia is being used as a case study to consider how lessons from other countries' experiences of ratifying ILO 169 and implementing its principles can be applied to understand some of the potential benefits and challenges associated with ratification of ILO 169 for countries that have not yet done so.

In considering the difficulties in cross-country policy transfer, Mossberger and Wolman identify differences in political systems and policy environments as being particularly relevant. The authors consider the following criteria as being part of a rational assessment of prospective policy evaluation, noting that not all of the criteria may be feasible in practice:

- Awareness of policy ideas, including two dimensions of assessing information quality: s*cope of information* and *adequacy and accuracy of information*
- Assessment of the policy as relating to the following criteria:
    - *Similarity of problems and goals* addressed by the policy in the originating country and the targeted problems and goals in the borrowing country;

- *Policy performance* in relation to the stated problems and goals; and
- *Differences in setting* between the originating and borrowing countries which may affect implementation

- Application with regards to whether and how information about the policy as enacted in the originating country is used in the borrowing country.[250]

Regarding the application of policy in the borrowing country, Stone (2012) considers the ongoing assimilation of the adopted policy as the forces of the borrowing country continue to shape the policy after it has been installed.[239] Stone indicates that this may lead to increased local ownership and receptivity over time. Nevertheless, this acceptance remains tied to an initial consideration of the appropriateness of the transfer to the borrowing country.[239] Stone's perspective is that of a dynamic interplay between the adopted policy and the local context, with the policy continuing to adapt to local factors.

The following sections apply the prospective policy evaluation framework in light of the experiences of Chile and other countries. In considering Australia's adoption of ILO 169, the policy in question would not only be ratification, but the development and installation of an adequate and supportive domestic legislative framework to ensure adherence to the principles of the Convention.

10.1.1 Scope and quality of available information on implementation of ILO 169

Mossberger and Wolman's criterion of *awareness* includes both active information-gathering as well as becoming aware of policy passively through networks, the media and professional organisations. The criterion incorporates two dimensions by which to assess information quality: the *scope of information* and the *quality and accuracy* of information. The existence of a broad scope of information allows for the incorporation of knowledge regarding where a policy has worked well, while accurate information supports an evaluation of the goals, design and operation of the relevant policy.

The experiences of various countries regarding the implementation and outcomes of the 23 countries that have ratified ILO 169 have been documented systematically and in detail over the course of nearly 30 years, ensuring a wealth of information and examples from a broad variety of contexts on this issue.[44,379,380] There are also a number of guides and handbooks to support implementation for ratifying countries.[41,42]

While Australia has not ratified the Convention, there has historically been awareness of it; specifically, there have been two key points where Australian ratification of ILO 169 was briefly under consideration. Australia considered ratifying ILO 169 in 1993, soon after it was adopted. At this time, the Aboriginal and Torres Strait Islander Commission (ATSIC) called for submissions regarding ratification in order to present Aboriginal and Torres Strait Islander peoples' and communities' viewpoints on the subject inform the Government's decision.[381] Despite this, however, the Australian Government ultimately declined to ratify the treaty. In 2011, the United Nations Human Rights Council (HRC) undertook a Universal Periodic Review (UPR). The UPR is a process under which the human rights records of all UN Member States are reviewed and recommendations are provided regarding how countries can work towards fulfilling their human rights obligations.[382,383] Following the 2011 UPR, Australia committed to formally consider ratifying ILO 169.[384] Again, however, there has been limited movement towards ratification since that time.

10.1.2 Assessing ratification of ILO 169

10.1.2.1 **Similarity of problems and goals**

Under the prospective policy evaluation framework, having a high *similarity of problems and goals* addressed by the policy in the originating country an intended to be addressed in the adopting country supports appropriate judgement regarding anticipated performance.[250] In this case, assessing this criteria involves reviewing the objectives of ILO 169 as intended when it was drafted in addition to the motivations of ratifying countries and identifying the issues it would be intended to address in Australia.

As a tripartite agreement, ILO 169 is intended to support shared understanding between governments, employers and workers regarding a common framework for the minimum terms of governmental obligation towards their Indigenous peoples and mechanisms for safeguarding their collective rights. It is aimed toward abolishing discriminatory practices and safeguarding Indigenous peoples' rights to participate in those matters that affect them with the end of promoting Indigenous self-determination and the preservation of cultural identity and distinctiveness.[42] In particular, the Convention articulates the obligations of governments of ratifying countries to protect the rights of consultation and participation of Indigenous peoples.[42]

Latin American and the Caribbean is the region that has the most ratifying countries.[43] During the time the Convention was being drafted, an increased level of recognition of Indigenous people was taking place, alongside a transition for many countries from authoritarian regimes and dictatorships to democracy.[385] As part of this, there was also a high degree of mobilisation among Indigenous and other marginalised groups and civil society more broadly for inclusive policy and equitable distribution of resources. As such, the ratification of ILO 169 can be understood as being part of a wave of initiatives to strengthen democratic and human rights frameworks.[385] Additionally, as described previously (see Section 2.1.3), the question of Indigenous land rights is fraught throughout Latin America. The implementation of a framework that could support the resolution of land rights conflicts is therefore particularly important for Latin America's Indigenous peoples, as is evident in the types of claims made against the Convention.[385] In a 2009 review of judicial decisions on matters relating to ILO 169, nine of the ten countries represented had judgements concerning lands and territories or natural resources.[44]

In Norway, ratification of ILO 169 in 1990 was preceded by a growing recognition of the Saami as an Indigenous and minority people, including through Constitutional amendment. The Saami Parliament was established in 1989, in part to ensure that Saami retained customary rights to their traditional lands and waters and connected resources. Against this backdrop, ratification of ILO 169 was an additional step in developing legislative structures to uphold the rights of the Saami people.[380]

While Australia is not a signatory to ILO 169, the right of its Indigenous peoples to consultation regarding matters that concern them is enshrined in international policy as Australia declared its formal support for the UN DRIP in 2009.[50] It is worth noting that Australia was one of the last countries to do so and one of only four countries that voted against adoption in 2007.[291] Australia is also a signatory to 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR), which recognises the right to health,[386] as does the 1948 Universal Declaration of Human Rights (UDHR).[51] However, as is the case with Chile and other Latin American countries, the principles of these international agreements are not fully reflected in Australia's national legislative framework. With regards to Australian health legislation, there is little recognition of Aboriginal and Torres Strait Islander health needs at either national or sub-national levels. Where these needs are acknowledged, there are few mechanisms outlined for Aboriginal and Torres Strait Islander input into decision-making or program development.[292] A systematic review of Australian legislation found that the existing

frameworks lent little support for good governance in Aboriginal and Torres Strait Islander health.[292]

Although not embedded in legislation, principles of ensuring the involvement of Indigenous communities and organisations in the planning, development and implementation of health policies and programs that affect them are found throughout the mainstream health care system. A review of principles espoused in national, state and territory planning documents in Aboriginal and Torres Strait Islander Health and wellbeing was recently undertaken.[387] The review indicated that all analysed documents explicitly included the principles of partnering and engagement with Aboriginal and Torres Strait Islander organisations and communities in the design, development and implementation of programs to address Aboriginal and Torres Strait Islander health and wellbeing. However, this same review found that these principles did not necessarily manifest as action in all aspects of health service operation.[387]

The *Native Title Act 1993*[388] was instituted as a mechanism for recognition of some Indigenous peoples' rights to their traditional land and waters and to resolve such claims.[389] The Act also provides avenues for engagement between Aboriginal and Torres Strait Islander communities and mining companies and other land users.[390] However, Aboriginal and Torres Strait Islander communities struggle to maintain the level of protection afforded by the 1993 law as over the years, a series of amendments to the Act proposed by the extraction industry have been criticised for undermining Aboriginal and Torres Strait Islander land rights.[391]

The current situation in Australia therefore demonstrates similarities with regards to the issues that ILO 169 is designed to address. That is, Australian policy and legislature is characterised by limited provisions for the engagement of Indigenous peoples across sectors and levels of government. Ongoing disputes over land use and the erosion of protections for Aboriginal and Torres Strait peoples' rights to their traditional lands also show parallels with the types of situations that prompted other countries to ratify the Convention.

10.1.2.2 **Differences in setting**

Attempting to strike a balance between assessing the experiences of others while acknowledging the *differences in setting* is common across the field of cross-country policy transfer. Mossberger and Wolman include such considerations as legal, political or administrative structures to support the policy, the influence of particular interest groups and cultural beliefs or popular opinion as local factors that may affect the performance of a policy within a particular setting.[250] In the case of Australia, widespread consultation with Aboriginal

and Torres Strait Islander communities and organisations, mining and extraction companies and other stakeholders would be needed in order to thoroughly understand the position and possible impact of each of these elements.

A trend amongst the countries that have ratified ILO 169 is a preceding push towards increased recognition of and engagement with Indigenous peoples. In these cases, the ratification of the Convention may be seen as a way to cement the Government's commitment to upholding Indigenous rights. In some ways, Australia's current Indigenous policy environment illustrates similar characteristics. Australia is currently undergoing a renewed debate regarding Constitutional recognition of Aboriginal and Torres Strait Islander peoples. As part of a wider move towards increased Indigenous representation and recognition, the Referendum Council was established in December 2015 to provide advice regarding the recognition of Aboriginal and Torres Strait Islander peoples in the Australian Constitution.[392,393] As part of its work, the Council undertook an extensive consultation process with Aboriginal and Torres Strait Islander peoples across Australia. A key outcome of this process was the Uluru Statement from the Heart, which called for two actions to support Aboriginal and Torres Strait Islander sovereignty:

- A national representative body, enshrined in the Constitution, which would advise parliament on laws affecting Indigenous peoples; and
- The establishment of a Makarrata Commission to support agreement-making between governments and Indigenous peoples and undertake a truth-telling process about Australia's history.[394,395]

The constitutional enshrinement of a national Indigenous advisory body was rejected by the Australian Government in October 2017.[396] This rejection was seen to have profound implications, including a curtailing of Indigenous governance and a lost chance to address inequitable power distributions between governments and Indigenous peoples.

Currently, where structures to support Aboriginal and Torres Strait Islander governance exist, such as regional health planning forums, they are based on a collective understanding of the ethical need for the involvement of Aboriginal and Torres Strait Islander peoples in decision-making and policy-making processes. This can be seen in the recent establishment of the ten-year Partnership Agreement on Closing the Gap 2019-2029.[397]

In 2007, the Council of Australian Governments (COAG) committed to 'closing the gap' in health outcomes between Aboriginal and Torres Strait Islander people and other Australians

by the year 2030. COAG represents federal, state and territory and local governments, indicating commitment across all levels of government.[398] To date, only one of the targets, halving mortality in children under five years old, is on track to be met by 2030.[399] The consistent underperformance of the Closing the Gap initiative has been tied to a lack of engagement and partnership with Aboriginal and Torres Strait Islander peoples.[400] This has extended to criticisms that the proposed 'Voice to Parliament' would have been the most important mechanism to enact the extended consultation proposed as part of the Closing the Gap 'refresh' in response to consistently failing to meet set targets.[401] As part of the Closing the Gap 'refresh,' the Partnership Agreement on Closing the Gap 2019-2029 was established, representing the first time Aboriginal and Torres Strait Islander people, through peak body representatives, will share decision-making with governments on Closing the Gap.[402]

However, as discussed above, the incorporation of Aboriginal and Torres Strait Islander peoples into decision-making processes is not established as a legal obligation. With the Government rejection of the Referendum Council's proposal to enshrine a 'Voice to Parliament' in the Constitution as set forth in the Uluru statement, the way forward for legal recognition of Aboriginal and Torres Strait Islander peoples and embedded mechanisms to ensure Aboriginal and Torres Strait engagement in matters that concern them has been characterised as uncertain.[403,404] In the wake of the Government's rejection of the proposal, this lack of established mechanisms for Aboriginal and Torres Strait Islander engagement has been repeatedly tied both to limits around Aboriginal and Torres Strait Islander peoples' self-determination and to the ongoing health inequalities faced by Aboriginal and Torres Strait Islander communities.[404]

In the midst of these discussions, Australia's 2009 decision to formally support the UN DRIP has been raised in order to signal the rights of Indigenous peoples and the obligations of the Australian government to uphold these rights as established by the Declaration.[1] Notably, the UN DRIP is mentioned repeatedly throughout the Referendum Council's report, as the UN DRIP principles were a consistent theme raised during the consultation processes undertaken as part of the report (First Nations Regional Dialogues). These conversations indicated a number of different proposals regarding the application of the principles in constitutional reform—from utilising the UN DRIP principles generally to guide and underpin the process of constitutional recognition to the incorporation into the Constitution of the specific rights of Indigenous peoples outlined by the Declaration.[394]

10.1.2.3 **Policy performance**

The previous section demonstrated that the *policy performance* of the ratification of ILO 169 is variable across different countries with regards to the installation of a coherent legislative environment to achieve the enshrined principles. Mossberger and Wolman make the point that although a particular policy may have problems in the lending country, this in itself may not indicate that it should be rejected for adoption outright. Rather, such examples of policy 'failure' may provide important information regarding elements needed for success in another country context.[250]

Taken as a whole, the implementation and outcomes of ILO 169 in other countries indicates the importance of having a coherent domestic policy and legislative framework to uphold the rights outlined in the Convention or the flexibility to develop such a legislative environment over time. In addition, the careful consideration of the likely roles and positions of stakeholders such as Indigenous communities, the private sector and governmental and non-governmental entities is crucial to understanding how to optimise implementation of the Convention principles. Serious consideration of ratification would therefore include, at a minimum, extensive consultation with Aboriginal and Torres Strait Islander communities and organisations as well as other stakeholders, alongside analysis of the current state of Australian law and its coherence with the requirements of the Convention.

10.1.3 Ratifying ILO 169: Perspectives of Aboriginal and Torres Strait Islander communities and other stakeholders providers

Mossberger and Wolman's final criterion, *application,* relates to how the available information is actually used in the process of deciding whether and how to install the borrowed policy. The next sections examine two aspects of Australia's possible ratification of ILO 169: extensive consultation with stakeholders in order to develop a thorough understanding of the likely influence of local factors on upholding the principles of the Convention; and a careful review of existing national legislation and the extent to which it already complies with the requirements of the Convention or could be adapted to do so in the future.

As stated previously (Section 2.1.3), ILO 169 has been criticised for 1) the initial lack of inclusion of Indigenous peoples in its drafting and implementation and 2) the limits around the level of protection it affords Indigenous peoples, such as not including the right to veto and the emphasis on consultation rather than consent.[41,42] Nevertheless, for many Indigenous peoples, it is accepted as being a step further than the level of recognition present within their own

national legislative frameworks. In Australia's current political climate, ratification of the Convention would establish governmental recognition of the obligation to consult as well as pushing forward the creation of effective mechanisms to fulfil it. There may therefore be strong support for ratification of ILO 169 from Aboriginal and Torres Strait Islander peoples.

Similarly to Latin America and Norway, the issue of native title and land rights is likely to be a key point of contention in relation to Australia's ratification of ILO 169. However, ILO 169 has already had some measure of influence in how Australian legislature considers the question of land rights. It has been noted that the *Native Title Act 1993* takes on some of the language of ILO 169, in referring to 'the right to negotiate' and consultation undertaken in 'good faith.'[405] Indeed, the *Native Title Act 1993* has been held up as an example of domestic law that adheres to and supports the principles of 'rights of ownership and possession of the peoples concerned over the lands which they traditionally occupy' laid out in the Convention.[41]

Given ongoing attempts by the mining sector to whittle away at Native Title,[391] some pushback from the sector against ratification of ILO 169 is likely to occur. However, given the ongoing engagement between Aboriginal and Torres Strait Islander communities and the mining sector, it is unlikely that this would escalate to the same level of intense resistance as seen in Latin American countries. The recognition of international standards of consultation could support a more solid basis for the protection of Aboriginal and Torres Strait Islander peoples' rights to their traditional lands. This may ultimately lead to reduced tension between Aboriginal and Torres Strait Islander communities and mining companies by clarifying and solidifying legal rights and responsibilities, similar to the effect of the *Native Title Act 1993*.

10.1.4 Coherence of Australian law with the requirements of the Convention

By ratifying a treaty, Australia agrees to be bound to the principles laid out therein. However, the treaty does not become part of Australia's domestic legislation unless it has been codified into national law.[406] Evident in the experience of Chile, other Latin American countries and Norway is the importance of considering the level of congruence between the principles espoused in international frameworks and the national legislative environment. As illustrated, a strong disjuncture between the principles of the international agreement and the national legislature can drive the creation of conflicting, contradictory policy and enhance tensions between Indigenous peoples, the government and the private sector. However, the decision to be bound by international legislation may involve a level of trade-off. As in the case of

Norway, while national legislation may not be completely compliant with the requirements of the treaty, it may also drive further progress towards fulfillment of these principles.

There is currently no overarching national framework, legislation or agreement that regulates government engagement with Aboriginal and Torres Strait Islander people. The *Native Title Act 1993* is the only national legislative instrument that provides a mechanism for engagement with Aboriginal and Torres Strait Islander communities.[388] Engagement between Aboriginal and Torres Strait Islander communities and organisations is much more evident at the regional level, where child care, environmental management and protection and health were the sectors most commonly represented in the literature. This engagement was normally based on partnership agreements and organisational policies, rather than being guided by legislation. As identified by Howse (2011), there is currently a gap in Australian health policy and legislation in relation to providing adequate mechanisms for Aboriginal and Torres Strait Islander engagement and input into decision-making processes in the area.[292]

There are indications that Australian law could be better aligned with the requirements of the Convention, either as a move towards ratification or afterwards, as a way of enacting compliance. The *Advancing the Treaty Process with Aboriginal Victorians Bill 2018* passed in June 2018 as part of the process for establishing a treaty between the state of Victoria and Aboriginal Victorians. This is the first ever piece of Aboriginal treaty legislation in Australia.[407] The bill allows for a progression of steps towards treaty negotiations, including:

- Requiring a partnership between an Aboriginal Representative Body and the State to establish a Treaty Authority and a treaty negotiation framework
- Establishing mechanisms by which the Aboriginal Representative Body will be formally recognised as the State's equal partner in the next phase of treaty
- Developing underlying principles for the treaty process, including self-determination and empowerment[408]

Victoria's treaty process continues to progress, with the recent establishment of the inaugural First People's Assembly, which will guide negotiations with the State government.[409] The advancement of Victoria towards a treaty with its Aboriginal peoples demonstrates both the political will that exists for such agreements and may serve as an example of how other jurisdictions may follow suit. Ultimately, this could lead to such measures being taken at the national level.

Moreover, despite the Australian government's rejection of the constitutional enshrinement of a 'Voice to Parliament' as proposed in the Uluru statement, there continues to be discussion and debate regarding this step.[410] If such an initiative ultimately does proceed, it would be an important move towards having significant compliance with the Convention's requirements.

With the available evidence, it seems likely that the ratification of ILO 169 may serve as a useful instrument to recognise the right of prior consultation of Aboriginal and Torres Strait Islander peoples and develop legislative mechanisms to ensure that this right is protected and promoted. In order for the principles of the Convention to be effectively implemented, a full review of Australia's current legislative and policy framework should be undertaken to ensure coherence between the principles and domestic law. This would also serve to comply with Australian Government policy to only become bound to treaties if domestic law provides adequate support for the fulfilment of treaty principles.[406]

Dolowitz and Marsh (2000) examine the rationale, processes and success of cross-country policy transfer, concluding that there are at least three factors that strongly impact on whether the transfer will fulfil the expected aims in the borrowing country:

- *Uninformed transfer*, where the borrowing country is lacking essential information regarding the implementation and operation of the policy;
- *Incomplete transfer*, with some element contributing to the policy's success in the lending country not instituted in the borrowing country; and
- *Inappropriate transfer*, where differences in the historical, political, economic and social contexts between the two countries have been insufficiently accounted for.[232]

The risk of uninformed transfer is mitigated by the extensive amount of information available regarding the ratification of the Convention across different contexts and the local factors that contribute to its implementation within the country. However, regarding incomplete and inappropriate transfer, Stone's perspective provides an alternate view on the impact of contextual differences on policy performance.[239] Stone's assertion that policies continue to shift and are continuously adapted to the borrowing context can be seen across all countries that have ratified ILO 169, with ongoing interpretation and implementation of the Convention principles being shaped by factors such as the development of the national legislative environment and court rulings. In this way, considering the differences in setting between the

lending and borrowing countries is not only about ensuring that the necessary elements for successful implementation of the policy are already in place, but also understanding how the policy can continue to adapt appropriately over time. Norway stands as an example of this, where the national legislature was assessed to be sufficient to uphold the requirements of the Convention, but there was also an accepted degree of flexibility in terms of how the legislative environment would be adapted to accommodate certain elements of the Convention in the future. This approach may be the most useful for Australia to adopt, with the understanding that while changes may need to be made to legislation in order to be fully compliant with the Convention, ratification itself will continue to influence the political and legislative environment.

10.2 Supporting community-controlled Indigenous health services as vehicles for community participation

This thesis has centred on the role of Indigenous community-controlled health services as a central component of community participation in health. In the next sections, lessons are drawn from Chile and other countries regarding the development of policy and practice to support effective implementation of Indigenous health services.

10.2.1 Development of supportive policy

Each country has its own pattern of how Indigenous community-led services are established. Indigenous health services may either be developed *de novo*—that is, from scratch, such as in the case of Boroa Filulawen Intercultural Health Centre—or created when an Indigenous community takes over a health service previously administered by the government or a non-governmental organisation, as with Makewe Hospital.

The cases of Chile, Australia and Canada each illustrate the importance of having supportive policy to underpin the creation or effective handover of Indigenous community-controlled health services. As covered previously, reliance on a policy framework in Chile that neither acknowledged the existence of Indigenous health care providers nor provided consideration of their unique circumstances was a consistent impediment to the work of Makewe Hospital and Boroa Filulawen Intercultural Health Centre (see Section 5.5.1). In Australia, Aboriginal community-controlled health services have largely been developed *de novo*, but there have been waves of existing services being transferred to community control, and a current push towards this being undertaken more comprehensively.[127] Governments have put forth

commitments to supporting ACCHOs, including investment in capacity-building;[411] however, there is no legislated governmental responsibility for Indigenous health or transference of health care to community control.[127,292] Of the three countries, Canada exhibits the strongest governmental commitment to supporting and expanding Indigenous community control. As mentioned in Section 2.2.3.1, Canada's Health Transfer Policy facilitates the transfer of government health services to tribal administration with varying levels of ongoing governmental support.[127,128] The installation of the Health Transfer Policy in 1989 carried with it explicit mechanisms for the handover of existing services to Indigenous community control, while also outlining expectations for continued governmental support and financing. [118,119] Under this policy, 89% of eligible First Nations communities were involved in planning, management or provision of community-controlled services by 2008.[127] The creation of policy that provides resources and commitment to strengthening the Indigenous community-controlled health sector assists in making explicit the mechanisms by which community control can be achieved and facilitates working with communities to enable this to happen.

10.2.2 Establish a clear understanding of roles and responsibilities for different stakeholders

Morgan (2001) refers to Rifkin (1996) and Chambers (1995) in stating that power struggles are central to community participation in health, as participation necessarily entails the expansion of formerly closed processes. However, while conflict in this instance can be productive, it must first be well-managed.[72,412,413] Interviews with Mapuche service providers and MINSAL staff reflect the literature more broadly in demonstrating variation in how stakeholders understand community participation (Section 5.2). Different actors in the same system may have differing expectations regarding the outcomes and processes of community participation, including who should be involved and the level of their involvement.[72]

An additional consideration in the case of Indigenous health services is managing the level of control exerted by the State in the form of funding mechanisms and reporting requirements. Onerous reporting requirements coupled with curtailing the autonomy of Indigenous health services and restricting their capacity to respond appropriately to local needs and priorities was a recurring theme in interviews with Mapuche health service administrators. In Canada and Australia, similar issues have been highlighted as having significant impacts on service provision.[414,415]

The use of reciprocal accountability agreements and more appropriate reporting requirements have been used to provide clarity about the expectations of different partners.[125,415] Both of these approaches require an element of trust. Morley (2015) found the existence of trusting relationships between Indigenous community-managed organisations and their partners to be a factor for success.[367] Building this trust necessitated taking time for reflection, inclusive decision-making and conflict resolution processes that allowed the relationships to remain intact.[367] Allowing the space and time for organisational partners to communicate their perspectives regarding participatory processes may allow for better relationships between organisational partners more generally and better ways of working together—although there may not be complete agreement on the underlying principles, there may be more understanding and tolerance of differing perspectives if these have been made explicit. This may therefore be one way to create space for productive conflict and serve to strengthen Indigenous community management. These processes may be more feasible at regional, rather than national levels—in Australia, regional governance is a key mechanism for Aboriginal and Torres Strait Islander engagement in health, and the BC Tripartite Agreement also demonstrates the viability of regional approaches.

10.2.3 Embed mechanisms for ongoing community engagement

As previously stated, a consistent objective for Indigenous health services worldwide is the preservation and strengthening of culture, including traditional social structures, community ties and traditional health systems. BFIHC and Makewe Hospital are also examples of this, whereby the health centres serve as community hubs where traditional ceremonies are practiced and the role of traditional authorities is validated and respected. The consistent communication between the health centres and their communities, as well as the strong ties between the two facilitated mutually supportive relationships.

In addition to supporting cultural retention and community strengthening, community engagement can also be central to conflict management and ensuring that health services are accessible and response to as wide a section of the community as possible. As with professional stakeholders, among the community there may be differences of opinion regarding the expected outcomes of participatory processes and what these processes should look like. Continuous engagement allows for these perspectives to be heard, acknowledged and accommodated as far as possible. At the same time, engagement allows administrators and program managers to keep abreast of community needs and priorities.

Community engagement mechanisms are likely to be different for each health centre, as illustrated by the distinct models of Makewe Hospital and BFIHC. Engagement will be influenced by the amount of funding and funding structures—for example, whether centres receive funding specifically for outreach services. Community engagement will also vary according to characteristics of the community itself—for example, engagement may look different for urban Indigenous communities, where the boundaries around 'community' may not be so proscribed as in rural areas and the Indigenous 'community' may in fact be made up of people from many different traditional lands or clans.[416] For these reasons, engagement mechanisms may need to be changed or refined over time.

Rather than a single strategy, community engagement is also likely to be multifaceted. Both BFIHC and Makewe Hospital exhibited multiple strategies that helped to ensure ties with their communities remained strong—employing local community members where possible, utilising home visits to undertake assessments of community needs, or conducting series of visits to community leaders with the express purpose of ensuring that each section of the community had their voice heard.

10.2.4 Establish robust governance structures

Stakeholder and community expectations should be reflected in the governance structures of the health centre. As covered in Chapter 6, governance takes place within the centre itself as well as within and between sectors and at different levels. Across each of these positions, governance mechanisms should be established with the aim of shared decision-making, rather than solely consultation.

At all levels, installation of robust governance structures helps in explicitly defining the roles and responsibilities of different stakeholders and partners and facilitating shared decision-making processes. The incorporation of reciprocal accountability principles should be utilised where possible to ensure that there is clarity in what is expected of each party in supporting Indigenous health and to establish equitable balances of power between Indigenous and non-Indigenous partners.

In recent years, there has been a proliferation of guidelines and resources to promote good governance in Indigenous community-controlled organisations.[328,417,418] Regarding good corporate governance, it is emphasised that to reflect these values, governance should be tailored to the specific circumstances. This includes the appointment or election of a Board

that is both representative of the community and possesses the skills and expertise necessary to maintain strong leadership and provide strategic direction.[419]

10.2.5 Acknowledge elements of Indigenous governance underlying Western organisational structures

Section 9.1.3 introduces the concept of 'cultural fit,' referring to the alignment between the formal governance mechanisms of an Indigenous organisation and traditional understandings of authority and decision-making processes.[318,325] Brigg and Curth-Bibb (2017) argue that despite the recognised importance of good governance in the Australian Aboriginal community-controlled sector, the current conceptualisations of governance do not fully account for the realities of governance undertaken in the context of intercultural relations between Indigenous communities and the wider Western health system.[328] This is a theme also reflected in interviews with MINSAL and Makewe Hospital staff members as well as in the wider literature.[328] Brigg and Curth-Bibb position recognition of Indigenous elements of governance as protective against Indigenous organisations becoming 'controlled communities.' This can happen when the organisation is either excessively controlled through state regulations and bureaucracies or, conversely, through inappropriate Indigenous governance, where a single family or group has undue authority. An intercultural viewpoint is therefore necessary to understand and manage both methods of governance.[328]

Moreover, the acknowledgement and acceptance of Indigenous forms of governance allows for the design and implementation of strategies to ensure good governance that are also in line with Aboriginal and Torres Strait Islander values and culture. By doing so, these methods of governance particular to Indigenous organisations may be strengthened and amplify the positive aspects of the connections between the organisations and their communities, which in turn may help to valorise traditional forms of decision-making by positioning them as legitimate and relevant. Relatedly, the acknowledgement of Indigenous governance structures also serves to give recognition to the principle of self-determination that underlies community control and sets Indigenous organisations apart from mainstream health services. Finally, recognising the interplay between Western and Indigenous methods of governance enables a smoother coexistence between the two. Incorporating an understanding of how Indigenous organisations operate and are governed apart from bureaucratic Western structures may allow for timelines that are more appropriate for decision-making processes and more effective discussions and negotiations between Indigenous organisations and mainstream or government organisations.

10.3 Conclusions

In any consideration of policy or knowledge transfer there is a need to find a balance between respecting the specific historical, cultural and political factors that shape a particular context and learning from others' experiences. This is particularly complicated in the field of Indigenous health, given the differences in how Indigenous health care systems are organised and administered even in contexts that are otherwise relatively similar. Nevertheless, the growing internationalisation of Indigenous policy and increased scope of formal and informal international Indigenous networks attests to the ongoing transfer of ideas, concepts and knowledge in this space.

Examination of Australian Indigenous policy in light of other countries' experiences of ratifying ILO 169 builds a strong case for utilising ratification as a tool to strengthen domestic legislature around Indigenous political representation and engagement. This is informed by both the successes and challenges brought about by ratification elsewhere. In the development of participatory Indigenous health programs, the need for strategies enabling management of different perspectives, the installation of strong and embedded community engagement and development of robust governance structures that successfully incorporate both Indigenous and Western elements are highlighted as being consistent themes across international contexts.

Chapter 11. Conclusions and future directions

This chapter reviews the scope, focus, findings and argument of the research, and suggests future directions for consideration.

This study has examined the influence of local and distant factors on the effectiveness of Indigenous community-controlled health centres as participatory mechanisms, including interactions between international and domestic legislation and policy regarding Indigenous participation in health. The relationships between adherence to international legislation, domestic policy frameworks, local community factors and the implementation of Indigenous community-controlled health services have not previously been considered as a whole in this way. Additionally, the research explored the applicability of lessons learned from countries' experiences in Indigenous community participation in health to other international contexts.

In responding to these research aims, case studies were undertaken with two Mapuche community-controlled health centres in Chile in order to gain perspective on the day-to-day workings and decision-making processes of the health centres. The case studies served to illustrate how Mapuche health centre administrators balanced relationships with the broader health system with a commitment to maintain and strengthen traditional social structures and knowledges. Interviews were also conducted with Ministry of Health personnel to provide a comprehensive picture of Indigenous health policy and stakeholders' perspectives. Evidence from international experiences was then used to contextualise the Chilean findings and provide some guidance for strengthening Indigenous community participation in health both in Chile and internationally.

The main findings of the research are outlined in more detail below. Overall, this thesis contributes new knowledge and understanding to the complex issues related to Indigenous community participation in health. It provides learnings for policymakers and Indigenous health administrators to support improved implementation and evaluation of Indigenous community control in health.

11.1 Alignment between international and national policy

A key objective of the research was to provide an examination of how international instruments and domestic policy interact to influence the avenues for community participation open to Mapuche health centres. Although Chile has endorsed the UN DRIP, this did not feature at all in key informant interviews; rather, the legally binding ILO 169 was seen as being relevant to

domestic Indigenous policy. However, the efficacy of ILO 169 was also severely curtailed by a lack of coherence with Chile's domestic legislation. Therefore, while interviewees from both Makewe Hospital and MINSAL cited ILO 169 as being an enabling factor in Indigenous community participation, they were also cognizant of its limitations in the current policy environment.

This trend of disjuncture between ILO 169 and domestic policy and legislation and resulting complexity in the application of ILO 169 is apparent throughout the ratifying Latin American countries. In these countries, while Indigenous communities may appeal to the court systems where State obligations have not been upheld, this has led to complex and contradictory judicial decisions regarding the processes of prior consultation and under what situations the right to consultation is applicable.

Overall, the evidence here indicates that international legislation alone carries little weight in facilitating consultation with Indigenous communities or other forms of participation; however, these instruments can provide guidance to countries for the alignment of domestic policy with established principles. This was the case with Norway, which took strides towards ensuring that domestic legislation was cohesive with the government's obligations under ILO 169 before ratification, and was subsequently the first country to ratify the Convention. The process and results of creating coherent policy may therefore reinforce each other—such alignment both enables countries to adopt international agreements and subsequently facilitates implementation of the relevant principles and obligations.

11.2 Indigenous governance at all levels

Mapuche health administrators cited the existence of a wider system that was extremely resistant to external influence and 'blind' to Mapuche health in particular as a key barrier to their work. This was supported by interviewees from MINSAL, who spoke about the system's 'fear' of communities and the strongly hierarchical processes of decision-making within the health system. This extended to decisions about allocation and priority setting, as well as funding and accountability mechanisms that were determined in Santiago for uniform application throughout the country, without regard for the context within which Indigenous centres are situated or the unique health needs of their communities. As a result, Mapuche health centres were highly restricted in terms of their capacity to respond to local priorities and needs, even as staff considered the centres themselves as potential vehicles for increased Mapuche political power within the health system. One of the primary aims of Indigenous

community control, increased autonomy and self-determination, is thereby curtailed. While the health centres engaged in advocacy in order to increase policymakers' awareness and responsiveness to their communities' needs, this was an ongoing battle without established structures in place to ensure accountability on the part of the State.

The establishment of Indigenous representation at all levels of government and stronger mechanisms for Indigenous governance in health would support decentralised systems of decision-making and enable formal and embedded engagement with Indigenous communities. Some progress towards this end has been taken in Chile, as demonstrated by the advancement towards the establishment of a Ministry for Indigenous Peoples and associated Congresses. Such an approach would also aid in supporting State obligations to consult and engage with their Indigenous peoples as outlined in the UN DRIP and ILO 169.

In conjunction with stronger political representation, incorporating the principles of reciprocal accountability into contractual agreements between the State and Indigenous health centres could support a shift towards relationships that are more equitable, provide greater stability for Indigenous health centres and facilitate increased latitude to respond to their communities' needs appropriately.

11.3 Internationalisation of Indigenous health policy

Despite extremely different contexts at both national and local levels, there has been increased internationalisation of Indigenous health policy, driven by recognition that the determinants of Indigenous health and wellbeing are shared across borders; use of international instruments that serve to form a universal set of standards for the rights, treatment and protection of Indigenous peoples as well as international Indigenous health networks that facilitate 'soft' policy transfer between countries.

Policy transfer is driven by the understanding that a policy approach that effectively addresses a shared problem in one context may be usefully applied in a different context. Decisions about whether, how and to what extent to borrow a policy or practice from another country are influenced by a number of considerations, including: similarities between the issues or problems addressed by the policy in the originating country and expected to be addressed in the borrowing country; differences in contextual factors such as policy and legislative environment and stakeholder perceptions of the policy; awareness and understanding of the policy and why it has been successful in the originating country.

The thesis utilised the Mossberger and Wolman prospective policy evaluation framework to consider a specific case of potential cross-country policy transfer in relation to Indigenous policy. In so doing, it was demonstrated that in this field, a high level of accurate information about the implementation of a policy across a number of countries, in conjunction with strongly shared goals may support the appropriate application and adoption of policy, as well as guidance for improved implementation within the borrowing country. In this case, the diversity of contexts within which a particular Indigenous policy approach may be utilised may be particularly advantageous, as it lends the opportunity to study how the policy may respond under the influence of a broad range of factors.

11.4 Strengths and limitations of the study

The strengths represented by this study are considerable. The relatively long period of fieldwork allowed for a depth of understanding of the context that would not have been possible otherwise, and enabled the development of friendship and trust between the researcher and staff and community members. In addition to being personally satisfying, this has supported a richness in the data and analysis.

Before beginning the fieldwork, the researcher brought with her years of experience in Indigenous health. While the Mapuche context is materially different from the Australian Indigenous context, nevertheless this experience was invaluable as a basis for recognising similarities with respect to determinants and conceptualisations of Indigenous health, the ongoing struggle for self-determination and sovereignty, and for drawing lessons from one setting for use in another.

Drawing from this, the research has successfully illustrated the interactions between different levels of governance influencing Indigenous participation in health; from local to national and international. It provides substantive knowledge regarding mechanisms to support and protect the rights of Indigenous peoples to accessible health care that responds to their needs, values and culture.

There were a number of limitations that affected the quality of the data that could be obtained for this research. Approval for the research to be undertaken with Boroa Filulawen Intercultural Health Centre had initially been granted and observation of meetings proceeded as planned. However, after approximately five months, when beginning to schedule interviews, disagreements regarding the research began to arise. Centre staff and directors expressed frustration and fatigue from being involved in a high number of research projects

over the years. Not only had the Centre seen little benefit from the results of this research, but staff reported that researchers often did not disseminate results back to the Centre, while themselves gaining professional benefit from the Centre's work in the form of publications, theses and other academic output. This reflects wider questions frequently raised regarding the burden of research on Indigenous communities and organisations in terms of their time and resources, the practical value and benefit they receive from research and how the two are weighed (see Section 3.4.1).[271,281] Centre directors also expressed concern that the research might have negative ramifications for BFIHC and spoke of being under constant scrutiny and having to continuously prove the validity of traditional medicine, the effectiveness of the intercultural model and the capacity of the Mapuche organisation to administer a health centre.

Due to these concerns, while allowing the research to proceed, the Centre directors declined to be interviewed and restrictions were placed around the types of questions that could be asked in interviews with staff members. The interview schedule was seen as too intrusive and involved. While some questions were eliminated due to being too similar to research that had previously been undertaken, questions regarding relationships between the Intercultural Health Committee of Boroa Filulawen and State health institutions and the workings of the Health Committee were identified as being particularly sensitive.

The amount of data collected was therefore reduced both in terms of both volume and content from what was initially anticipated. The small number of interviews means that the perspectives obtained are necessarily quite limited; there may be a number of conflicting viewpoints that are not represented within this research. Given the sensitivities raised by the staff and directors, it may also be possible that even those staff members that were able to be interviewed would be reluctant to voice negative or dissenting opinions.

Data were collected only from people directly involved with Boroa Filulawen Intercultural Health Centre and Makewe Hospital. This introduces bias as it does not capture information from those in the surrounding community who may avoid the health centres due to negative experiences or critical attitudes. For both Makewe Hospital and BFIHC, planned methods included a review of organisational documents and observation of professional meetings. However these methods were ultimately rejected due to concerns that they were overly intrusive and an imposition on staff time. These methods were initially conceptualised to provide a level of triangulation with interview data. These limitations meant that it was not possible to independently verify information provided by participants.

A possible further limitation concerns the positioning of the researcher (ASF). ASF is neither Mapuche nor Chilean. However, it is difficult to say how the researcher's outsider status may have affected the data provided by interviewees and the following interpretation. It may be that being removed from the local context allowed interviewees to be more open, as she may have been perceived to be more impartial and the risk of negative ramifications may have been perceived to be lower than if she were directly involved with the organisations. On the other hand, interviewees may have been inclined to be less open with an outsider.[420] Both of these possibilities may be true simultaneously—interviewees may have been more open to talking about topics such as the operation of the health centres or conflicts with other stakeholders than they would be with someone more directly involved; while also being more reluctant to speak about sensitive cultural topics. This outsider status, coupled with the researcher speaking Spanish as a second language, may also have limited the researcher's ability to fully interpret the data.

These limitations were addressed in a number of ways. First, the fieldwork period was over a year, enabling the researcher to 1) become more familiar with the context as a whole, 2) engage in many informal conversations in addition to the formal interviews, both of which supported a more complete understanding of the issues involved and 3) develop personal as well as professional relationships based on trust and mutual respect. As the research was focused on how participatory processes manifested in relation to the health centres, culturally sensitive topics were generally avoided for the most part, or spoken about in broad terms. In addition, one of the student researcher's supervisors (AMO) is based in Chile and is a recognised expert in the field of intercultural health. AMO has had a professional relationship with Makewe Hospital spanning 20 years and lent her support in interpreting the data, including assisting with translation.

While the interviews were undertaken in Spanish, rather than Mapudungun, this is not considered to be a serious limitation. All interviewees spoke Spanish fluently and only a small proportion of Mapuche in La Araucanía (mainly the very elderly) do not speak Spanish. No interviewees expressed a preference to be interviewed in Mapudungun.

11.5 Future directions

From analysis of the two case studies and an incorporation of international evidence, a range of different approaches have been outlined for strengthening participatory process and engagement with Indigenous communities in Chile and internationally. As it currently stands,

Indigenous community participation in health and Indigenous community-controlled health services are frequently unable to fulfil the goals of increased autonomy for Indigenous peoples and localised responsiveness that underpin such initiatives due to policy environments that perpetuate State control over resource allocation and decision-making processes.

The research makes the case for approaches to Indigenous health policy that are undertaken with an eye towards building cohesion between legislation and policy across all levels to support engagement with Indigenous peoples. Analysis of Indigenous health policy, programs and services that takes a holistic perspective of the international, national and community-level factors impacting implementation would support decision-making in this area.

Comparative studies in the area of Indigenous health policy have, to date, focused overwhelmingly on Australia, Canada, New Zealand and the United States, with little attention being paid to the region of Latin America. This is despite Latin America having a larger share of the world's Indigenous people than the four countries combined, and encompassing hugely diverse contexts and approaches to Indigenous health policy. Increased research into the utility of cross-country policy transfer with Latin American originating countries may therefore serve to provide some additional perspective on addressing shared goals in Indigenous health.

With progress being made in Chile towards the establishment of the Ministry of Indigenous Peoples and associated Congresses, there is the possibility to utilise the knowledge gained in other contexts regarding best practice in engagement and coordination of Indigenous policy and programs. There is also the opportunity to contribute to this body of knowledge through examination of the process of developing the new Ministry and its integration with existing governmental agencies. Appropriate lines of research could include whether and how these new governmental bodies contribute to improved consultation and engagement with Chile's Indigenous peoples, whether there are reductions in the number of cases being brought for failure to comply with ILO 169 over time, and whether there are improvements in the level of cohesion demonstrated by Chile's Indigenous policy.

Section 3.4 details the ethical considerations that were present throughout the research. Tensions between Indigenous communities and academia was a constant theme during the fieldwork and ultimately affected the quality of the research, as well as being stressful for the Mapuche organisations, particularly Boroa Filulawen Intercultural Health Centre, as presented in more detail below. Ultimately, lessons from this experience led to a publication on the ethics of undertaking Indigenous health research in Chile (see Appendix 2). As it currently stands,

Indigenous health research is not fulfilling its potential to offer substantial benefits to communities. However, this could be addressed by the establishment of more equitable and collaborative relationships between academia and Indigenous communities. The publication outlines a number of approaches that can be taken by academics and universities to work towards this goal. This includes the installation of guidelines to support ethical research with Indigenous communities, developed in collaboration with communities themselves, and an increase in Indigenous-led research.

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Appendix 1: Interviews conducted

Institution	Total number of interviewees	Mapuche interviewees
MINSAL	7	3
Boroa Filulawen Intercultural Health Centre	4	2
Makewe Hospital (staff)	8	7 (4 Members of the Mapuche Health Association of Makewe-Pelale)
Makewe Hospital patients	39	39

Appendix 2: Interview schedules

Spanish

Boroa Filulawen Centro de Salud Intercultural
Pauta de entrevista

Introducción

- Me podría decir su nombre y su rol en la Organización Territorial?

Participación comunitaria

- Qué es para usted, una buena participación en salud en su comunidad? Cuáles son sus beneficios?

La Organización Territorial

- Cómo se formó la Organización al principio? Me podría decir en qué contexto-circunstancia-situación se formó?
- Podría explicarme el papel de la Organización Territorial? ¿Qué tipo de decisiones toma la Organización Territorial? En qué tipo de decisión o actividad participa la Organización? Me puede dar un ejemplo?

La comunidad

- Me podría contar sobre el área que atiende el Centro? ¿Cuántas comunidades abarca? ¿Qué personas y comunidades se atienden y cuales no se atienden, si es que hay alguna?
- Podría describir el tipo de relación entre las personas que viven en las comunidades de Boroa y la Organización? Entre los dirigentes, los longkos y la Organización?
- ¿Qué formas de comunicación hay entre la Organización y las personas quien viven en Boroa?
- ¿Cómo se determinan las necesidades de salud la comunidad? Si surge un tema en particular, ¿cómo se comunica la Organización? ¿Cómo responde la Organización Territorial de Boroa Filulawen?
- Algunos de los objetivos de la Organización que usted ha mencionado eran ... ¿Qué obstáculos o dificultades han tenido para cumplirlos? ¿Me puede contar sobre alguna? O darme ejemplos?

Relaciones con instituciones y organizaciones

- ¿Cómo cree usted que el SSAS y otros servicios públicos podría aportar mejor al trabajo y objetivos del Centro?
- ¿Cuáles son algunas de las organizaciones e instituciones públicas con que trabaja el Comité? ¿Podría contarme más de qué forma trabaja con ellas?

Terminar de entrevista

- ¿Hay alguna otra cosa que usted crea importante que yo sepa, sobre lo que aún no le haya preguntado?

Asociación Indígena para la Salud Makewe-Pelale

Introducción

- Me podría decir su nombre y su rol en la Asociación?

Participación comunitaria

- Qué es para usted, una buena participación en salud en su comunidad? Acción comunitaria en salud? Cuáles son sus beneficios?
- Me podría dar un ejemplo de buena participación comunitaria?

La Asociación

- Cómo se formó la Asociación al principio? Me podría decir en qué contexto-circunstancia-situación se formó?
- ¿Cómo se determina o eligen sus miembros? ¿Eso ha cambiado con el tiempo? ¿Cómo se hizo ser socio de la Asociación inicialmente? Cuales cargos ha tenido?
- Cuáles son los objetivos y metas de la Asociación? ¿Han cambiado con el tiempo? ¿Cómo? ¿Porque?
- Podría explicarme el papel de la Asociación? Entiendo que la Asociación administra el Hospital, pero ¿qué significa eso en la práctica? ¿Qué tipo de decisiones toma la Asociación? En qué tipo de decisión o actividad participa la Asociación? Me puede dar un ejemplo?
- Me podría contar o explicar más acerca de cómo se toman las decisiones? ¿Hay normalmente una reunión formal (formal de acuerdo a la cultura), o es más informal? ¿Cómo se determinan las prioridades? ¿Qué pasa si hay un desacuerdo? ¿Cómo se resuelve? ¿Quién tiene la última palabra?

La comunidad

- Me podría contar sobre el área que atiende el Hospital? ¿Cuántas comunidades abarca? ¿Qué personas y comunidades se atienden y cuales no se atienden, si es que hay alguna?
- Podría describir el tipo de relación entre las personas que viven en las comunidades del área de Makewe-Pelale y la Asociación? Entre los dirigentes, los longkos y la Asociación?
- ¿Qué formas de comunicación hay entre la Asociación y las personas quien viven en Makewe-Pelale?
- ¿Cómo se determinan las necesidades de salud la comunidad? Si surge un tema en particular, ¿cómo se comunica a la Asociación? ¿Cómo responde la Asociación?
- Algunos de los objetivos de la Asociación que usted ha mencionado eran ... ¿Qué obstáculos o dificultades han tenido para cumplirlos? ¿Me puede contar sobre alguna? O darme ejemplos?

Relaciones con instituciones y organizaciones

- ¿Qué puede contarme sobre la relación entre la Asociación y el SSAS? Entre la Asociación y PROMAP?
- ¿Siente que el SSAS/PROMAP apoya a la Asociación en sus objetivos/metas? ¿Por qué si? O ¿por qué no? Me puede dar ejemplos de cada situación?
- ¿Cómo cree usted que el SSAS/PROMAP podría aportar mejor al trabajo y objetivos de la Asociación?
- ¿Cuáles son algunas de las organizaciones con que trabaja la Asociación? ¿Podría contarme más de qué forma trabaja con ellas?

Terminar de entrevista

- ¿Tiene alguna sugerencia sobre alguna persona con la que sería útil hablar sobre este tema?
- ¿Hay alguna otra cosa que usted crea importante que yo sepa, sobre lo que aún no le haya preguntado?

Informantes claves de agencias gubernamentales

- ¿Me podría contar acerca de su rol en [X institución]?
- Me podría contar acerca del rol de su institución dentro del Ministerio de Salud?

Determinar las necesidades médicas del pueblo mapuche

- Como hablamos acerca de la participación de la comunidad en la salud, ¿me podría decir cómo definiría usted una comunidad mapuche? Hay alguna definición que utiliza la organización?
- Con esa definición en mente, ¿cuáles son las formas en las que el pueblo mapuche podría influir en el sistema de atención médica, para asegurarse de que cumpla con sus necesidades? [Al nivel de políticas de salud o al nivel de centros de salud]
- Actualmente, al nivel de políticas de salud, ¿cómo se determinan las prioridades de salud del pueblo mapuche? ¿Cómo participa la comunidad en la determinación de prioridades? Y al nivel de centros de salud? (Qué flexibilidad existe para que un centro pueda responder a las necesidades particulares de una comunidad?)

Definir la participación de la comunidad

- Hablando a grandes rasgos, para usted, ¿Cuáles serían los beneficios de una buena participación de la comunidad? ¿Cuáles serían las desventajas? ¿Cómo sería una participación ideal de la comunidad en la salud?
- ¿Me podría dar un ejemplo de una buena participación de la comunidad?
- ¿Cuáles son los resultados que se ha obtenido la participación de la comunidad (si la hubo)?

Factores externos que tienen un impacto en la participación de la comunidad

- ¿Podría contarme más acerca de los facilitadores de la participación de la comunidad en Chile? ¿Cuáles son las barreras?
- Hay algunas políticas o algunos regalamientos que facilitan la participación? Hay algunos que forman barreras a la participación?

Roles organizacionales en el apoyo de la participación comunitaria

- ¿Cuál cree usted que es el rol de [institución X] en el apoyo de la participación de la comunidad en la salud, si lo hay?
- Si la [institución X] en realidad apunta a apoyar la participación de la comunidad en la salud, ¿cuál es la razón tras esto?
- ¿Me podría dar algún ejemplo de cómo la [institución X] cumple con este rol?
- ¿Hay alguna manera en que crea que las agencias gubernamentales puedan entregar más apoyo a la participación de la comunidad en salud?
- Me interesa el proceso de financiamiento de servicios interculturales. Me podrías explicar un poco acerca de eso? Cuál es la diferencia entre el financiamiento de servicios occidentales y tradicionales?

Proceso de toma de decisiones

- Desde la perspectiva de las agencias gubernamentales, hay algunas frustraciones o tensiones en trabajando con centros de salud interculturales? Me podría contar un poco acerca de estas? Desde la perspectiva de los prestadores de servicio?
- Si hubiera algún desacuerdo entre los centros de salud y la [organización X], ¿cómo se resuelven?

Terminar de entrevista

- ¿Tiene alguna sugerencia sobre alguna persona con la que sería útil hablar sobre este tema?
- ¿Hay alguna otra cosa que usted crea importante que yo sepa, sobre lo que aún no le haya preguntado?

Pauta de entrevistas de usuarios

Interacción con el Hospital

- Para empezar, cuál es su comunidad? A qué distancia está? Cuánto demora a llegar al Hospital? Su comunidad está baja el área de cobertura de Makewe?
- Desde cuándo ha sido un paciente del hospital? Además, usted es paciente de otro hospital o consultorio? Por qué decidió usted ahora a venir a este hospital?

Participación comunitaria

- Considera que el Hospital Makewe es de la comunidad Mapuche? Por qué o por qué no? En qué sentido?
- Cómo se relaciona su comunidad con el Hospital? Considera que su comunidad participa en las actividades del Hospital?
- Cree que es importante que la comunidad participe en la administración del Hospital? Por qué? Cómo?
- Cree que la participación de la comunidad tiene un efecto en la gestión del Hospital?

Conocimiento de la Asociación

- Para usted es importante que una Asociación Mapuche administre el hospital a diferencia de un administrador no Mapuche? Conoce usted la Asociación que administra el Hospital? Podría explicarme el papel de la Asociación, desde su punto de vista?
- Podría describir el tipo de relación entre las personas que viven en las comunidades del área de Makewe-Pelale y la Asociación? Entre los dirigentes, los longkos y la Asociación?
- Sabe usted de las reuniones comunitarias que tiene el Hospital? Las ha asistido alguna vez?
- Me podría decir, si tuviera Ud alguna sugerencia o algún reclamo para el Hospital, ¿cómo se comunicaría esto al Hospital?

Terminar de entrevista

- Para terminar, está bien si le pido su edad? Puede ser su edad aproximada, si prefiere.

English

Boroa Filulawen Intercultural Health Centre
Interview schedule

Introduction

- Could you tell me your name and your role in the Territorial Organisation?

Community participation

- For you, what is good participation in health in your community? What are its benefits?

The Territorial Organisation

- How was the Organisation formed in the beginning? Can you tell me the context/circumstances/situation within which it was formed?
- Could you explain to me the role of the Territorial Organisation? What type of decisions does the Territorial Organisation make? What types of decisions or activities does the Organisation take part in? Can you give me an example?

The community

- Could you tell me about the area that the Centre serves? How many communities are included? Which people and communities attend and which don't attend, if any?
- Could you describe the type of relationship between the people that live in the communities of Boroa and the Organisation? Between the leaders, the longkos and the Organisation?
- What types of communication are there between the Organisation and the people that live in Boroa?
- How are the health needs of the community determined? If a particular issue comes up, how is this communicated to the Organisation? How does the Territorial Organisation of Boroa Filulawen respond?
- Some of the objectives of the Organisation that you've mentioned were…What obstacles or difficulties have there been in achieving them? Can you tell me about some? Or give me examples?

Relationships with institutions and organisations

- How do you believe SSAS and other public services could better support the work and objectives of the Centre?
- What are some of the public organisations and institutions that the Committee works with? Can you tell me more about how the Committee works with them?

Ending the interview

- Is there anything else that you believe is important for me to know, that I haven't asked you about yet?

Indigenous Health Association of Makewe-Pelale

Introduction

- Could you tell me your name and role in the Association?

Community participation

- For you, what is good participation in health in your community? Community action in health? What are its benefits?
- Could you give me an example of good community participation?

The Association

- How was the Association formed in the beginning? Can you tell me the context/circumstances/situation within which it was formed?
- How are its members determined or elected? Has this changed over time? How did you come to be a member of the Association initially? What responsibilities have you had?
- What are the objectives and aims of the Association? Have these changed with time? How? Why?
- Could you explain to me the role of the Association? I understand that the Association administers the Hospital, but what does this mean in practice? What type of decisions does the Association make? What types of decisions or activities does the Association take part in? Can you give me an example?
- Could you tell me or explain more about how decisions are made? Is there normally a formal meeting (formal according to the culture), or is it more informal? How are priorities determined? What happens if there's a disagreement? How is it resolved? Who has the last word?

The community

- Could you tell me about the area that the Hospital serves? How many communities are included? Which people and communities attend and which don't attend, if any?
- Could you describe the type of relationship between the people that live in the communities of Makewe-Pelale and the Association? Between the leaders, the longkos and the Association?
- What types of communication are there between the Association and the people that live in Makewe-Pelale?
- How are the health needs of the community determined? If a particular issue comes up, how is this communicated to the Association? How does the Association respond?
- Some of the objectives of the Association that you've mentioned were…What obstacles or difficulties have there been in achieving them? Can you tell me about some? Or give me examples?

Relationships with institutions and organisations

- What can you tell me about the relationship between the Association and SSAS? Between the Association and PROMAP?
- Do you feel that SSAS/PROMAP supports the Association in its objectives/aims? Why or why not? Can you give me examples of each situation?
- How do you believe SSAS/PROMAP could better support the work and objectives of the Association?
- What are some of the organisations that the Association works with? Can you tell me more about how the Association works with them?

Ending the interview

- Do you have any suggestion for anyone it would be useful to speak to about this topic?
- Is there anything else that you believe is important for me to know, that I haven't asked you about yet?

Key informants from government agencies

- Could you tell me about your role in [X institution]?
- Could you tell me about the role of your institution within the Ministry of Health?

Determining Mapuche medical needs

- Since we're talking about community participation in health, could you tell me how you would define a Mapuche community? Is there a definition that the organisation uses?
- With that definition in mind, what are the ways in which Mapuche people could influence the medical system to ensure that it meets their needs? [At the level of health policy or at the level of health centres]
- Currently, at the level of health policy, how are Mapuche health priorities determined? How does the community participate in the determination of priorities? And at the level of health centres? (What flexibility exists so that the centre can respond to the particular health needs of a community?

Defining community participation

- Speaking in broad terms, for you, what would be the benefits of good community participation? What would be the disadvantages? What would be an ideal community participation in health?
- Could you give me an example of good community participation?
- What are some outcomes that community participation has achieved (if any)?

External factors that have an impact on community participation

- Could you tell me more about facilitators of community participation in Chile? What are the barriers?
- Are there policies or regulations that facilitate participation? Are there some that form barriers to participation?

Organisational roles in support of community participation

- What do you believe is the role of [X institution] in the support of community participation in health, if there is one?
- If [X institution] does aim to support community participation in health, what is the reason behind this?
- Could you give me an example of how [X institution] fulfils this role?
- Is there some way in which you believe that government agencies can give more support to community participation in health?
- I'm interested in the process of financing intercultural services. Could you explain a bit about this? What is the difference between financing Western and traditional services?

Decision-making process

- From the perspective of government agencies, are there some frustrations or tensions in working with intercultural centres of health? Could you tell me a bit about these? From the perspectives of service providers?
- If there were some disagreement between the health centres and [X organisation], how would it be resolved?

Ending the interview

- Do you have any suggestion for anyone it would be useful to speak to about this topic?
- Is there anything else that you believe is important for me to know, that I haven't asked you about yet?

Interview schedule for patients

Interaction with the Hospital

- To start with, what is your community? How far away is it? How long does it take to reach the Hospital? Is your community within Makewe's catchment area?
- How long have you been a patient of the Hospital? Are you a patient of another hospital or health service as well? Why did you decide now to come to this hospital?

Community participation

- Do you consider Makewe Hospital as part of the Mapuche community? Why or why not? In what way?
- How do the community and the Hospital interact? Do you believe that your community participates in Hospital activities?
- Do you believe that it's important that the community participate in the administration of the Hospital? Why? How?
- Do you believe that community participation has an effect on the management of the Hospital?

Knowledge of the Association

- For you is it important that a Mapuche Association administer the hospital, as opposed to a non-Mapuche administrator? Do you know the Association that administers the Hospital? Could you explain to me the role of the Association, from your point of view?
- Could you describe the type of relationship between the people that live in the communities of Makewe-Pelale and the Association? Between the leaders, the longkos and the Association?
- Do you know about the community meetings that the Hospital has? Have you ever attended?
- Could you tell me, if you had some suggestion or complaint for the Hospital, how would you communicate this to the Hospital?

Ending the interview

- To finish, is it okay if I ask your age? It can be your approximate age, if you prefer.

Appendix 3: Reflections on ethics in Indigenous health research in Chile

Reflections on ethics in Indigenous health research in Chile

Reflexiones sobre la ética en la investigación de la salud de la población indígena en Chile

Reflexões sobre a ética na pesquisa em saúde indígena no Chile

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Abstract

The article aims to reflect on the creation of a more solid ethical research infrastructure in relation to Indigenous health research in Chile. It presents an ethical research framework that aims to support a more equitable and collaborative relationship between academics and Indigenous communities, which may lead to more relevant research and increased benefits for communities in accordance with bioethical research principles. We use international experiences to inform consideration of how ethical Indigenous health research infrastructure could be established in the Chilean context. We then present the development and adoption of guidelines for ethical Indigenous health research and orientation towards collaborative and community-led research as mechanisms that may assist in achieving these aims.

Keywords: Bioethics, research, Indigenous, Mapuche.

Resumen

El objetivo de este artículo es reflexionar sobre la creación de una infraestructura de investigación ética más sólida en relación con la investigación de la salud de la población indígena en Chile. Se expone un marco de investigación ética que apunta a apoyar una relación más equitativa y colaborativa entre académicos y comunidades indígenas, lo que puede conducir a investigaciones más pertinentes y a mayores beneficios para las comunidades de conformidad con los principios de la investigación bioética. Se emplearon experiencias internacionales para informar sobre la forma en que se podría establecer una infraestructura de investigación de la salud de la población indígena en el contexto chileno. Luego, se presenta el desarrollo y la adopción de directrices para la investigación ética de la salud de la población indígena y la orientación hacia la investigación colaborativa y dirigida por la comunidad como mecanismos que pueden ayudar a lograr estos objetivos.

Palabras clave: bioética; indígenas; investigación; mapuche.

Resumo

O artigo busca refletir sobre a criação de uma infraestrutura de pesquisa ética mais sólida em relação à pesquisa em saúde indígena no Chile. Apresenta-se um âmbito de pesquisa ética que visa corroborar um relacionamento mais justo e colaborativo entre a academia e as comunidades indígenas, o que pode resultar em estudos mais relevantes e no aumento dos benefícios para as comunidades, de acordo com os princípios bioéticos da pesquisa. Usamos experiências internacionais para indicar como a infraestrutura da pesquisa em saúde indígena poderia ser estabelecida no contexto chileno. Em seguida, apresentamos o desenvolvimento e adoção de diretrizes para a pesquisa ética em saúde indígena e a orientação em direção a uma pesquisa colaborativa e à comunidade como mecanismos que podem ajudar a alcançar esses objetivos.

Palavras-chave: bioética, indígena, Mapuche, pesquisa.

Background

Academia and Indigenous peoples

Historically, research carried out in Indigenous contexts has been associated with colonization and oppression. Eugenic theories associated with academic institutions have formed the basis of policies and laws that have had a disastrous impact on Indigenous peoples. Such theories have been used to justify genocidal and assimilationist practices such as the forced removal of Indigenous children from their families, the forced sterilization of Indigenous women, the dispossession of Indigenous peoples from their lands, and other dehumanising treatment (Cervini, 2011; Dobbin, 2015; Grekul, Krahn, & Odynak, 2004; Kukkanen, 2006; Nahuelpán, 2013). Dominant Western academic thought has considered Indigenous epistemologies to be inferior and has alternatively delegitimized and exploited Indigenous knowledge (Dudgeon, Kelly, & Walker, 2010; Kukkanen, 2006; Kwaymullina, 2016; Tuhiwai Smith, 2012). In this way, it has contributed to the loss of Indigenous identity, such as cultural and religious beliefs, and undermined the way in which Indigenous peoples understand themselves and the world around them (Kerwin, 2011; Quilaqueo Rapimán, Quintriqueo Millán, Riquelme Mella, & Loncón Antileo, 2016).

This way of conceptualising research continues to have an impact on Indigenous peoples today, with attitudes regarding the superiority of Western cultures and thought along with associated processes of colonisation underlying interpersonal and systemic racism and the loss of Indigenous language, land, familial ties, and social structures. This has had ongoing implications for the health of Indigenous peoples, with inequities in socioeconomic status, educational attainment, adequate employment, experiences of racism and discrimination and living conditions having been identified as particularly relevant to Indigenous health (Commonwealth of Australia, 2013; King, Smith, & Gracey, 2009).

Cultural factors, including identity, language, and social connection, are important determinants of Indigenous health; such that loss or weakening of identity has been tied to higher levels of suicide risk (Chandler & Lalonde, 2009), mental illness (Durie, Milroy, & Hunter, 2009), and the use of alcohol and other drugs (Brady, 1995); on the other hand, culture has been identified as a source of resilience for some Indigenous communities (Danto & Walsh, 2017; Wexler, 2014). The pathways through which these determinants affect Indigenous health are interconnected and reinforce each other: they lead to stress, maladaptive coping mechanisms, and social fragmentation (King et al., 2009).

When constructing an understanding of Indigenous health and the health disparities experienced by Indigenous peoples, academic research has centred around Western, rather than Indigenous, conceptualisations of health and imposed priorities that have originated outside of Indigenous communities. In this way, and despite the high volume of research being carried out in this field, serious questions have been raised by Indigenous communities, leaders, and scholars regarding the utility of the work being undertaken and whether Indigenous communities, who bear

the brunt of the risks and burden of research, are receiving adequate benefit (Mohindra, 2016; Mohindra, 2015). This has led to the perception within Indigenous communities that Indigenous health research has primarily been undertaken as a way to further academics' careers rather than for the purpose of improving Indigenous health outcomes (Tuhiwai Smith, 2012). For these reasons, there is a distrust towards academics and academia as a whole that is rooted in long-standing experience indicating that little consideration is paid to incorporating the needs and concerns of Indigenous communities in research and that research practices are not aligned to Indigenous priorities and values.

However, well-conducted health research can improve the well-being of Indigenous peoples by providing high-quality and accurate data to underpin appropriate policy; evaluation of health programs, and policies to ensure that Indigenous communities are benefitting from these initiatives; and increasing understanding of cultural aspects of health and heath care (Dudgeon et al., 2010). In reconciling these two perspectives, Indigenous leaders and scholars worldwide have shifted to seeing research as a potential tool towards decolonisation of Indigenous peoples when undertaken in ways that strengthen Indigenous autonomy in research and centres Indigenous values and perspectives.

Approaches to ethical Indigenous health research

Although the field of bioethics is relatively young, it has expanded rapidly in the few decades of its existence. As an academic discipline, bioethics was established in the 1930s and 1940s as a mechanism for addressing ethical issues in relation to medical practice (particularly the medico-patient relationship) (Silber, 1982). From this time, it has become a broad transdisciplinary field that encompasses bioethics in research into human beings, public policy, and health and human rights, etc. (Gordon, 2011; Silber, 1982). The current article is located at the intersection between these areas and presents the ways in which academic health research can incorporate and respond to those ethical principles that correspond with Indigenous peoples' rights to self-determination and sovereignty. In this way, the article also relates to public policy and the capacity to establish health policies that align with the priorities and values of the affected Indigenous communities and address their needs. To achieve these goals, academia will need to profoundly change its relationship with Indigenous communities and peoples.

The decolonisation of research engages with the history between researchers and Indigenous peoples and seeks to reorient this relationship in a way that supports Indigenous peoples' right to self-determination, sovereignty, and control over their own histories and knowledges. Linda Tuhiwai Smith (2012) positions this decolonisation process as a direct response to the harm experienced by Indigenous communities as a result of academic research as well as a way of validating and recovering Indigenous methods of enquiry and ways of knowing (Tuhiwai Smith, 2012). This approach seeks to invert the co-option of Indigenous knowledges and experiences by non-Indigenous individuals

and organisations as Indigenous people and communities use research tools to serve their own needs and purposes, imbuing research processes with their values, perspectives, priorities, and epistemologies.

Smith's *Decolonizing Methodologies* explicitly targets Indigenous scholars, leaders and communities; it problematizes the role of the non-Indigenous scholar undertaking research in Indigenous contexts. By examining the work undertaken by non-Indigenous researchers, Smith outlines questions regarding trust, power, accountability, the balances between benefit and harm, and the positioning that the non-Indigenous researcher brings to their work. Leyva and Speed (2008) carry out a detailed examination of the challenges and possibilities of developing knowledge through *co-laborative* work between Indigenous and non-Indigenous academics, as well as with scholars from Indigenous communities and organisations. In working towards decolonised research that privileges Indigenous knowledges and perspectives, the participants in the *co-labour* project faced issues that ranged from questioning the fundamentals underpinning research aims to logistical considerations such as equitable pay (Leyva Solano, Burguete, & Speed, 2008). It is worth noting that Smith as well as Leyva and Speed reach similar conclusions: given that much of the conflict between Indigenous communities and academic researchers stems from the clash of differing and opposing worldviews, as well as the continuing dominance of western epistemological frameworks over Indigenous ones, equitable engagement and collaboration with Indigenous peoples and communities requires a profound reconsideration of the positioning and biases associated with academia (Nahuelpán M, 2013). A reflexive approach questions the way knowledge and meanings are constructed, as well as examining the influence of the relative positions of the researcher and participants within social, political, and historical contexts. Guillemin and Gillam (2004) argue that reflexivity in research represents "ethics in practice" or grappling with the day-to-day ethical issues that arise during research, which are often unanticipated or outside the scope of ethics committees and guidelines (Guillemin & Gillam, 2004).

While Guillemin and Gillam largely situate reflexivity at the level of the individual researcher, Nicholls (2009) speaks about reflexivity in research in an Indigenous context as something that is practiced on three levels: The first is self-reflexivity, or how the individual recognises their own biases, assumptions, and ways of working. This reflexivity is tied to the second type, which is interpersonal reflexivity or the ways in which the research works with or collaborates with others and incorporates self-awareness and building trust and rapport. The third type is collective reflexivity, which examines participation in research and the relative roles of the researcher and the community (Nicholls, 2009). Finally, institutional reflexivity must also be considered as necessary to facilitate embedded changes in academic research practices such as funding allocation, organisational partnerships, and patterns of knowledge dissemination as. The task of enabling ethical Indigenous health research will require academic institutions to reimagine

their own positioning in relation to Indigenous communities and organisations.

Academic institutions are increasingly formalising ethical research practice and incorporating special ethical research considerations according to context and the intended participants and/or beneficiaries. Included in this is a growing number of ethical guidelines in relation to research carried out in Indigenous contexts. Tunón, Kvarnström, and Lerner (2016) reviewed ethical principles in sets of documents relevant to ethical research conduct in Indigenous contexts from Australia, Aotearoa/New Zealand, the Nordic Saami Parliaments (representing Saami communities across three Nordic countries), Canada, and the United States as well as in international policy documents. Tunón et al. also included documents that, while not ethical research guidelines *per se*, were concerned with ethical conduct in relation to Indigenous peoples and influential in the development of ethical thought in this field. The authors also included ethical research guidelines that were not directly concerned with Indigenous research. While the review is not comprehensive, the comparison provides an overview of the principles commonly seen by Indigenous and non-Indigenous institutions to be ethically relevant to research in Indigenous contexts (Tunón, et al., 2016).

Across the documents, they found eighteen listed principles, five of which were present in at least eleven of the thirteen documents. These five most common principles were:

- Full disclosure
- Prior informed consent
- Confidentiality
- Respect
- Reciprocity, mutual benefit, equitable sharing

In addition, each document was summarised into a single core principle, which was seen to be its unifying focus:

- Respect
- Recognition of rights
- Responsibility as a scholar
- Mindfulness
- Participation
- Mutual benefits

Overall, the documents align with the principles of biomedical ethics, including free and informed consent, respect, benefit, and justice. They also focus primarily on the relationship between the researchers and the participants (Beauchamp & Childress, 2013; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Tunón et al. also make the point that the focus of the guidelines depends on the developers—Guidelines that originated from academic institutions tended to focus on research issues, while those that were developed by Indigenous organisations strongly emphasised principles that stem from a health equity or human rights perspective, such as the involvement of local stakeholders in setting priorities, community benefits before and after the research, capacity-building, and research partnerships.

Current thinking regarding ethics in Indigenous health research is not static and continues to evolve worldwide. Examination of Indigenous health research ethics outside the researcher-participant relationship continues to expand by considering the role of funding bodies, publication methods, and other aspects of the research process. There are, for example, strengthening calls for the ethical dimensions of Indigenous health research to be explicitly considered in evaluating and reviewing the quality of academic publications in this field (The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange, 2015). There are also calls for the development of mechanisms to ensure that data control and ownership can be governed in ways that are in accordance with Indigenous uses and customs (Kwaymullina, 2016).

Ethics of Indigenous health research in Chile

The genesis of this article is based on the principal author's (ASF) experience of Indigenous health research in Temuco, Chile and Indigenous health in Australia. In Chile, many conversations were undertaken with Mapuche leaders about the communities' relationships with and expectations of academic researchers as well as about the utility of Indigenous health research. These conversations were complemented by discussions with Chilean academics who reflected on their own research practice.

It quickly became evident that issues of distrust between Indigenous communities and non-Indigenous academics is a constantly recurring theme. Indigenous community leaders and scholars express dissatisfaction with the behaviour of non-Indigenous researchers and the lack of community benefits derived from the research. Community leaders recall with frustration academics who have entered Indigenous communities with their own agendas and upon finishing their studies preferred to publish in academic journals or theses; they left behind no record of their research findings that was accessible to communities. Indigenous communities and organisations, therefore, lack control over how they are represented publicly and resent the time and effort spent in participating in research which—from their perspective—only contributes to furthering researchers' careers. The Mapuche historian Héctor Nahelpán has described in detail how these suspicions continue to echo those generated from the first experiences of Mapuche communities with research that was undertaken to further the processes of colonisation (Nahuelpán, 2013).

Within Chile, there is a lack of evidence needed to development of appropriate health services for Indigenous peoples. This refers not only to epidemiological data but also to cultural understandings and conceptualisations of health to support service provision and the examination of social determinants of health for Indigenous communities. In this way, the situation in Chile, with respect to the relationship between academia and Indigenous peoples, is similar to that seen in other countries. León (2008) argues that Chile is entering an era characterised by the expansion of bioethical consideration from the clinical to the social and that the application of eth-

ical principles in health must be brought to bear on the protection of human rights and the elimination of social inequities (León Correa, 2008). In order to fulfil this objective, and to undertake research that contributes to the health and well-being of Indigenous peoples, there is a need to strengthen ethical research practice in the field of Indigenous health.

Therefore, this paper aims to contribute to the construction of a conceptual and methodological framework to undertake ethical Indigenous health research through the provision of international examples that illustrate mechanisms that may serve to underpin such a framework in the Chilean context.

Here, a conceptual and methodological research framework refers to approaches that support Indigenous governance in research, foster community-controlled and community-driven research, and enable equitable, respectful relationships between academic institutions and Indigenous communities. In particular, the paper focuses on the role that academic and non-Indigenous institutions play in the development and adoption of guidelines for conducting ethical Indigenous health research and orientation towards collaborative partnerships and community-led research. These are presented together as evidence from international Indigenous contexts indicates that interlocking strategies are necessary for the effective reframing of Indigenous health research (Ball & Janyst, 2008; Tobias, Richmond, & Luginaah, 2013).

Ethical guidelines for Indigenous health research

There is a lack of formal guidance in Chile regarding ethical research conduct in Indigenous settings. The National Commission for Scientific Research and Technology (Comisión Nacional de Investigación Científica y Tecnología, CONICYT) has produced a number of documents regarding ethics in research, but this material is limited and superficial in relation to ethical research with Indigenous peoples. It includes a publication regarding the inclusion of vulnerable participants in scientific research, which only contains one line acknowledging the ethical necessity of incorporating Indigenous values and perspectives in all stages of research that concerns these populations (Comisión Nacional de Investigación Científica y Tecnológica, 2014). In 2006, Chile introduced legislation regarding research carried out on human beings. Law 20.120 *Regarding scientific research on human beings, their genomes, and prohibiting human cloning*, is largely concerned with ensuring that scientific research is undertaken by professionals using appropriate methods and limiting the harm to research participants. This includes mandating the use of informed consent and the approval of an ethics committee before research can proceed. The same law also created the National Bioethics Commission (Comisión Nacional de Bioética, CNB) (Ministerio de Salud, 2006). In 2012, another law regarding bioethics was introduced: Law 20.584 *Regulating the*

rights and responsibilities of people in relation to actions connected to their health care. This law prohibits the participation of disabled people who cannot express consent and places limitations around access to medical records (Ministerio de Salud, 2012). In each of these cases, conceptualisation of ethics in research is heavily based on bioethics with a view towards regulating biomedical research. Neither legislation considers the case of ethics specifically in relation to Indigenous peoples. University ethics committees evaluate research project applications with respect to this documentation and legislation as well as international declarations and guidelines such as the Declaration of Helsinki and the UN Declaration on Human Rights (Oyarzún et al., 2014; Universidad de Chile).

The purpose of ethical guidelines for Indigenous health research

While guidelines and ethics committees are understood to be neither the beginning nor the end of considering ethical issues in research, they serve the purpose of providing a starting point of engagement and the establishment of a framework around acceptable practice as considered by both community members and researchers. The lack of formal guidance with respect to ethical Indigenous health research in Chile means that there is little space to come to a shared understanding between academia and Indigenous communities regarding themes such as: the purpose of Indigenous health research and expected community benefit, identifying relevant Indigenous values and the incorporation of these values into research, and the roles of academic and community partners and other stakeholders. It is largely left to the individual researcher and Indigenous organisation or community to reach an agreement on these issues, and they sometimes have little common language to do so.

The development of guidelines either written by Indigenous organisations or in collaboration with them and their subsequent adoption by universities' and research institutions' ethical processes may, therefore, serve a number of uses: First, to encourage research that is primarily designed to address priorities identified by Indigenous peoples and in accordance with their expectations. Instituting ethical review processes that incorporate special consideration regarding research in Indigenous contexts and mandating that research projects are approved before they start will ensure that researchers begin the process of designing projects with ethical principles in mind. Second, the guidelines may help to strengthen an academic framework that supports researchers to fulfil their ethical obligations towards Indigenous communities and to provide mechanisms to enforce expectations held by the Indigenous communities. Under this system, researchers have the benefit of clear expectations regarding appropriate research conduct from their institutions. Finally, embedding ethical guidelines and related structures provides the basis for a shared understanding and transparency between academics and Indigenous communities regarding what constitutes ethical research practice as well as formal pathways for Indigenous communities and individuals to pursue redress if a researcher does not meet their ethical obligations.

Principles to guide ethical Indigenous health research

In order to be effective, ethical research guidelines must be based on strong and clearly defined principles and also provide actionable indicators for ethical practice. In 2013, the Australian National Health and Medical Research Council (NHMRC) evaluated their documents relating to ethics in Aboriginal and Torres Strait Islander health research. Within Australia, all university-based researchers are obliged to comply with the principles in the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2004* document (National Health and Medical Research Council, 2003). One of the evaluation's main findings was that participants felt that the values espoused in this document could be strengthened through providing examples of good and bad practice and case studies to demonstrate how the principles would be applied in practice (Australian Institute of Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, 2014). The inclusion of concrete examples could be especially valuable by showing the particularities of local issues and what ethical practice looks like in these instances.

Principles of ethical Indigenous health research can be grouped into three overlapping clusters:

- Principles regarding basic research practice such as obtaining informed consent and issues of confidentiality;
- Principles informed by the particularities of Indigenous contexts or based on Indigenous values, including cultural retention, sovereignty, capacity-building, community engagement and values specific to an Indigenous people or community; and
- Principles that encompass stakeholders beyond the researchers and participants, such as the role of funding bodies, research institutions, national governments and/or policy-makers.

As outlined above, the key principles of ethical research frameworks relating to Indigenous contexts, as identified by Tunón et al., broadly align with the principles of biomedical ethics. Basic research practices are contained in all or nearly all documents (Beauchamp & Childress, 2013; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; Tunón et al., 2016).

A central critique of traditional bioethics is that it does not sufficiently engage with social and cultural aspects of ethics. Instead, it relies on a basis of individualistic and Western analytical thought (Hedgecoe, 2004; León Correa, 2009). This conceptualisation of ethics has proven to be insufficient in addressing the complexity and diversity of attitudes towards ethics and morality represented by varying cultures (Carrese & Rhodes, 1995). This is also reflected in the wider literature regarding ethics in Indigenous research contexts, which consistently references the decolonisation of research frameworks and a community-based understanding of human rights. Ethical Indigenous health research is primarily considered to be research that respects and upholds Indigenous peoples' rights to self-sovereignty and autonomy and is characterised by accountability and rec-

iprocity (Dudgeon et al., 2010; First Nations Centre, 2005; Glass & Kaufert, 2007; Kukkanen, 2006).

Principles informed by these perspectives posit that ethical research necessitates the active involvement of Indigenous peoples, reinforces the capacity of Indigenous peoples to have control over research that affects them, and ensures that such research is in line with their own priorities. Similarly, research should provide clear benefit to Indigenous communities and populations and exhibit reciprocity and respect for Indigenous knowledge (Ball & Janyst, 2008). Data governance protocols—providing a clear understanding of who owns and controls research data—as well as the dissemination of research findings to the community and engagement with the community regarding how research outputs are utilised are also necessary to comply with the principles of ethical Indigenous health research (First Nations Centre, 2005; Harding et al., 2012).

Considering international guidelines for ethical research in Indigenous contexts, the inclusion of principles specific to Indigenous peoples has been addressed in various ways. In many instances, Indigenous principles and values are embedded in the guidelines through discussion of how they should inform research practice. *Te Ara Tika* stands out regarding how it presents key Indigenous ethical concepts. *Te Ara Tika* is the ethical guidelines document for Māori health research developed by the Health Research Council of New Zealand. *Te Ara Tika* is strongly rooted in traditional Māori ethical values (*matauranga Māori*), which encompasses the right way to do things (*tikanga*) and concepts regarding justice and equity (*mana*). The Māori Ethical Framework, which underpins *Te Ara Tika,* sets out four main ethical values based on *tikanga*: *tika* (research design), *manaakitanga* (cultural and social responsibility), *whakapapa* (relationships), and *mana* (justice and equity). These values and concepts are then integrated with Western principles, which helps understanding for both Māori and non- Māori readers (Australian Institute of Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, 2013; Hudson, Milne, Reynolds, Russell, & Smith, 2010).

The majority of ethical research guidelines focus nearly exclusively on the relationship between the researcher and the participant. For example, when questions of benefit are considered, they are constructed to place the responsibility for delivering benefit on the researcher. However, in cases where research is intended to inform policy or practice, the primary capability to deliver such benefit does not necessarily rest with the researcher—rather, it depends on policy-makers, practitioners, funding bodies, and other stakeholders.

Ethical consideration regarding the benefit of research to Indigenous communities should, therefore, encompass the roles of these other entities as well as the researcher; however, the development of these issues and consideration of stakeholders' ethical obligations is currently limited. The *Research for health justice* framework (2014) provides a concrete way of conceptualising the ethical obligations of various actors in health

research (Pratt & Loff, 2014). For example, the framework highlights the responsibility of governments and policy-makers to create incentives for and remove barriers to the development of research that will provide reliable evidence to underpin effective policies and interventions. Under this framework, responsibility for particular ethical obligations is allocated in accordance with the work normally undertaken by each institution or entity. Therefore, as researchers normally work at the level of the individual or community, they would have the responsibility of building capacity within the communities that they work with through their research practice. However, this responsibility also extends to their host institutions to form sustainable institutional-level collaborations and relationships with relevant organisations. While the *Research for health justice* framework was constructed to inform international clinical research, the principles are also applicable to Indigenous health research (Pratt & Loff, 2014).

Processes for the development and institutionalisation of ethical guidelines for Indigenous health research

International examples demonstrate variation in the processes by which guidelines for ethical research in Indigenous contexts have been developed and institutionalised. As outlined above, the development of ethical research guidelines has been undertaken both by academic and other non-Indigenous institutions (normally through consultation or in collaboration with Indigenous communities), and by Indigenous communities and organisations (Tunón et al., 2016).

While in Australia there is general agreement on the principles espoused in the national guidelines (National Health and Medical Research Council, 2003), in Canada there is less consensus between Indigenous leaders and communities regarding a specific set of principles. This reflects the diversity of opinion and viewpoints on the subject (Ball & Janyst, 2008). A review of international ethical guidelines and frameworks found that a more local approach to research allowed Canadian First Nations communities to exercise stronger self-determination over research that concerned them as communities could refuse or interrupt research that was noncompliant with their ethical standards (Australian Institute of Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, 2014). Tools also exist to support Canadian First Nations communities in thinking through the ethical research issues that are relevant to them and to establish committees and other structures to engage with researchers and research institutions from outside their communities (First Nations Centre, 2003, 2007a, 2007b). The same review recommended that a similar process be developed in Australia as local guidelines may be a more appropriate way of respecting the wide diversity of Aboriginal and Torres Strait Islander communities and perspectives than using national guidelines (Australian Institute of Aboriginal and Torres Strait Islander Studies & The Lowitja Institute, 2014). In New Zealand, rather than committees operating at a local level, community ethics review is achieved through

Māori representation on regional ethics review committees. Regional ethics review contains a separate review process to ensure the relevance, benefit, and acceptability of the research to Māori communities (Glass & Kaufert, 2007). In the United States, there is no national framework or set of guidelines in relation to research with American Indian and Native Alaskan communities; rather, approval from the relevant tribal government is necessary for research to proceed (Glass & Kaufert, 2007).

In each of these cases, challenges exist in balancing procedural ethics—that is, the steps a researcher must go through to obtain institutional approval to conduct research in Indigenous communities—and the viewpoints of Indigenous communities regarding research that affects them. There are numerous reports in the literature regarding conflicts between the positioning and perspectives of institutional research ethics committees and Indigenous communities; for example, where a community has offered ethical guidance that contravenes university -or federal- based ethical protocols (Glass & Kaufert, 2007). These tensions have been reported to hinder collaboration between researchers and Indigenous community organisations as well as Indigenous autonomy in research. In the case of conflicting ethical mandates, a researcher may find themselves in the position of having the choice to either undertake practice that goes against institutional guidelines and thus risking their funding or professional reputation, or proceed against community advice, undermining the rights of Indigenous communities to have a say in research that concerns them (Stiegman & Castleden, 2015).

When considering the case of Chile, a number of interrelated questions on the development and implementation of ethical guidelines regarding Indigenous health research arise. Such guidelines must reflect the significant diversity in ethical thought regarding research with Indigenous peoples both within Indigenous communities and at the national level; at the same time, a system of institutional processes that is functional for researchers and communities needs to be established. Accomplishing these complementary goals will require a strong and sustained collaboration and coordination between all stakeholders, including Indigenous leaders, communities and organisations, academic and research institutions, and research funding bodies and government agencies.

There is also likely to be a need to train members of institutional ethics committees in relation to ethical issues in Indigenous research from an Indigenous-community perspective as well as structures to support adequate Indigenous representation on such committees. Given the high numbers of foreign researchers who undertake research in Indigenous Chilean contexts, mechanisms to ensure accountability of these researchers adhere to established ethical norms should be included.

Using international examples as a starting point, the next section presents a number of possibilities to develop and implement guidelines for ethical Indigenous health research in Chile. Each has their own advantages and challenges:

1. An initial set of guidelines is developed at the national level; for example, through CONICYT in collaboration with Indigenous communities and organisations in order to centre Indigenous perspectives and values regarding research. Research based in or commissioned by government institutions or undertaken by universities would be obliged to comply with these guidelines. While this has the advantage of having a single, cohesive approach, it may lack representation of the diversity of ethical frameworks and perspectives that exist across Chile's Indigenous peoples.

2. Guidelines are developed not by a national body but rather by individual universities, research institutions, and/or professional organisations, which would then govern the research of institutional members. As in the case of the previous approach, mechanisms for sufficient collaboration with and input from Indigenous communities and organisations would need to be established. Structures to support cross-institutional collaboration and avoid excessive bureaucracy, such as coherence in application forms and/or fast-tracking projects that have received previous approval from another organisation, could be helpful.

3. Guidelines could be developed by Indigenous organisations , reflecting those values and principles of particular importance and relevance to them. If frameworks are developed by Indigenous organisations and communities, there will need to be subsequent consideration as to whether and how these guidelines are embedded into institutional processes, such as through adoption by university ethics committees.

4. Similar to the system that exists in Canada, Indigenous communities could form local processes and committees to guide and govern research that pertains to them. The tools that currently exist to support Indigenous communities in Canada and internationally to develop research governance processes could be reviewed and adapted for use in Chile. This approach would strengthen Indigenous autonomy at the community level, but it could prove to be a disjointed system for researchers to navigate, particularly in the case of research operating across multiple communities.

A hybrid approach to these options may help to address the weaknesses of any particular one. Specifically, option four could be used in conjunction with the other three options in order to improve the responsiveness of research to local concerns, increase communities' control over research that affects them, and strengthen the incorporation of diverse Indigenous values and perspectives. That is, the ethical approval processes could be conducted on multiple levels—internally, within research institutions, as well as at the community level. In this case, mechanisms to support cohesion between the processes should also be developed.

While an important step forward, the installation of ethical guidelines alone does not guarantee the formation of equitable research practice. The over-reliance on ethics guidelines as a tool to shape research has been criticised as being insufficient to conceptualise a more inclusive and responsive

dynamic between researchers and Indigenous communities (Humphery, 2001). In addition to the use of ethical guidelines, there is also a need for more explicit involvement of Indigenous people and communities during all stages of the research process.

Collaborative partnerships and community-led research

Examining Indigenous health research through the lens of decolonisation and human rights leads to the view that ethical research respects and upholds Indigenous peoples' rights to self-sovereignty and autonomy and is characterised by accountability and reciprocity (First Nations Centre, 2005). This approach to research is given the space to take place by incorporating Indigenous and community-led approaches and the centring of Indigenous perspectives, values and priorities as well as the creation of institutional structures that facilitate such research being undertaken (Tuhiwai Smith, 2012). For research carried out by academic institutions, this necessitates research conduct that has at its centre strong partnerships with Indigenous communities and an emphasis on capacity-building.

In the last decade, a move towards community-led research and collaborative relationships has been positioned as an essential approach to increase engagement with Indigenous communities and organisations in research. This process involves all stages of the research, from the conception of research questions and directions to the execution and dissemination stages (Bharadwaj, 2014). Moreover, sustained partnership-building is seen as upholding values of Indigenous sovereignty and autonomy as communities retain greater control over and input into research that affects them (Ball & Janyst, 2008).

The road between undertaking research and generating data that could lead to a positive influence on policy and practice and actually seeing this potential realised can be long, uncertain, and often difficult. There is, therefore, a valid concern that research activities will use up scarce community resources such as the time of participating individuals and organisations without delivering expected benefits.

Working in partnership with and under the guidance of Indigenous communities and organisations may support increased benefit to communities in multiple ways. This way of working has been demonstrated to limit harms and increase community benefit from research (Menzies, 2004) by ensuring that it is more relevant and corresponds to community priorities. It should also facilitate the positioning of Indigenous communities as the experts on what does and does not work within their context.

Working in partnership with Indigenous communities can also aid the production of good research by generating ongoing relationships and fostering trust and understanding between the different parties, thereby increasing individuals' and communities' willingness to be involved as well as the quality and rigour of the research (Jamieson et al., 2012). Ultimately, continuing to work with a given community over time also enables cohesion in research, with the opportunity to build and expand on previous work,

rather than undertaking piecemeal projects. Additionally, effective partnership-building can support clearer communication between researchers and communities about what benefits are likely and reasonable to expect from a particular piece of research and what the process is for realising these benefits.

Given the positive aspects of working in partnership with Indigenous communities, the necessity to engage with communities during all stages of the research and the community's right to have a say regarding research that affects them, there is increasing expectation that funding allocation will prioritise research that incorporates community partnerships or is driven by community. The creation of the Interdisciplinary Centre for Intercultural and Indigenous Studies (ICIIS) by the Chilean government illustrates how concerns regarding Indigenous research funding can generate strong pushback from Indigenous academics, organisations, and communities when this research is based in institutions that have few ties to or knowledge about these communities and is conducted without Indigenous participation. Scepticism was expressed about the utility of the research that would be generated from the investment of approximately US$ 8 million and the benefit that Indigenous communities would receive from this research (Comunidad de Historia Mapuche, 2013). Similarly, strong reservations regarding the equitable participation of Indigenous people in research resulted from the finding that, of the 103 projects relating to Indigenous peoples funded by CONICYT between 1982 and 2011, only 17 were undertaken by teams that included Indigenous people, and only one was led by an Indigenous institution (Nahuelpán, 2013).

There is no single model for either partnerships between academic institutions and Indigenous communities and organisations or for the development of community-led research. Bharadwaj (2012) visualises research partnerships with Indigenous peoples as a five-phase cyclical framework: Pre-research, where interpersonal relationships are established; community consultation; community entry, where research partnerships are established; research; and research dissemination. This model centres around the key elements of discussion, consultation, engagement, co-learning, collaboration and communication (Bharadwaj, 2014). Examples of successful and productive Indigenous community-academic partnerships include those driven by the community that have encompassed a re-imagining of research funding mechanisms, re-established data governance protocols, and shared responsibilities for research design, data collection, interpretation and dissemination. For example, one health initiative driven by Indigenous communities in Canada (Musqueam) and Ecuador (Quichua), was undertaken in partnership with Indigenous organisations, universities, international agencies, and governmental and nongovernmental organisations. The initiative involved research and other activities centred around local cultural knowledge, diversity, and access to food and food security. The collaboration guidelines stressed knowledge, possession, access and dissemination to the Indigenous communities (Couzos, Lea, Murray, & Culbong, 2005). In Australia, a community-controlled heath research mod-

el was developed where Aboriginal community-controlled health services undertook a large-scale double-blind, multi-centre, randomised controlled trial to examine the management of chronic suppurative otitis media. In this model, research priorities were set, and the academic partnership was initiated by the Aboriginal community-controlled health sector (Couzos et al., 2005).

The term 'partnership' can be vague and have a variety of meanings, depending on who is using the term and in what context it is used. There has been some concern that the term encompasses superficial arrangements between researchers and Indigenous communities that exist solely to fulfil the conditions of institutional ethical approval. Moreover, consultation, collaboration, and partnership processes can be a burden for a community with competing priorities. In the case of service providers, there may be very little time or interest in being involved with research in addition to their core business of health care. (Brunger & Wall, 2016). There may also be a need to build the capacity of researchers who work with Indigenous communities to incorporate culturally appropriate methods in their practice.

For these reasons, establishing sustainable collaborations between academic institutions and Indigenous communities and organisations may be difficult, particularly in the initial phases during which a significant amount of time, patience, and trust is necessary on both sides. A persistent theme in previous experiences is that all involved parties must invest time to ensure the success of such initiatives. As previously indicated, in order for community-based and -directed research centred on mutual collaboration to be carried out, research funding must prioritise these projects and principles. Funding guidelines should ensure that the timelines for Indigenous health research are adequate to be able to establish relationships and consultation, participation, and communication throughout the course of the research process.

Conclusions

Bioethical frameworks primarily based on principles such as informed consent and individual autonomy are insufficient for research with Indigenous populations. Rather, ethical research with Indigenous populations must involve not only the individual but the community as a whole and centre the priorities and values of the communities themselves. This idea can be clearly seen in the work of various Indigenous academics worldwide as well as in ethical guidelines developed by Indigenous organisations. However, the international academic community has been relatively resistant to accept and apply this approach to ethical Indigenous health research.

In Chile, there is a long and continuing history of tension and conflict between Indigenous communities and non-Indigenous academic researchers, which is indicative of the complexities in Indigenous health research worldwide. This distrust between academia and Indigenous communities results in a lack of capacity to effectively address those inequities that characterise Indigenous health. Without research that illuminates the current status of Indigenous health and Indigenous

communities' needs, the capacity to establish health policies and programs that adequately correspond to Indigenous contexts will continue to be limited.

For these reasons, the relationship between academia and Indigenous peoples is increasingly being reoriented to better suit community needs and incorporate Indigenous perspectives and values within a rights-based framework. The infrastructure necessary for consistent ethical Indigenous health research practice is currently underdeveloped in Chile. As such, strengthening structural mechanisms to support ethical practice could provide the basis for more productive research that better represents Indigenous priorities and values Indigenous self-determination.

International experiences in Indigenous health research may provide support to establish such mechanisms, as they represent the diversity that exists in this field in terms of both the distinct institutional contexts that influence how the academy operates in each country as well as the ways Indigenous communities work. Therefore, the strategies presented are not prescriptive; rather, they are a starting point for reflexion and dialogue about what could be appropriate approaches for particular contexts.

Establishing guidelines regarding ethical Indigenous health research and embedding such guidelines into ethics approval processes may serve as the basis for a common understanding of what constitutes ethical practice in this area and provide mechanisms to hold researchers adherence. Genuine research partnerships and collaboration between academic institutions and Indigenous organisations and communities are critical to ensure that Indigenous communities are part of the research process and that Indigenous values, priorities, and knowledge are centred. In order to be effective, these approaches will need to be underpinned by reflexive and transparent research practice on the part of academics and academic institutions.

The process of reorienting Indigenous health research to be in line with the expectations, needs, and values of the communities involved is situated within a context in which the field of bioethics continues to expand and deepen—not only in Chile but throughout Latin America (León Correa, 2008; Lolas Stepke, 2010). As part of the field's development there has been a push towards a social bioethics that is able to converse with diverse ethical systems, thus transcending traditional bioethics, which has been characterised by a limited perspective with regards to diversity (León Correa, 2008, 2009; Myser, 2003). In this way, implementing processes that respond to those ethical dimensions particular to research with Indigenous communities may also serve as a concrete example of how to develop and institute a research bioethics that is more responsive to the complexities encountered in practice.

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Reflexiones sobre la ética de la investigación en salud indígena en Chile

Reflections on ethics in Indigenous health research in Chile

Reflexões sobre a ética na pesquisa em saúde indígena no Chile

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Resumen

El presente artículo constituye una reflexión sobre la creación de una infraestructura de investigación ética más sólida en relación con la investigación en salud de los pueblos indígenas en Chile. A este respecto, se presenta un marco de investigación ética que tiene como fin facilitar una relación más equitativa y colaborativa entre académicos y comunidades indígenas, que podría generar estudios de mayor relevancia, así como mayores beneficios para las comunidades en concordancia con los principios de bioética en la investigación. Igualmente, se documentan algunas experiencias internacionales que proveen información sobre el tema propuesto. Como mecanismos que pueden ayudar a lograr estas metas, se postulan el desarrollo y adopción de guías para la investigación ética en la salud de los pueblos indígenas y la orientación hacia la investigación colaborativa en conjunto con las comunidades.

Palabras clave: bioética; indígena; investigación; pueblo Mapuche, salud.

Abstract

The article aims to present a reflection on the creation of a more solid ethical research infrastructure in relation to Indigenous health research in Chile. The article presents an ethical research framework that aims to support a more equitable and collaborative relationship between academics and Indigenous communities, which may lead to more relevant research and increased benefits for communities, in accordance with bioethical research principles. International experiences are used to inform consideration of how ethical Indigenous health research infrastructure could be established in the Chilean context. The development and adoption of guidelines for ethical Indigenous health research and orientation towards collaborative and community-led research are presented as mechanisms that may assist in achieving these aims.

Keywords: bioethics; research; indigenous; Mapuche; health.

Resumo

O artigo busca refletir sobre a criação de uma infraestrutura de pesquisa ética mais sólida em relação à pesquisa em saúde indígena no Chile. Apresenta-se um âmbito de pesquisa ética que visa corroborar um relacionamento mais justo e colaborativo entre a academia e as comunidades indígenas, o que pode resultar em estudos mais relevantes e no aumento dos benefícios para as comunidades, de acordo com os princípios bioéticos da pesquisa. Usamos experiências internacionais para indicar como a infraestrutura da pesquisa em saúde indígena poderia ser estabelecida no contexto chileno. Em seguida, apresentamos o desenvolvimento e adoção de diretrizes para a pesquisa ética em saúde indígena e a orientação em direção a uma pesquisa colaborativa e à comunidade como mecanismos que podem ajudar a alcançar esses objetivos.

Palavras-chave: bioética, indígena, Mapuche, pesquisa.

Antecedentes

Academia y pueblos indígenas

Históricamente, la investigación llevada a cabo en contextos indígenas se ha relacionado con procesos de colonización y opresión. Teorías eugenésicas asociadas con instituciones académicas han formado la base de políticas y leyes que han tenido un impacto desastroso en pueblos indígenas. Se han utilizado tales teorías para justificar prácticas genocidas y asimilacionistas, como el traslado obligado de niños indígenas desde sus familias, la esterilización forzada de mujeres indígenas, el desalojo de pueblos indígenas desde sus tierras, o el trato deshumanizado hacia ellos como personas (Dobbin, 2015; Nahuelpán, 2013). La dominación del pensamiento occidental académico ha considerado las epistemologías indígenas en una posición inferior y alternadamente ha deslegitimizado y explotado el conocimiento indígena (Kukkanen, 2006; Tuhiwai Smith, 2012; Kwaymullina, 2016). De esta forma, ha contribuido a la pérdida de la identidad indígena, así como a creencias culturales y religiosas, socavando la forma en que los pueblos indígenas se conciben a sí mismos y al mundo a su alrededor (Kerwin, 2011; Quilaqueo Rapimán et al., 2016).

Esta manera de concebir la investigación en pueblos indígenas sigue incidiendo en la actualidad, con actitudes sobre la superioridad de las culturas y del pensamiento occidental, a los que se suman procesos de colonización donde subyace el racismo tanto interpersonal como sistémico y la pérdida de idiomas, tierras, lazos familiares y estructuras sociales indígenas. Esto ha tenido implicaciones permanentes en la salud de los pueblos indígenas, ya que se han identificado inequidades en el estatus económico, el acceso educativo, el empleo adecuado, así como experiencias de racismo y discriminación que configuran condiciones de vida particularmente deterioradas (King, Smith & Gracey, 2009; Commonwealth of Australia, 2013).

Los factores culturales, como la identidad, el idioma y la conexión social, son determinantes sociales importantes para la salud; así se ha ligado la pérdida o el debilitamiento de identidad a riesgos elevados de suicido (Chandler & Lalonde, 2009), enfermedades mentales (Durie, Milroy & Hunter, 2009), y uso de alcohol y otras drogas (Brady, 1995); en el sentido contrario, se ha identificado la cultura como una fuente de resiliencia por algunas comunidades indígenas (Wexler, 2014; Danto & Walsh, 2017). Los caminos por los que estos determinantes impactan la salud de los pueblos indígena están interconectados y se refuerzan mutuamente, provocando estrés, débiles mecanismos de defensa, y fragmentación social (King, Smith & Gracey, 2009).

Para construir un marco de comprensión de la salud indígena y de las desigualdades experimentadas por estos pueblos, la investigación académica se ha centrado en conceptualizaciones de salud occidentales en vez de indígenas y ha impuesto prioridades desde esos enfoques externos a estas comunidades. En este sentido, y a pesar del gran volumen de investigación llevada a cabo en este tema; las comunidades, líderes e investigadores indígenas han planteado dudas so-

bre la utilidad del trabajo realizado y sobre los beneficios reales que reciben las comunidades, que en última instancia son las que enfrentan los riesgos y la carga de la investigación (Mohindra, 2016; Mohindra, 2015). Esto ha generado en los líderes y comunidades indígenas una percepción de que los estudios sobre salud indígena han sido realizados, en primer lugar, para avanzar en las carreras académicas de los investigadores, en vez de mejorar la situación de salud de los pueblos indígenas (Smith, 2012). Existe, por lo tanto, una desconfianza hacia los académicos y la academia en su totalidad, arraigada en experiencias de largo tiempo basadas en la poca consideración con que esta ha incorporado las necesidades y preocupaciones de las comunidades indígenas incluyendo prácticas que no están alineadas con sus prioridades y valores.

No obstante, la investigación en salud bien conducida puede contribuir a incrementar el bienestar de los pueblos indígenas aportando datos precisos y de alta calidad necesarios para sustentar y evaluar políticas y programas apropiados; así como para asegurar que las comunidades se beneficien con esas iniciativas, aumentando el conocimiento sobre aspectos culturales de la atención en salud (Dudgeon, Kelly & Walker, 2010). Al reconciliar estas dos perspectivas, en el ámbito mundial el punto de vista de algunos líderes y académicos indígenas ha sido manejar la investigación como una herramienta potencial hacia la descolonización de los pueblos indígenas, en tanto se realice de manera que fortalezca su autonomía y esté centrada en los valores y las perspectivas indígenas de investigación.

Enfoques de la investigación ética en salud indígena

Aunque el campo de la bioética es relativamente joven, se ha ampliado rápidamente en las pocas décadas de su existencia. Como disciplina académica, la bioética se instauró en las décadas de 1930 y 1940 como mecanismo para enfrentar cuestiones éticas respecto de la práctica médica (en particular, la relación médico-paciente) (Silber, 1982). Desde entonces, se ha transformado en un campo transdisciplinario con bordes difusos que abarca la bioética de la investigación en seres humanos, la política pública, la salud y los derechos humanos, entre otros tópicos (Silber, 1982; Gordon, s. f.). El presente artículo se ubica en la intersección de estas áreas y presenta como eje central la forma en que la investigación académica en salud puede incorporar y responder a los principios éticos que corresponden a los derechos de autodeterminación y soberanía de las comunidades indígenas. En este sentido, tiene una relación directa con la política pública y la capacidad de establecer políticas de salud que coinciden con las prioridades y los valores de las comunidades indígenas afectadas y que cumplen con sus necesidades; por lo que se requiere que la academia cambie profundamente su relación con los pueblos y las comunidades indígenas.

La descolonización de la investigación se enfrenta con la historia previa entre investigadores y pueblos indígenas y procura reorientar esta relación de una manera que fortalezca los derechos de los pueblos indígenas de autonomía, soberanía y control sobre sus propias historias y conocimientos. Linda Tuhiwai Smith (2012) la sitúa como

una respuesta directa al daño experimentado por las comunidades indígenas debido a la investigación académica convencional, así como una manera de validar y recuperar los métodos indígenas de indagar y saber (Smith, 2012). En este enfoque se busca revertir que el conocimiento y experiencias indígenas estén cooptados por el uso de individuos y organizaciones externas, ya que son precisamente las personas y comunidades indígenas las que utilizan las herramientas de investigación para cumplir con sus propias necesidades y finalidades, incluyendo en los procesos de investigación sus valores, perspectivas y epistemologías.

En este sentido el libro, *A descolonizar las metodologías* (Smith, 2012) está explícitamente dirigido a académicos, líderes y comunidades indígenas, problematizando el rol de los académicos no indígenas que realizan investigación en contextos indígenas. Al examinar el trabajo realizado por estos investigadores, Smith problematiza sobre la confianza, el poder, la responsabilidad, y el equilibrio entre beneficio y daño, así como sobre la postura que el investigador posee en su trabajo. Leyva, Burguete y Speed (2008) examinan en profundidad los desafíos y potencialidades en el desarrollo del conocimiento a través de trabajo *co-laborativo* entre académicos indígenas y no indígenas, así como con intelectuales de comunidades y organizaciones indígenas. Mediante el desarrollo de una investigación descolonizada que privilegia conocimientos y puntos de vistas indígenas, los participantes en el proyecto de *co-labor* enfrentan temas que van desde cuestionar los fundamentos subyacentes a las metas de la investigación hasta consideraciones logísticas tales como el pago equitativo (Leyva, Burguete & Speed, 2008). Cabe destacar que tanto Smith como Leyva y Speed llegan a conclusiones similares recalcando que —dado que la mayor parte del conflicto entre comunidades indígenas e investigadores académicos se origina en el choque de cosmovisiones distintas y opuestas, así como en el continuo dominio de los marcos epistémicos occidentales sobre los indígenas— el compromiso y asociación equitativa con pueblos y comunidades indígenas requiere una profunda reconsideración de las posturas y sesgos asociados con la academia (Nahuelpán, 2013).

Un enfoque reflexivo cuestiona la manera en que se construye el conocimiento, los significados, además pone en el debate la influencia de la posición relativa del investigador y de los participantes dentro del contexto social, político e histórico. Guillemin y Gillam (2004) plantean que la reflexividad en investigación representa una "ética en práctica", o el enfrentamiento a las cuestiones éticas cotidianas que surgen en el camino de la práctica de investigación, que son frecuentemente inesperadas o están fuera del ámbito de comités y guías de ética (Guillemin & Gillam, 2004). Mientras Guillemin y Gillam sitúan la reflexividad en gran medida en el ámbito del investigador individual, Nicholls (2009) plantea la reflexividad de la investigación en contextos indígenas en tres niveles, el primero de los cuales corresponde a la *autorreflexividad*, es decir, cómo el individuo reconoce sus propios sesgos, suposiciones y maneras de trabajar. Esta reflexividad está ligada al segundo tipo que es la *reflexividad interpersonal*, que corresponde a las formas en que la investigación colabora con los demás, incor-

porando la autoconsciencia y construyendo confianza y entendimiento. El tercer tipo es la *reflexividad colectiva*, que examina la participación en la investigación y los roles relativos del investigador y la comunidad (Nicholls, 2009). Finalmente, también hay que considerar la reflexividad institucional, que se necesita para facilitar los cambios integrados en la investigación académica, tales como: la asignación de financiamiento, las colaboraciones organizacionales y los patrones de diseminación de conocimiento; también se requiere que las instituciones académicas reimaginen su propia postura en relación con las comunidades y las organizaciones indígenas.

Las instituciones académicas están progresivamente formalizando la práctica de investigación ética e incorporando consideraciones éticas especiales de acuerdo al contexto y los participantes y/o beneficios planeados. En este marco, existe un número creciente de guías éticas con el objetivo de apoyar la investigación llevada a cabo en contextos indígenas. Tunón et al. (2016) revisan los principios éticos en una serie de documentos relevantes sobre la conducta ética en investigación en contextos indígenas de Australia, Aotearoa/Nueva Zelandia, los Parlamentos Nórdicos Saami (representando comunidades Saami que cruzan tres países nórdicos), Canadá y los Estados Unidos, tales como documentos de política internacional. Tunón et al también incluyen documentos que, si bien no son guías de investigación ética *per se*, se relacionan con la conducta ética en contextos indígenas y que son influyentes en el desarrollo de pensamiento ético en este tema (guías de investigación ética que tratan directamente de investigación en pueblos indígenas). Aunque la revisión no incluye toda la documentación relevante, la comparación provee un resumen de los principios éticamente relevantes a la investigación en contextos indígenas que se usan con más frecuencia por instituciones indígenas y no indígenas (Tunón, Kvarnström & Lerner, 2016). Estos se pueden sintetizar en dieciocho principios, cinco de los cuales están presentes en once de los trece documentos, y que son: 1) divulgación completa, 2) consentimiento previo e informado, 3) confidencialidad, 4) respeto, y 5) reciprocidad, beneficio mutuo y equidad al compartir.

Además, resume en cada documento un principio clave singular y unificador: 1) respeto, 2) reconocimiento de derechos, 3) responsabilidad como académico, 4) consciencia, y 5) participación y beneficios mutuos.

En general, los documentos se alinean con los principios de ética biomédica, incluyendo consentimiento libre e informado, respeto, beneficio y justicia, poniendo el foco de manera prioritaria en la relación entre investigadores y participantes ("The Belmont report…", 1979; Beauchamp & Childress, 2013). Tunón et al. también destacan que el enfoque de los documentos depende de su origen; en este sentido, las guías que se originan en instituciones académicas tienden a enfocarse en cuestiones de investigación, mientras aquellas desarrolladas por organizaciones indígenas ponen énfasis en los principios que se originan desde una perspectiva de equidad en salud o derechos humanos; tales como la participación de las partes interesadas en la determinación de prioridades, los beneficios comunitarios antes y después del estudio, y el

desarrollo de capacidades y relaciones entre investigadores y comunidades.

Lógicamente, el pensamiento respecto de la ética de la investigación en salud indígena no es estático y sigue evolucionando en todo el mundo. El examen de la ética de investigación en la salud de los pueblos indígenas, más allá de la relación investigador-participante, sigue aumentando e incluye el rol de los organismos de financiamiento, los métodos de publicación y otros aspectos del proceso de investigación. Por ejemplo, hay demandas crecientes de que las dimensiones éticas de la investigación en salud indígena sean consideradas explícitamente en la evaluación de la calidad de las publicaciones académicas en este campo (The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (2015); también para el desarrollo de mecanismos que aseguren el control y propiedad de los datos, de manera que sean acordes con los usos y costumbres indígenas (Kwaymullina, 2016).

La ética de la investigación en salud indígena en Chile

La génesis del artículo se basa en la experiencia de investigación en salud indígena de la autora principal (ASF), en Temuco, Chile, y en salud indígena en Australia. En Chile, se mantuvo numerosas conversaciones con dirigentes mapuche acerca de la relación y expectativas de las comunidades con los investigadores académicos, así como sobre la utilidad de la investigación en salud indígena. El debate se complementó con discusiones con académicos chilenos con una mirada reflexiva sobre su propia práctica de investigación.

En ese período, rápidamente se hizo evidente que la desconfianza de las comunidades indígenas hacia los académicos no indígenas era un tema permanente. Líderes comunitarios y académicos mapuche expresaban descontento con la conducta de los investigadores y sobre la falta de beneficios concretos de las investigaciones para las comunidades. En ese sentido, mencionaban con frustración a académicos que investigaron en las comunidades indígenas con sus propias agendas y cuando finalizaron sus estudios prefirieron publicarlos en revistas académicas o tesis, sin dejar ningún registro de sus hallazgos accesibles a las comunidades. Esto permite constatar que a las organizaciones indígenas les falta control sobre cómo los representan públicamente, y por ello manifiestan resentimiento por el tiempo y esfuerzo gastado en investigaciones que —desde su perspectiva— solo sirven para avanzar en las carreras de los investigadores. El historiador mapuche Héctor Nahelpán describe en detalle cómo se siguen levantando ecos de sospechas similares a los generados por los primeros encuentros de las comunidades mapuche con la investigación que se realizaron para facilitar los procesos de colonización (Nahuelpán, 2013).

En Chile la evidencia que sustenta el desarrollo de servicios de salud pertinentes para gente indígena es limitada. Esto se refiere no solo a los datos epidemiológicos, sino también a enfoques socioculturales y conceptualizaciones sobre salud que puedan sustentar una atención de salud en las comunidades indígenas desde el marco de los determinantes sociales. De esta manera, la situación en Chile respecto al tipo de relación entre la academia

y los pueblos indígenas es similar a la del resto de otros países. León (2008) postula que Chile está entrando a un período caracterizado por el aumento de consideraciones bioéticas, desde lo clínico hasta lo social; y que la aplicación de los principios éticos se debe utilizar para la protección de los derechos humanos y la eliminación de las inequidades sociales (León Correa, 2008). Para alcanzar este objetivo y realizar investigaciones que contribuyan a la salud y bienestar de los pueblos indígenas existe la necesidad de reforzar la práctica de investigación ética en esta área. Esto requiere de reflexividad, ideas y esfuerzo hacia la reorientación de la relación que tiene la academia con las comunidades indígenas.

En este escenario, este artículo pretende aportar a la reflexión en la construcción de un marco conceptual y metodológico para la realización de investigaciones éticas en la salud de los pueblos indígenas a través de ejemplos internacionales que ilustran mecanismos sobre los que se puede fundar tal marco en el contexto chileno.

El marco conceptual y metodológico de la investigación ética se refiere a los enfoques que apoyan la gestión indígena en la investigación, facilitan los estudios controlados e impulsados por las comunidades y posibilitan relaciones equitativas y respetuosas entre instituciones académicas y comunidades indígenas. En particular, este artículo se enfoca primariamente en el papel de las instituciones académicas no indígenas, asociaciones colaborativas y las propias comunidades indígenas en el desarrollo y la adopción de guías para realizar este tipo de estudio. Cabe señalar que estos mecanismos se presentan juntos, ya que la evidencia en contextos indígenas internacionales indica que son precisamente las estrategias interconectadas las que permiten reformular de manera eficaz la investigación en salud indígena (Tobias, Richmond & Luginaah, 2013; Ball, & Janyst, 2008).

Guías éticas para la investigación en salud indígena

Chile presenta una falta de dirección formal pertinente a la conducta ética en la investigación en entornos indígenas. La Comisión Nacional de Investigación Científica y Tecnología (CONICYT) ha producido diversos documentos acerca de la ética en investigación, pero limitados y superficiales respecto a la investigación ética en pueblos indígenas. Esto incluye una publicación que trata de la inclusión de participantes vulnerables en la investigación científica, que contiene solo una línea que reconoce la necesidad ética de incorporar valores y perspectivas indígenas en todas las etapas de investigación que relaciona con estas poblaciones (Comisión Nacional de Investigación Científica y Tecnológica, 2014). El 2006, Chile instauró la Ley 20.120 sobre la investigación en seres humanos denominada: *Sobre la investigación científica en el ser humano, su genoma, y prohíbe la clonación humana*. Esta se concentra en gran medida en asegurar que la investigación científica sea llevada a cabo por profesionales a través de métodos adecuados, en la limitación de los daños a los participantes de la investigación, e incluye el mandato de usar consentimiento informado y la aprobación de un comité de ética antes de que la investigación pueda realizarse. También, la misma ley crea la Comi-

sión Nacional de Bioética (CNB) (Ministerio de Salud, 2006). Además, durante el 2012 se decreta otra ley vinculada a la bioética: la Ley 20.584 que *Regla los derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención en salud*. En esta se prohíbe la participación de personas con situación de discapacidad que no pueden expresar consentimiento e impone límites en el acceso a registros médicos (Ministerio de Salud, 2012). En cada uno de estos casos, la conceptualización de la ética en investigación está netamente enraizada en la bioética con una perspectiva hacia la regulación de estudios biomédicos. Ninguna legislación considera el caso de la ética en los estudios en pueblos indígenas; así los comités de ética universitarios evalúan los aspectos éticos de los proyectos de acuerdo tanto con esta documentación y legislación, como con declaraciones internacionales y guías como la Declaración de Helsinki y la Declaración Universal de Derechos Humanos (Oyarzún et al., 2014; Universidad de Chile, s. f.).

Propósito de guías éticas de investigación en salud indígena

Aunque se entiende que guías y comités de ética no son ni el principio ni el fin de las cuestiones éticas en la investigación, sirven de igual manera, ya que otorgan un principio de participación y el establecimiento de un marco sobre lo que se considera conducta aceptable desde el punto de vista de los miembros de la comunidad e investigadores. La falta de dirección formal con respecto a la investigación ética en salud indígena en Chile significa que hay poco espacio para llegar a un acuerdo entre la academia y las comunidades indígenas sobre temas como: el objetivo de la investigación en salud indígena y en los beneficios esperados por la comunidad; la identificación de valores indígenas pertinentes y la incorporación de ellos en la investigación; y los roles de las partes interesadas académicas, comunitarias y de otro tipo. Más bien, se deja al a investigador como individuo y a la organización o comunidad indígena la tarea de ponerse de acuerdo en estas cuestiones, posiblemente con muy poco lenguaje común para hacerlo.

El desarrollo de guías éticas, ya sea impulsado por organizaciones indígenas o en colaboración con ellas, y la adopción de estas en los procesos éticos de universidades e instituciones de investigación puede servir para varios propósitos. En primer lugar, para estimular que la investigación sea diseñada en conjunto desde el inicio asegurando las prioridades de los pueblos indígenas y sus expectativas. Es importante que los investigadores inicien el diseño de los estudios considerando los principios éticos con procesos que incorporen consideraciones sobre la investigación en contextos indígenas y que los proyectos reciban la aprobación antes de que procedan. Segundo, para fortalecer un marco de referencia académico que acorde con las expectativas de que los investigadores cumplan con las obligaciones éticas hacia las comunidades indígenas y asegurar mecanismos para hacer valer estas expectativas. Bajo este sistema, los investigadores tienen el beneficio de conocer a tiempo las expectativas sobre lo que se espera de sus instituciones durante la investigación. Por último y relevante a lo anteriormente descrito, la incorporación de guías

éticas y estructuras relacionadas provee la base para una comprensión compartida y transparente entre académicos y comunidades indígenas respecto a la práctica ética en la investigación, como a los caminos formales para que tanto las comunidades indígenas como sus miembros puedan rectificar en el caso de que un investigador no cumpla con sus obligaciones.

Principios directrices de la investigación ética en salud indígena

Para que sean efectivas, las guías éticas de investigación deben estar basadas en principios sólidos y bien definidos, y también proveer de indicaciones para la práctica ética. En el 2013, el Consejo Nacional de Salud e Investigación Médica (National Health and Medical Research Council, NHMRC) de Australia realizó una evaluación de sus documentos relacionados con la ética en la investigación en salud de los Aborígenes e Isleños del Estrecho de Torres. En ese país, todos los investigadores de las universidades deben cumplir con los principios del documento: *Valores y ética: guías de conducta ética y criterios para la investigación en salud de los Aborígenes e Isleños del Estrecho de Torres 2004* (National Health and Medical Research Council, 2003). Uno de los principales hallazgos de la evaluación fue que los participantes percibían que se podían fortalecer los principios contenidos en el documento con ejemplos positivos y negativos, así como con estudios de caso que demostraran la aplicación en la práctica (Australian Institute of Aboriginal and Torres Strait Islander Studies and The Lowitja Institute, 2014). La inclusión de ejemplos concretos era especialmente valiosa para mostrar las particularidades en temas locales y en cómo se percibe la práctica ética en esas circunstancias.

Los principios de la investigación ética en salud indígena se pueden organizar en tres grupos superpuestos:

- Principios que se relacionan con la práctica básica de investigación, tales como la obtención del consentimiento informado y cuestiones de confidencialidad.
- Principios basados en las particularidades de los contextos indígenas o en los valores indígenas, incluyendo la revitalización cultural, la soberanía, el apoyo de las capacidades, la participación de la comunidad y los valores específicos a un pueblo o una comunidad indígena.
- Principios que incluyen partes interesadas externas a los investigadores y a los participantes, tales como el rol de organismos de financiamiento, instituciones de investigación, gubernamentales, nacionales y/o legislativas.

Como se destacó anteriormente, los principios claves de la investigación ética en contextos indígenas identificados por Tunón et al (2016) se alinean en general con los principios de la ética biomédica y con las prácticas básicas de investigación representadas en todos o casi todos los documentos (Tunón, Kvarnström & Lerner, 2016; Beauchamp & Childress, 2013).

Una crítica clave de la bioética tradicional es que enfrenta de manera insuficiente los aspectos sociales y culturales de la ética, más bien depende de una base de pensamiento

analítico individualista y occidental (Hedgecoe, 2004; León Correa, 2009). Se ha demostrado que esa conceptualización de la ética no es suficiente para abordar la complejidad y diversidad de las actitudes hacia la ética y la moralidad que presentan las diversas culturas (Carrese & Rhodes, 1995). Este punto también está presente en la literatura general sobre la ética de investigación en contextos indígenas, con referencias consistentes con el marco de la descolonización de la investigación y de una comprensión de los derechos humanos basados en la comunidad. En estos escritos, se concibe la investigación ética en salud indígena primariamente como una investigación que respeta y apoya los derechos de los pueblos indígenas de autosoberanía y autonomía, y que se caracteriza por la responsabilidad y la reciprocidad, basado en los principios colectivos como pueblos (Kukkanen, 2006; Dudgeon, Kelly & Walker, 2010; First Nations Centre, 2005; Glass, & Kaufert, 2007).

Principios basados en estas perspectivas plantean que la investigación ética necesita la participación activa de los pueblos indígenas y el fortalecimiento de su capacidad para controlar la investigación que los afecta, asegurando que tal investigación esté alineada con sus propias prioridades. De manera similar, la investigación debería aportar beneficios claros para las comunidades y poblaciones indígenas y demostrar reciprocidad y respeto por el conocimiento indígena (Ball & Janyst, 2008). Tanto los protocolos de gestión de datos —es decir, una comprensión clara de quién posee y controla los datos de la investigación— como la diseminación de los hallazgos y la participación de la comunidad respecto a la utilización de los resultados de la investigación, son requisitos necesarios para cumplir con los principios de investigación ética en la salud de los pueblos indígenas (First Nations Centre, 2005; Harding et al., 2012).

Al considerar las guías internacionales para la investigación ética en contextos indígenas, se ha considerado de varias maneras la inclusión de los principios particulares de los pueblos indígenas. En varias instancias, se han integrado los principios y valores indígenas en el documento a través de la discusión de cómo estos deberían sustentar la práctica de la investigación. *Te Ara Tika* sobresale en la presentación de los conceptos éticos claves de un pueblo indígena. Se trata de un documento de guías éticas de la investigación en salud maorí desarrollado por el Concejo de Investigación en Salud de Nueva Zelandia. *Te Ara Tika* está fuertemente enraizado en los valores éticos tradicionales de los maorí (*Matauranga Māori*), que considera la forma correcta de hacer las cosas (*Tikanga*) y contiene conceptos sobre la justicia y la equidad (*Mana*). El marco ético maorí, que subyace a *Te Ara Tika*, destaca cuatro valores principales basados en *Tikanga*: *Tika* (diseño de la investigación), *Manaakitanga* (responsabilidad cultura y social), *Whakapapa* (relaciones) y *Mana* (justicia y equidad). En forma posterior, estos valores y conceptos se articulan con principios occidentales, lo que fortalece la comprensión tanto de lectores maorí como no maorí ("Researching the right way…", 2013; Hudson et al., 2010).La mayoría de las guías éticas de investigación se enfocan casi exclusivamente en la relación individual entre el investigador y el participante. Por ejemplo, si se consideran asuntos sobre beneficios, las guías se construyen para

responsabilizar del este la investigadora. Por el contrario, en casos donde la investigación se orienta a sustentar políticas o prácticas, la capacidad de proporcionar un beneficio no se reduce al nivel del investigador, sino más bien depende en primera instancia de legisladores, profesionales, organismos de financiamiento y otras partes interesadas.

Por ende, la consideración ética en relación con el beneficio de la investigación para las comunidades indígenas debería incluir los roles de estas otras entidades, además de investigadores individuales; no obstante, y aun considerando la ética de las responsabilidades de las partes interesadas, el desarrollo de estos asuntos es limitado. El marco denominado: *La investigación para la justicia en salud* (2014) proporciona una manera concreta de concebir las obligaciones de los distintos actores en la investigación de salud (Pratt & Loff, 2014). Por ejemplo, se destaca la responsabilidad de los gobiernos y los legisladores en la creación de incentivos y en anular las dificultades para el desarrollo de la investigación que otorga evidencia válida para la formación de políticas e intervenciones efectivas. Bajo este marco, se asigna la responsabilidad por deberes éticos según el trabajo normalmente hecho por cada institución u entidad. Por ende, ya que investigadores normalmente trabajan a nivel del individuo o la comunidad, tendrán la responsabilidad de facilitar las capacidades dentro de las comunidades con las que trabajan, a través de la práctica investigativa. No obstante, la responsabilidad de aumentar la capacidad de la comunidad también se hace extensiva a las instituciones anfitrionas con el fin de establecer colaboraciones sostenibles en el ámbito institucional y para formar relaciones con las organizaciones pertinentes. Aunque el marco *La investigación para la justicia en salud* se construyó para sustentar la investigación clínica internacional, sus principios también son aplicables a la investigación en salud indígena (Pratt & Loff, 2014).

Procesos para el desarrollo y la institucionalización de guías éticas para la investigación en salud indígena

Los ejemplos internacionales muestran variación en los procesos de desarrollo e institucionalización de las guías éticas para la investigación ética en contextos indígenas. Como se señaló anteriormente, su desarrollo se ha realizado tanto por instituciones académicas y por otras instituciones no indígenas (normalmente incorporando consulta o en colaboración con comunidades indígenas); como directamente por comunidades y organizaciones indígenas (Tunón, Kvarnström & Lerner, 2016).

Aunque en Australia existe un acuerdo general en relación con los principios que sustentan las guías nacionales (National Health and Medical Research Council, 2003), en Canadá hay menor consenso entre líderes y comunidades indígenas respecto a los principios específicos que deberían cubrir con diversidad de opiniones y perspectivas en este tema (Ball & Janyst, 2008). En una revisión de guías y marcos éticos internacionales, se encontró que un enfoque más local a la investigación favorece que las Primeras Naciones de Canadá ejerzan más control sobre la investigación, ya que las comunidades pueden rehusar o interrumpir las investigaciones que no cum-

plen con los estándares éticos (Australian Institute of Aboriginal and Torres Strait Islander Studies and The Lowitja Institute, 2014). También existen herramientas para apoyarlas en estas cuestiones a través del establecimiento de comités de ética y otras estructuras externas a las comunidades que comprometen a los investigadores e instituciones de investigación (First Nations Centre, 2003; First Nations Centre, 2007b). La misma revisión recomendó que se estableciera un proceso similar en Australia, ya que el uso de las guías locales puede ser una manera más adecuada de respetar la amplia diversidad de las comunidades y de las perspectivas de los Aborígenes e Isleños del Estrecho de Torres en la utilización de las guías nacionales [38]. En Nueva Zelandia, en vez de comités en el ámbito local, la revisión comunitaria de las guías se logra por la representación maorí en los comités de éticas regionales. Esta revisión contiene un proceso separado para asegurar la relevancia, el beneficio y la aceptabilidad de la investigación en las comunidades maorí (Glass & Kaufert, 2007). En Estados Unidos, no hay un marco o guía nacional en relación con la investigación ética con comunidades de Indios Americanos y Nativos de Alaska; más bien, se requiere de la aprobación del gobierno tribal pertinente para que pueda llevarse a cabo una investigación (Glass & Kaufert, 2007).

Más allá del modelo, existen varios desafíos para equilibrar los procesos éticos —es decir, los pasos que un investigador debe dar para obtener la aprobación institucional para investigar en comunidades indígenas— y los puntos de vista de las comunidades indígenas en relación con la investigación que los afecta. Existen numerosa bibliografía sobre conflictos entre la postura y las perspectivas de los comités éticos institucionales de investigación y las comunidades indígenas. Por ejemplo, si una comunidad posee guías éticas que contravienen los protocolos éticos establecidos por la universidad o el gobierno (Glass & Kaufert, 2007). Se ha reportado que estas tensiones obstaculizan la colaboración entre investigadores y organizaciones comunitarias y limitan la autonomía indígena en la investigación. En el caso de principios éticos en conflicto, un investigador se puede encontrar en la posición de tener que optar por realizar prácticas que contradicen las guías institucionales, poniendo en riesgo su financiamiento o reputación profesional; o proceder contra el consejo comunitario, socavando los derechos de las comunidades indígenas de tener voz en una investigación que les impacta (Stiegman & Castleden, 2015).

Al considerar el contexto de Chile, surgen una cantidad de interrogantes con respecto al desarrollo y la implementación de guías éticas para la investigación en salud indígena. Tales guías requieren asegurar, por una parte, que se refleje la amplia diversidad de opiniones sobre la ética en los estudios en pueblos indígenas tanto al interior de ellos como a nivel nacional; al mismo tiempo que se crea un sistema de procesos institucionales de ética funcional para los investigadores y las comunidades. De manera complementaria, se necesita de una sólida colaboración y coordinación entre todas las partes interesadas, incluyendo líderes, comunidades y organizaciones indígenas; instituciones académicas y de investigación; y organismos de financiamiento de investigación y agencias gubernamentales.

También es probable que surja la necesidad de capacitación de los miembros de los comités institucionales de ética respecto a cuestiones específicas a la investigación en salud indígena desde la perspectiva de las comunidades, además de mecanismos de representación indígena adecuada en esas instancias. Debido a la gran cantidad de investigadores extranjeros que realizan investigación en contextos indígenas chilenos, se deben incluir los mecanismos para asegurar la responsabilidad de estos investigadores en el cumplimiento de las normas éticas establecidas.

Basado en ejemplos internacionales, en la siguiente sección se presentan varias posibilidades para el desarrollo y ejecución de guías para la investigación ética en salud indígena en Chile, cada una con sus ventajas y desafíos:

1. Una guía inicial desarrollada a nivel nacional, por instancias tales como conicyt en colaboración con comunidades y organizaciones indígenas, que permita aunar perspectivas y valores indígenas relacionados con la investigación. Las investigaciones llevadas a cabo por universidades o instituciones gubernamentales estarían obligadas a cumplir con estas directrices. Aunque esta forma tendría la ventaja de un enfoque singular y cohesivo, puede limitar la representación de la diversidad de marcos y perspectivas éticas que pueden presentar los distintos pueblos indígenas de Chile.

Guías desarrolladas por universidades, instituciones de investigación y/u organizaciones profesionales, las que luego aplicarán a la investigación de los socios institucionales. Igual como en el caso del enfoque anterior, se deben establecer mecanismos para asegurar la colaboración y el aporte de las comunidades y organizaciones indígenas. En este caso, puede ser útil la creación de estructuras que apoyen la colaboración transversal de las instituciones para evitar la burocracia excesiva; con iniciativas como asegurar la coherencia de los formularios de aplicación y/o la tramitación de los proyectos que ya han recibido aprobación previa de otra organización.

2. El desarrollo de guías por organizaciones indígenas, que reflejen los valores y principios de mayor importancia y relevancia para ellos. En caso del desarrollo de un marco ético elaborado por las organizaciones y comunidades indígenas, se necesitará considerar la forma en que estas guías se incorporan en los procesos institucionales, tales como por su adopción por parte de los comités de ética universitarios.

3. Implementar un sistema similar al que existe en Canadá, donde las comunidades indígenas podrían formar comités locales para guiar y gestionar la investigación que los afecta. Las herramientas que actualmente existen para apoyar a las comunidades indígenas en Canadá, así como otras en el ámbito internacional podrían ser revisadas y adaptadas para su utilización en Chile. Este enfoque fortalecería la autonomía indígena en el nivel local, pero podría resultar ser un sistema desarticulado para orientar a los investigadores, particularmente en el caso de estudios que se realicen a través de varias comunidades.

Un enfoque que combine estas opciones puede ayudar a fortalecer las opciones más débiles. La opción cuatro en particular se puede utilizar en conjunto con las otras tres opciones para mejorar la capacidad de reacción por parte de los investigadores a los asuntos locales, aumentar el control de las comunidades sobre los estudios que los impactan y fortalecer la incorporación de diversos valores y perspectivas indígenas. Es decir, los procesos de aprobación ética podrían ser desarrollados en varios niveles —internamente dentro de instituciones de investigación y además en el ámbito de la comunidad. En este caso, se deben desarrollar mecanismos para apoyar la cohesión entre los procesos.

Si bien representan un avance importante, la instalación de las guías éticas por sí solas no garantiza una práctica equitativa en la investigación. Se ha criticado una dependencia excesiva de estas guías, como una herramienta paliativa de la poca inclusión y respuesta entre investigadores y comunidades indígenas (Humphery, 2001). Por ende, además de la utilización de las guías éticas, también hay una necesidad de una participación más explícita de personas y comunidades indígenas en todas las etapas del proceso de investigación.

Asociaciones colaborativas e investigación dirigida por la comunidad

Examinar la investigación académica en salud indígena a través del lente de la descolonización y de los derechos humanos, necesariamente lleva a una perspectiva de la investigación ética que respeta y apoya los derechos colectivos de autosoberanía y autonomía de los pueblos indígenas y se caracteriza por responsabilidad y reciprocidad (First Nations Centre, 2005). Este enfoque de investigación se sustenta en la incorporación de perspectivas dirigidas por la comunidad y la gente indígena, poniendo en el centro sus perspectivas, valores y prioridades; y, además, por la necesidad de creación de marcos institucionales que posibiliten que ese tipo de estudios se pueda llevar a cabo (Smith, 2012). De esta forma, la investigación realizada por instituciones académicas requiere de una manera de investigar con una sólida asociación con las comunidades indígenas y un énfasis en mejorar la capacidad comunitaria en tal escenario.

En la última década ha surgido un movimiento hacia la investigación dirigida por la comunidad y por las asociaciones colaborativas, como una estrategia esencial para aumentar la participación de las comunidades y las organizaciones indígenas en la investigación. Este proceso abarca desde la creación de las preguntas y guías de la investigación hasta las etapas de ejecución y diseminación (Bharadwaj, 2014). Más aún, la construcción permanente de colaboración se percibe como un fuerte apoyo a los valores de soberanía y autonomía indígena ya que las comunidades mantienen más control sobre los estudios (Ball & Janyst, 2008).

El camino entre una investigación para generar datos con impactos positivos en una política y su concreción puede ser largo, inseguro y difícil. Por ende, hay una preocupación válida sobre las actividades investigativas que pueden consumir los escasos recursos con que cuenta la comunidad, como por ejemplo

el tiempo y disponibilidad de los individuos y organizaciones participantes sin que se obtengan los beneficios esperados para ellas.

El trabajar en colaboración y bajo la dirección de las comunidades y las organizaciones indígenas puede aportar a las comunidades de varias maneras. Además, se reducen los daños y aumentan los beneficios a las comunidades (Menzies, 2004), ya que se asegura que la investigación sea más relevante, corresponda a prioridades comunitarias y facilite la posición de comunidades indígenas como expertos con una voz autorizada para decir lo que funciona o no en cada contexto.

También trabajar en colaboración con comunidades indígenas puede facilitar la producción de investigación de calidad a través de la generación de relaciones permanentes y del establecimiento de confianzas y entendimiento entre las distintas partes, aumentando el involucramiento de los individuos y comunidades e incrementando el rigor de la investigación (Jamieson et al., 2012). Por último, seguir trabajando con una comunidad con el paso de tiempo posibilita la cohesión en la investigación, puesto que ofrece la oportunidad de avanzar y expandir el trabajo previo, en lugar de llevar a cabo proyectos desvinculados. En adición, la construcción efectiva de colaboración puede aumentar la claridad en la comunicación entre investigadores y comunidades sobre los beneficios esperados y razonables con respecto a una investigación particular y sobre el proceso adecuado para que se concreten esos beneficios.

Dado los aspectos positivos de trabajar en colaboración con comunidades indígenas, la necesidad de involucrarlas en todas las etapas de la investigación y el derecho de las comunidades de tener voz en investigación que los afecta permite suponer que se priorizará la asignación de recursos a las investigaciones que incorporen la colaboración con la comunidad o que estén dirigidas por la comunidad. Además, el financiamiento en la investigación sin la participación de comunidades y organizaciones indígenas, basado en instituciones que tienen pocos lazos, o escaso conocimiento de ellas puede generar resistencia por parte de académicos, organizaciones y comunidades indígenas. Un ejemplo de esto es la creación del Centro de Estudios Interculturales e Indígenas (ICIIS) por el gobierno chileno. Se expresó escepticismo hacia la utilidad de la investigación que habría generado una inversión de aproximadamente 8 millones USD y el beneficio que recibirían las comunidades indígenas de esa investigación (Comunidad de Historia Mapuche, 2013). Similarmente, surgieron dudas acerca de la participación equitativa de personas indígenas en la investigación debido al hallazgo que, de los 103 proyectos en relación a pueblos indígenas financiados por CONICYT entre 1982 y 2011, solo 17 fueron realizados por equipos que incluyeron personas indígenas, y solo uno fue encabezado por una institución indígena (Nahuelpán, 2013).

No hay un modelo único de colaboración entre instituciones académicas y comunidades y organizaciones indígenas, así como tampoco para el desarrollo de investigación dirigida por la comunidad. Bharadwaj (2012) visualiza la colaboración como un marco cíclico de cinco fases: 1) preinvestigación, donde se establecen relaciones interpersonales; 2) consulta comunitaria; 3) entrada a la comunidad, donde se establecen relaciones de

investigación; 4) investigación; y 5) diseminación de los resultados. Este modelo se centra en los elementos claves de discusión, consulta, participación, coaprendizaje, colaboración y comunicación (Bharadwaj, 2014). Ejemplos de colaboraciones exitosas entre comunidades indígenas e instituciones académicas incluyen aquellas dirigidas por estas y las que han reelaborado creativamente los mecanismos de financiamiento de la investigación, re-estableciendo protocolos de gestión de información y responsabilidades compartidas por el diseño, recolección de datos, interpretación y diseminación de la investigación. Por ejemplo, una iniciativa de salud que fue dirigida por comunidades indígenas en Canadá (Musqueam) y en Ecuador (Quichua) fue llevada a cabo en colaboración con organizaciones indígenas, universidades, agencias internacionales y organizaciones gubernamentales y no gubernamentales. La iniciativa incluyó investigación y otras actividades centradas en el conocimiento cultural local, diversidad, acceso y seguridad alimentaria. En las guías de la colaboración, se enfatizaron el conocimiento, la posesión, el acceso y la diseminación hacia las comunidades indígenas (Couzos et al., 2005). En Australia, se desarrolló un modelo de investigación en salud dirigida por la comunidad donde los servicios de salud dirigidos por comunidades aborígenes realizaron una prueba controlada aleatorizada masiva en varios centros para examinar el control de otitis media supurativa crónica. En este modelo, las prioridades de la investigación se determinaron por la comunidad y la colaboración académica partió por el sector de salud controlado por la comunidad aborigen (Couzos et al., 2005).

El término 'colaboración' puede ser vago y tener una variedad de significados puesto que depende de quien lo esté utilizando y en qué contexto. Existe la inquietud de que se use de una manera superficial entre investigadores y comunidades indígenas, solo para cumplir con las condiciones de aprobación ética institucional. Además, los procesos de consulta y colaboración, aunque necesarios para la investigación ética en salud indígena, pueden ser una carga para una comunidad con otras prioridades y, en el caso de los proveedores de servicios, con muy poco tiempo o interés para involucrarse con la investigación debido a las presiones de atención, sobre todo en un contexto de recursos insuficientes (Brunger & Wall, 2016.). También se puede necesitar de la capacidad de investigadores que trabajen en conjunto con la comunidad para incorporar métodos culturalmente apropiados en la práctica investigativa.

Por las razones anteriormente descritas, la creación de relaciones de colaboración sostenibles entre instituciones académicas y comunidades, particularmente en las etapas iniciales, necesita una cantidad considerable de tiempo, paciencia y confianza por ambas partes. Un tema que surge constantemente en las experiencias previas, es la necesidad de una inversión substancial de tiempo por parte de todas las entidades pertinentes para que tales iniciativas sean exitosas. Por lo anterior, para que se lleve a cabo una investigación dirigida por la comunidad y basada en la colaboración mutua, las fuentes de financiamiento de las investigaciones deben priorizar aquellos proyectos e instituciones que presenten estos principios y aseguren que los cíclicos y cronología asignados a los estudios en

salud indígena son adecuados para la construcción de relaciones de colaboración con consulta, participación y comunicación a lo largo de todo el proceso investigativo.

Conclusiones

Los marcos de bioética basados principalmente en principios tales como el consentimiento informado y la autonomía individual no son suficientes para la investigación con poblaciones indígenas. Más bien, es necesario que la investigación ética con poblaciones indígenas involucre no solamente el individuo, sino la comunidad en su totalidad y se centre en las prioridades y los valores de las mismas comunidades indígenas. Se evidencia esta idea en el trabajo de varios académicos indígenas en el ámbito internacional como en las guías éticas desarrolladas por organizaciones indígenas. Sin embargo, la comunidad académica internacional ha sido relativamente reacia a aceptar este enfoque y aplicarlo a la ética de investigación de la salud indígena.

En Chile, existe una historia larga de tensión y conflictos entre las comunidades indígenas y los investigadores académicos no indígenas, lo que refleja las mismas complejidades que existen a nivel internacional en la investigación en salud indígena. Esta desconfianza entre la academia y las comunidades indígenas tiene como trasfondo una incapacidad de enfrentar de manera efectiva las inequidades que caracterizan la salud indígena. Sin investigaciones que pueden clarificar las condiciones de salud indígena y las necesidades presentes dentro de las comunidades, se seguirá limitando a la capacidad de crear políticas y programas de salud relevantes para los contextos indígenas.

Por estas razones, la relación entre la academia y los pueblos indígenas se está reorientando progresivamente para ajustarse mejor a las necesidades de la comunidad e incorporar perspectivas y valores indígenas desde un marco de derechos. La infraestructura necesaria para una práctica ética sistemática es limitada en la actualidad en Chile. En este escenario, se postula que el fortalecimiento de mecanismos de apoyo a prácticas éticas puede sustentar una investigación más productiva y que represente mejor las prioridades y valores indígenas en un contexto de autodeterminación indígena.

La elaboración de estos mecanismos tiene como aporte experiencias internacionales en la investigación en salud indígena que representan la diversidad que existe en este campo tanto por los distintos contextos institucionales que influencian la academia de cada país, como por las maneras de trabajar de las comunidades indígenas. Por ende, las estrategias presentadas no son prescriptivas; más bien son un punto de partida para la reflexión y el diálogo sobre cuáles serían los enfoques aptos para un contexto particular.

El establecimiento de guías para la investigación ética en salud indígena y la incorporación de estas guías en procesos de aprobación ética pueden servir como base para un entendimiento compartido de lo que constituye la práctica ética en este campo y proveer los mecanismos para responsabilizar a los investigadores para que cumplan con estas normas. Relaciones de asociación y colaboración genuinas de investigación entre instituciones

académicas y organizaciones y comunidades indígenas son fundamentales para asegurar que las comunidades indígenas sean parte de un proceso investigativo centrado en valores, prioridades y conocimientos indígenas. Para que sean efectivos, estos enfoques necesitarán ser respaldados por una práctica reflexiva y transparente por parte de académicos e instituciones académicas.

El proceso de reorientar la investigación en salud indígena hacia las expectativas, las necesidades y los valores de las comunidades involucradas está situado dentro de un contexto en el que se sigue ampliando y profundizando la bioética, no solamente en Chile, sino a través de América Latina (León Correa, 2008; Lolas Stepke, 2010). Como parte de este desarrollo del campo, hay una promoción de una bioética social que puede dialogar con una diversidad de sistemas éticos, trascendiendo la bioética tradicional, caracterizada por una falta de perspectiva acorde a la diversidad (León Correa, 2008; León Correa, 2009; Myser, 2003). En este sentido, la implementación de medios para responder a los elementos éticos que son particulares a la investigación con comunidades indígenas puede servir como ejemplo concreto de cómo impulsar y concretar una bioética de investigación que se adecúa mejor con las complejidades encontradas en la práctica.

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Appendix 4: Indigenous engagement in health: Lessons from Brazil, Chile, Australia and New Zealand

International Journal for Equity in Health

Indigenous engagement in health: Lessons from Brazil, Chile, Australia and New Zealand

--Manuscript Draft--

Manuscript Number:	IJEH-D-19-00485
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Abstract:	Background Given the persistence of Indigenous health inequities across national contexts, many countries have adopted strategies to improve the health of Indigenous peoples. Governmental recognition of the unique health needs of Indigenous populations is necessary for the development of targeted programs and policies to achieve universal health coverage. At the same time, the participation of Indigenous peoples in decision-making and program and policy design helps to ensure that barriers to health services are appropriately addressed and promotes the rights of Indigenous peoples to self-determination. Due to similar patterns of Indigenous health and health determinants across borders, there have been calls for greater global collaboration in this field. However, most international studies on Indigenous health policy link Anglo-settler democracies (Canada, Australia, Aotearoa/New Zealand and the United States), despite these countries representing a small fraction of the world's Indigenous people.Aim This paper examines national-level policy in Australia, Brazil, Chile and New Zealand in relation to governmental recognition of differential Indigenous health needs and engagement with Indigenous peoples in health. The paper aims to examine how Indigenous health needs and engagement are addressed in national policy frameworks within each of the countries in order to contribute to the understanding of how to develop pro-equity policies within national health care systems.Methods For each country, a review was undertaken of national policies and legislation to support engagement with, and participation of, Indigenous peoples in the identification of their health needs, development of programs and policies to address these needs and which demonstrate governmental recognition of differential Indigenous health needs. Government websites were searched as well as the following databases: Google, OpenGrey, CAB Direct, PubMed, Web of Science and WorldCat.Findings Each of the four countries have adopted international agreements regarding the engagement of Indigenous peoples in health. However, there is significant variation in the extent to which the principles laid out in these agreements are reflected in national policy, legislation and practice. Brazil and New Zealand both have established national policies to facilitate engagement. In contrast, national policy to enable engagement is relatively lacking in Australia and Chile. Australia, Brazil and New Zealand each have significant initiatives and policy structures in place to address Indigenous health. However, in Brazil this is not necessarily reflected in practice and although New Zealand has national policies these have been recently reported as insufficient and, in fact, may be contributing to health inequity for Māori. In comparison to the other three countries, Chile has relatively few national initiatives or policies in place to support Indigenous engagement or recognise the distinct health needs of Indigenous communities.Conclusions The adoption of international policy frameworks forms an important step in ensuring that Indigenous peoples are able to participate in the formation and implementation of health policy and programs. However, without the relevant principles being reflected in national legislature, international agreements hold little weight. At the same time, while a national legislative framework facilitates the engagement of Indigenous peoples, such policy may not necessarily translate into practice. Developing multi-level

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	approaches that improve cohesion between international policy, national policy and practice in Indigenous engagement in health is therefore vital. Given that each of the four countries demonstrate strengths and weaknesses across this causal chain, cross-country policy examination provides guidance on strengthening these links.
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Additional Information:	
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Have you submitted similar articles (including as part of a series or from the same project) to this or any other journals?	No

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Indigenous engagement in health: Lessons from Brazil, Chile, Australia and New Zealand

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Abstract

Background

Given the persistence of Indigenous health inequities across national contexts, many countries have adopted strategies to improve the health of Indigenous peoples. Governmental recognition of the unique health needs of Indigenous populations is necessary for the development of targeted programs and policies to achieve universal health coverage. At the same time, the participation of Indigenous peoples in decision-making and program and policy design helps to ensure that barriers to health services are appropriately addressed and promotes the rights of Indigenous peoples to self-determination.

Due to similar patterns of Indigenous health and health determinants across borders, there have been calls for greater global collaboration in this field. However, most international studies on Indigenous health policy link Anglo-settler democracies (Canada, Australia, Aotearoa/New Zealand and the United States), despite these countries representing a small fraction of the world's Indigenous people.

Aim

This paper examines national-level policy in Australia, Brazil, Chile and New Zealand in relation to governmental recognition of differential Indigenous health needs and engagement with Indigenous peoples in health. The paper aims to examine how Indigenous health needs and engagement are addressed in national policy frameworks within each of

the countries in order to contribute to the understanding of how to develop pro-equity policies within national health care systems.

Methods

For each country, a review was undertaken of national policies and legislation to support engagement with, and participation of, Indigenous peoples in the identification of their health needs, development of programs and policies to address these needs and which demonstrate governmental recognition of differential Indigenous health needs. Government websites were searched as well as the following databases: Google, OpenGrey, CAB Direct, PubMed, Web of Science and WorldCat.

Findings

Each of the four countries have adopted international agreements regarding the engagement of Indigenous peoples in health. However, there is significant variation in the extent to which the principles laid out in these agreements are reflected in national policy, legislation and practice. Brazil and New Zealand both have established national policies to facilitate engagement. In contrast, national policy to enable engagement is relatively lacking in Australia and Chile. Australia, Brazil and New Zealand each have significant initiatives and policy structures in place to address Indigenous health. However, in Brazil this is not necessarily reflected in practice and although New Zealand has national policies these have been recently reported as insufficient and, in fact, may be contributing to health inequity for Māori. In comparison to the other three countries, Chile has relatively

few national initiatives or policies in place to support Indigenous engagement or recognise the distinct health needs of Indigenous communities.

Conclusions

The adoption of international policy frameworks forms an important step in ensuring that Indigenous peoples are able to participate in the formation and implementation of health policy and programs. However, without the relevant principles being reflected in national legislature, international agreements hold little weight. At the same time, while a national legislative framework facilitates the engagement of Indigenous peoples, such policy may not necessarily translate into practice. Developing multi-level approaches that improve cohesion between international policy, national policy and practice in Indigenous engagement in health is therefore vital. Given that each of the four countries demonstrate strengths and weaknesses across this causal chain, cross-country policy examination provides guidance on strengthening these links.

Key words: Indigenous; health; policy; Chile; Brazil; Australia; New Zealand; engagement; participation

Background

Global epidemiological research has established a persistent health gap existing between Indigenous and non-Indigenous populations across various national contexts. The available evidence overwhelmingly indicates that Indigenous peoples worldwide have higher morbidity and mortality rates than non-Indigenous people in the same community or area, including in such indicators as life expectancy, adequate child nutrition and infant and maternal mortality.[1,2] In reflecting on why Indigenous health inequities continue to persist across diverse contexts internationally, King *et al* (2009) centre the ongoing experiences and impacts of colonisation, globalisation and disrupted ties to land and culture.[3] Loss or weakening of identity has been tied to higher levels of suicide risk,[4] mental illness[5] and use of alcohol and other drugs[6,7] in some Indigenous communities. Chandler and Lalonde's work in Canada demonstrates that the variation in suicide rates among First Nations youth in British Colombia is strongly associated with the extent to which their communities engaged in practices that fostered cultural continuity.[4,8] Autonomy and self-determination underpinning Indigenous cultural continuity and strengthened retention of identity are therefore key principles to interrupt pathways to Indigenous ill health and support Indigenous well-being.[3]

Within the health care system, mainstream services are often not designed with the health care needs of Indigenous populations at the forefront. This causes a number of barriers preventing Indigenous people from receiving appropriate and accessible health care, contributing to the health gap. Health services may be geographically inaccessible to Indigenous people who live in rural and remote areas.[9] Biomedical services provided may not incorporate Indigenous health values or concepts, such as a holistic approach that recognises connections to land, community and familial

ties, mental health and spirituality.[3] Indigenous people may experience racism or discrimination in health care settings, reducing their ability to safely access such services.[10-12]

Given the persistence of Indigenous health inequities, many if not all countries with Indigenous populations have developed strategies to improve the health outcomes of Indigenous peoples. Moreover, due to similar patterns of Indigenous health and health determinants across borders, there have been increased calls for greater global collaboration in this field.[13] In the field of Indigenous health much of the comparative literature is centred around Australia, Canada, New Zealand and the United States,[14-16] as are many of the professional networks,[17,18] despite these countries representing a small fraction of the world's Indigenous people.[19] This is primarily due to these four countries sharing a dominant language, a history of settler colonialism and other historical similarities, as well as Anglosphere privileging at a global level.

Latin American countries have demonstrated considerable innovation in developing strategies to improve Indigenous health, alongside a willingness to engage in cross-country learning regarding best practice across the region.[20] However, this level of cross-country transfer has not extended to outside of Latin America. There is therefore a lack of mutual reflections between Latin America and countries outside the region regarding their different strategies developed to support the health and wellbeing of Indigenous peoples. Lixinski (2017) presents the case that Latin America may provide a rich source of knowledge and experience in engagement with Indigenous peoples, particularly for Australia.[21] Lixinski cites the historical reluctance of Canada, Australia, New Zealand, and the United States to engage with international agreements regarding Indigenous peoples such as the United Nations Declaration on the Rights of Indigenous Peoples (UN DRIP) and the International Labour Organisation's Convention No. 169: Indigenous and Tribal Peoples Convention (ILO 169). This leads to the suggestion that looking towards countries that are more willing to do so, such as in Latin America, may provide relevant lessons. The relative ease and frequency with

which countries in the region exchange ideas, policy and best practice regarding Indigenous issues also speaks to the possibility of opening this network to English-speaking countries.[21]

This paper considers Australia, Brazil, Chile and New Zealand and how each country approaches the question of Indigenous health. These countries represent a high level of variety with regards to their national contexts (Table 1), Indigenous demographics (Table 2), and approaches to improving Indigenous health and wellbeing.

Table 1. Country and health system characteristics

Characteristic	Australia	Brazil	Chile	New Zealand
Economic development				
OECD member country[22]	Yes	Yes	Yes	Yes
Gross national income per capita (US$, 2017)[23]	50,362	15,065	22,170	38,561
Health system				
Percent GDP spent on health (%, 2018 or latest available)[24]	9.3	9.2	8.9	9.3

Table 2. Indigenous population characteristics by country

Characteristic	Australia	Brazil	Chile	New Zealand
Percent population Indigenous	2.8[25]	<0.5[26]	13[27]	16.5[28]

Indigenous groups/languages	>100[29]	>300[30]	9[27]	1
Percent Indigenous population in urban areas	61.4[25]	35.1[30]	75.3[31]	38.9[32,33]
Indigenous infant mortality (deaths/1,000 live births): ratio of Indigenous to baseline[2]	1.70 (1.55–1.87)	2.65 (2.46–2.86)	1.13 (0.96–1.33)	1.64 (1.45–1.86)

Indigenous engagement and recognition of Indigenous health needs in national policy

Participation in health is particularly relevant for Indigenous populations, who are often excluded from decision-making and priority-setting processes in the development and implementation of mainstream health services. Indigenous participation involves rectifying this exclusion and reorienting relationships between Indigenous communities and health systems to be more balanced. As such, participation is tied to principles of social, economic and political equity. Moreover, the ability of Indigenous peoples to have control over the health services that serve their communities is underpinned by the principles of Indigenous sovereignty and self-determination.

Governmental recognition of differential Indigenous health needs refers to the willingness of governments to acknowledge that Indigenous peoples have different priorities, values and needs in

relation to health from the rest of the population. This recognition is necessary for coordinated action on factors that affect Indigenous health and drives practices such as disaggregated data collection, which allows for development and evaluation of targeted programs and policies. *Engagement with Indigenous peoples in health* helps to ensure that health programs and services reflect the values, priorities and contexts of Indigenous communities and enables Indigenous peoples to have control over the factors that affect their health. The principle of Indigenous participation in health and the right of Indigenous peoples to be consulted with in regards to matters that affect them is enshrined in both the UN DRIP and ILO 169.[34,35] For countries that have a treaty or treaties in place, this forms the basis for the relationship between the government and Indigenous peoples, including in matters relating to health. This may encompass who has responsibility for Indigenous health, Indigenous health equity and participation and engagement in health.[36] However, in some cases, treaties may run counter to national legislature, creating contradictions and ambiguity.[37]

The current article asks to what extent national-level policy in Australia, Brazil, Chile and New Zealand reflects governmental recognition of the health needs of Indigenous peoples, and whether there is policy in place to support engagement with Indigenous peoples in addressing these needs. The article focuses on policy, rather than practice and implementation. There are often significant differences between formal Indigenous health policy and what happens in practice.[38,39] However, an examination of policy is valuable as it offers insight into how governments understand and respond to their obligations towards Indigenous populations. That is, formal policy illustrates government intentions and provides a set of expectations against which progress can be measured. A national-level focus has been selected for two reasons: first, for ease of comparison and second, because regional-level policy is, on the whole, shaped by the political/governance agenda at the national level.

Methods

For each country, a review was undertaken of national policies and legislation to support engagement with, and participation of, Indigenous peoples in the identification of their health needs, development of programs and policies to address these needs and which demonstrate governmental recognition of differential Indigenous health needs. The search strategy was designed to find not only policies and legislation, but also to capture discussion of these in both grey and peer-reviewed literature. Search strategies varied for each country in order to reflect differences in language, correct terminology and names for Indigenous peoples, and in using country-specific databases. However, search terms for each country included 'Indigenous', 'Health', 'Engagement', 'Participation', 'Legislation' and 'Policy' in English. The terms were also used in Spanish for Chile and in Portuguese for Brazil. For each country, government websites were searched as well as the following databases: Google, OpenGrey, CAB Direct, PubMed, Web of Science and WorldCat.

Results

Governmental recognition of differential Indigenous health needs

Governmental recognition of Indigenous health needs was demonstrated firstly by the acceptance of international agreements which lay out guidelines for the protection of Indigenous peoples' rights. Each of the four countries has accepted international frameworks regarding the rights of Indigenous peoples. All four have given their official support of the UNDRIP, and Chile and Brazil are also signatories to ILO 169.

At the national level, governmental recognition was illustrated in a variety of ways across the four countries, including through a treaty, the establishment of national Indigenous health plans, national legislation relating to Indigenous health and the creation of a health care system centred around provision to Indigenous peoples.

Brazil

To protect and promote the rights of Indigenous peoples, the National Indian Foundation (FUNAI) of the Ministry of Justice was created in 1967, under the Brazilian military regime. FUNAI established the first organisation of a national health care delivery system for Indigenous groups and continues to contribute to and monitor the healthcare for Indigenous populations currently delivered by the Ministry of Health.[40]

During the re-democratisation process of the 1970s and 1980s, against the background of the health reform movement and the pressure of international organisations,[41,42] Indigenous social movements led to the recognition of ethnic and cultural specificity and differentiated social rights in the federal constitution of 1988 (Art. 231, Art. 232, Cap. VIII, Tit. VIII). This included constitutional recognition of the rights of Indigenous peoples to the use of their lands, as well as the protection of Indigenous customs, languages and traditions.[43]

In order to reduce cultural barriers for Indigenous people accessing to healthcare, legislation was introduced in 1999 for a 'differentiated but complementary' healthcare subsystem (SASISUS).[44] This model is based within the Ministry of Health Special Secretary of Indigenous Health (SESAI) and monitored by a specific health information system (SIASI). The Special Indigenous Subsystem is organised around 34 special Indigenous health districts which provide differentiated community-level primary healthcare services. Articulation with more complex levels of public healthcare services in urban areas is managed by the hosting service of the Indigenous Houses (CASAI).

The National Indigenous Healthcare Policy (PNASPI, 2002) is based on the principle of 'primary differentiated healthcare,'[45] which recognises the cultural specificity of Indigenous communities' health needs. This policy outlines the articulation between traditional/Indigenous and biomedical/western healthcare knowledges as a strategy to operationalise respect for Indigenous health systems in intercultural contexts as well as the inclusion of Indigenous people in primary health care services. Under this policy, health workforce training is a key strategy to orient public health care practices to the specificities of Indigenous groups.[45]

New Zealand

There are a number of policies and legislative statues that underpin the New Zealand governments interaction with Māori. The Treaty of Waitangi is the founding document of New Zealand. The Treaty is an agreement, in Māori and English, that was made between the British Crown and the Māori rangatira (chiefs).[36] Governmental recognition of the distinct health needs of Māori people are encapsulated in three principles that were derived from the Treaty of Waitangi by the Royal Commission on Social Policy and subsequently used to guide government policy.[36,46] These principles are: *partnership*, or working together with iwi, hapū, whānau and Māori communities; *participation*, the involvement of Māori at all levels of decision-making, planning, development and delivery services; and *protection*, which involves the Government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.[47,48] The New Zealand Public Health and Disability Act 2000 sets out the District Health Boards' (DHBs) objectives around health inequities and Māori participation in health decision-making.[49]

New Zealand has a number of policies that acknowledge the unique health values and priorities of Māori. New Zealand's Māori Health Strategy, He Korowai Oranga, is based on a holistic vision of Māori health, *pae ora*, and implemented across four pathways for action:

- supporting whānau, hapū, iwi and community development;
- supporting Māori participation at all levels of the health and disability sector;
- ensuring effective health service delivery; and
- working across sectors.[50]

He Korowai Oranga is designed to address the New Zealand Health Strategy,[51] Objective 11 of the New Zealand Disability Strategy (promote the participation of disabled Māori)[52] and the New Zealand Public Health and Disability Act 2000.[49] Responsibility for the implementation of He Korowai Oranga is shared among the Ministry of Health and the DHBs and encompasses the whole of the health and disability sector.[50]

However, a recently released Waitangi Tribunal report found that current legislation, primary care policy and strategy frameworks, funding of Māori primary care providers, and monitoring of the primary health sector were not compliant with the Treaty of Waitangi and did not reflect a meaningful commitment to health inequities for Māori.[53] The report addresses claims concerning the way the New Zealand primary care system has been legislated, administered and monitored by the government since the New Zealand Public Health and Disability Act 2000 came into effect. This is the first of a series of reports and investigates whether Māori inequities in health status are the result of the legislative and policy framework of primary care in New Zealand. It recommends that the treaty principles relevant to the provision of health care for Māori should be extended from participation, partnership and protection to include the principles of equity and options.[53] The report found the although the health sector cannot be held wholly responsible and that other sectors are involved in influencing the social determinants of health, the persistent inequitable health outcomes are indicators of health sector-related Treaty breaches resulting from Crown actions, insufficient actions or omissions.[53]

Australia

In Australia, the Council of Australian Governments (COAG) committed to the 2007 national initiative to 'Close the Gap' in health outcomes between between Aboriginal and Torres Strait Islander people and other Australians by the year 2030.[54] The *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* represents a long-term, evidence-based policy framework to underpin the Closing the Gap program.[55,56] Recognising the strong influence of social determinants of health, the Health Plan takes a broad view of health and centres culture and connection to country in its conceptualisation of Aboriginal and Torres Strait Islander wellbeing.[55]

Apart from the National Aboriginal and Torres Strait Islander Health Plan,[55] there are a number of specific strategies and policies aimed at addressing Aboriginal and Torres Strait Islander health issues, including the 2015 National Aboriginal and Torres Strait Islander Cancer Framework,[57] the National Aboriginal and Torres Strait Islander Suicide Prevention Strategy,[58] the Indigenous Australians' Health Programme[59] and the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023.[60]

Despite a high number of Indigenous health policies and strategies, in 2011, Howse identified a lack of recognition of the specific needs of Aboriginal and Torres Strait Islander people in a review of existing health legislation in Australia.[61] The author reviewed the 69 principal Acts administered by the Commonwealth Department of Health and Ageing, and found that only three specifically refer to Aboriginal and Torres Strait Islander people.[61]

Chile

In comparison to the other three countries, Chile has relatively few national initiatives or policies in place to protect the health of its Indigenous peoples. Chile is the only country in Latin America that does not have Constitutional recognition of its Indigenous peoples. However, there is legal

recognition in the form of the Indigenous Law 19.253, which also created the National Corporation of Indigenous Development, CONADI. Law 20.584, *The rights and responsibilities of the patient in relation to health care* was enacted in 2012.[62] Article 7 of the law establishes the right of Indigenous peoples to receive culturally appropriate medical attention from public health services situated in areas with high Indigenous populations. In addition, the Special Health and Indigenous Peoples Program (*Programa Especial de Salud y Pueblos Indígenas*, PESPI), situated within the Ministry of Health, aims to contribute to the improvement of Indigenous health, primarily through the development of a model of health that includes an intercultural focus.

Table 3. Governmental recognition of differential Indigenous health needs across the four countries

	Brazil	New Zealand	Australia	Chile
Support for UNDRIP	✓	✓	✓	✓
Signatory to ILO 169	✓	×	×	✓
Constitutional recognition of Indigenous peoples and their right to health	✓	✓	×	×
National legislation regarding Indigenous health	✓	✓	×	½

National Indigenous health policy	✓	✓	✓	✖
Has a treaty in place with Indigenous peoples	✖	✓	✖	✖

Engagement with Indigenous peoples in health

Both the UNDRIP and ILO 169 outline expectations of governments in their treatment and engagement with indigenous peoples. This includes the right of indigenous peoples to prior consultation with regards to matters that concern them.[34,35] Apart from participation in these international frameworks, the four countries exhibited very different ways of conceptualising Indigenous engagement in health in national policy and legislation.

Brazil

The PNASPI clearly outlines a number of strategies for Indigenous engagement in the Indigenous public health system. First, the inclusion of two categories of Indigenous community health workers in Multidisciplinary Health Professionals Teams (EMSI), which operate within Indigenous primary health services: Indigenous community worker (AIS) and Indigenous sanitation agent (AISAN). The health program 'Working with Traditional Midwives' was established in 2000 in order to provide stronger articulation between traditional Indigenous midwives and primary health services.[63]

Secondly, engagement is established through mechanisms for Indigenous participation, labelled 'indigenous social control' in the Indigenous health policy. 'Indigenous social control' is operationalised by the participation of Indigenous community leaders at different levels of Indigenous health public organisations:

- The Local Indigenous Councils (CLSI), which are consultative and are comprised of local Indigenous councillors named by the Indigenous communities;
- The State Indigenous Councils (CONDISI) for policy evaluation and control as well as deliberative functions. These Councils are composed of 50% Indigenous community leaders, 25% health service managers and 25% health workers;
- The National Forum of the Presidents of State Indigenous Councils (Fórum de Presidentes do CONDISI) at the federal level has consultative attributions and meets every 3 months;
- The Indigenous Health National Conference (CNSI) is a process of consultation which takes place every 4 years. The CNSI delivers health policy recommendations and proposals to the government regarding Indigenous from the local to the national level;[44]
- Indigenous representatives also have a seat in the National Health Council (CNS), which can deliberate on health policies.

New Zealand

As referenced above, partnership and participation are two of the key principles which encourage government agencies and departments to work in conjunction with iwi and Māori communities with regards to Māori health.[47,64]

The second pathway for action in He Korowai Oranga is Te Ara Tuarua: Māori participation in the health and disability sector. Participation in this instance is largely conceptualised as consisting of the engagement of Māori health service providers and other Māori institutions and having a robust Māori health workforce.[64]

In 2015, Statistics New Zealand conducted a study examining the nature and drivers for Crown-Māori engagement.[65] The report found that in recent years, Māori have become more influential

stakeholders in both national and local contexts, and that close working relationships between government agencies and Māori have become more common, including in the health sector. This is attributed in part to Whānau Ora, a cross-governmental public sector initiative that aims to support coordination and service delivery across the health, education and social sectors and devolve the delivery of services to community-based commissioning services.[65,66] Whānau Ora places greater responsibility both on Māori for service delivery and on government to further incorporate approaches that centre Māori communities.[65,66] Within the Ministry of Health, the report found that key drivers for Māori engagement included Legislation, the introduction of Iwi (tribal) Leader Groups and Treaty settlements that required or supported engagement and Government strategies and programmes.[65]

In contrast to this research, the recently released Waitangi Tribunal report into primary care concluded that both the Public Health and Disability Act and the Primary Healthcare framework in New Zealand are in breach of the Treaty of Waitangi.[53] It stated that not enough was being done by government agencies to reduce health inequities for Māori and that the prescribed principles of the Treaty of Waitangi partnership, participation and protection were not considered important by DHBs or other health agencies. In fact, it recommended the addition of the principles of equity and options.[53]

Australia

The principle of engagement with Aboriginal and Torres Strait Islander people is generally reflected in Australian national policies and strategies. For example, the Aboriginal and Torres Strait Islander Health Plan 2013-2023 takes an approach that builds on the UNDRIP, as well as Aboriginal and Torres Strait Islander community control and engagement, partnership and

accountability.[55] While the Closing the Gap initiative was heavily criticised for using a top-down approach, in 2016 COAG agreed to 'refresh' the strategy to reframe focus around a community-led, strengths-based approach.[67]

However, the principle of engagement is largely missing from legislation, as referred to previously. Even where the specific needs of Aboriginal and Torres Strait Islander people are represented in the Commonwealth health legislation, mechanisms for shared decision-making and governance are generally not included.[61]

Chile

In Chile the principles of engagement and consultation of the UNDRIP and ILO 169 are inadequately supported at the level of national legislation and policy. Supreme Decree 66, *Approved regulation governing the indigenous consultation procedure under Article 6 N^{o} 1 Letter A) and N^{o} 2 Convention N^{o} 169 of the International Labour Organization and repealing stated regulations*,[68] lays out details of who is entitled to consultation and the mechanisms of such consultation. The Decree is widely criticised for being put in place to limit the rights of Indigenous peoples affirmed in ILO 169[69] and has led to Chilean legislature being characterised as contradictory regarding Indigenous rights to prior consultation. Intensive nation-wide consultation regarding Article 7 of Law 20.584 was conducted over 2015 and 2016 with the nine Indigenous peoples recognised under the Indigenous Law with the aim to come to a shared understanding regarding the concepts relevant to the rights and responsibilities of patients to culturally appropriate health care.[70] This was the first national consultation undertaken with Indigenous peoples by the Ministry of Health.[71] However, the practical outcomes of this consultation remain uncertain.

Table 4. Engagement with Indigenous peoples in health across the four countries

	Brazil	New Zealand	Australia	Chile
Establishment of national policy/legislation for engagement with Indigenous peoples	✓	✓	×	×
Established mechanisms for shared decision-making and governance	✓	✓	×	×

Discussion

Overall, examination of these four countries in combination highlights the need for multi-level approaches to ensuring that Indigenous peoples have adequate control and participation in the development of policies and decision-making practices that affect their health. While each of the countries exhibit some strengths in the areas of international policy, national policy and legislation and/or Indigenous health practice, the countries also show a lack of cohesion across these levels. In a cohesive system, the national policy environment would facilitate the operationalisation of principles espoused in international frameworks, which would then be reflected in practice. In contrast, each of the four countries have adopted international agreements regarding the engagement of Indigenous peoples and the recognition of their special status. However, there is significant variation in the extent to which the principles laid out in these agreements are reflected in national policy, legislation and practice.

Brazil and New Zealand both have established national policies to facilitate engagement. In contrast, national policy to enable engagement is relatively lacking in Australia and Chile. Australia, Brazil and New Zealand each have significant initiatives and policy structures in place to address Indigenous health. However, in Brazil this is not necessarily reflected in practice and in New Zealand the Waitangi Tribunal has found that the existing NZ Public Health and Disability Act, the Primary Care Strategy and Framework, monitoring of the health sector and the funding of Māori primary care providers are in breach of the Treaty of Waitangi. In comparison to the other three countries, Chile has relatively few national initiatives or policies in place to support Indigenous engagement or recognise the distinct health needs of Indigenous communities.

Coherence between national and international policy

The last few decades have seen a rise in international Indigenous networks and the establishment of international frameworks for conceptualising the rights of Indigenous peoples within the context of their self-determination and cultural and territorial retention. ILO 169 has been instrumental in establishing national and international standards in relation to free, prior and informed consent with Indigenous peoples in relation to matters that concern them. ILO 169 obligates governments to 1) consult with Indigenous peoples 'through appropriate procedures and in particular through their representative institutions,' regarding legislative and administrative issues that affect them and 2) allow Indigenous peoples to participate in 'the formulation, implementation and evaluation of plans and programs for national and regional development which may affect them directly.'[35] In Article 24, ILO 169 specifically outlines the rights of Indigenous peoples to maintain their health and healing traditions as well as the right to access all social and medical services without discrimination.[72,73] Similarly, the UNDRIP states that '…indigenous peoples have the right to be actively involved in

developing and determining health… programmes affecting them and, as far as possible, to administer such programmes through their own institutions.'[34]

Australia, Brazil, Chile and New Zealand have each lent their formal support to the UNDRIP and Chile and Brazil have additionally become signatories to ILO 169. The UNDRIP is not legally binding under international law, although it represents the commitments of countries to adhere to the rights codified therein. Upon signing ILO 169, on the other hand, countries agree to legally bind themselves to the obligations expressed. However, the process of ratifying or adopting international agreements is separate from the establishment of domestic legislation that allows for coordinated implementation.[74,75]

The extent to which the principles in these international frameworks have been reflected in national policies regarding recognition of Indigenous health needs and establishment of mechanisms for engagement is variable across the four countries. While Chile and Brazil are both signatories to the legally binding ILO 169, Brazil exhibits the strongest policies for Indigenous recognition, engagement and governance across the comparator countries, while Chile demonstrates the weakest. Although Australia has lent its formal support to the UNDRIP, mechanisms for Indigenous engagement are based on established ethical and practice norms, rather than formal policies or legislation. The basis for Māori engagement rests much more strongly on the Treaty of Waitangi rather than the UNDRIP.

Amongst these case studies, the direct impact of the adoption of international frameworks on domestic policy and legislation is therefore uncertain. However, this is not to say that such frameworks carry no weight. Rather, there is evidence that the establishment of international agreements facilitates the 'soft transfer'[76] of agreed-upon principles regarding the treatment of Indigenous peoples which then has a follow-on effect on how Indigenous health is addressed. This transfer may even occur to some extent in cases where an individual country has not adopted a

particular international agreement. While Australia is not a signatory to ILO 169, its passage has been influential in the development of key pieces of Indigenous policy. It has been noted that the *Native Title Act 1993* takes on some of the language of ILO 169, in referring to 'the right to negotiate' and consultation undertaken in 'good faith.'[77] Indeed, the *Native Title Act 1993* has been held up as an example of domestic law that adheres to and supports the principles of 'rights of ownership and possession of the peoples concerned over the lands which they traditionally occupy' laid out in the Convention.[78]

Recognition and engagement in national policy and legislation

New Zealand and Brazil demonstrated the strongest policy frameworks with regards to governmental recognition of Indigenous health needs and the engagement of Indigenous peoples in health. These two countries recognise Indigenous peoples and their right to health and health care and have established mechanisms for shared decision-making and governance, supported by national policies or legislation for Indigenous engagement; however, in both countries these frameworks have not been successfully implemented.

An international comparison of legislative approaches to Indigenous health found that Constitutional recognition of Indigenous peoples and their special status helped to form the basis of coherent national Indigenous health legislation in the cases of New Zealand and the United States.[61] This is important in creating congruence both between international and national frameworks and within the country's jurisdictional levels. The current case studies uphold this pattern, which suggests that Constitutional recognition may engender the creation of legislation to facilitate Indigenous engagement and thereby protect Indigenous peoples' rights.

New Zealand's Treaty of Waitangi between Māori and the British Crown is often recognised as having a major influence in the establishment of legal recognition of Māori peoples and in

establishing obligations of the Government with respect to Māori sovereignty. Principles derived from the treaty were used to support the incorporation of Māori health needs in national legislation through the *New Zealand Public Health and Disability Act 2000*. In addition, this legislation outlines mechanisms by which the health needs of Māori peoples are to be determined and addressed, including through community participatory processes.[61,79,80] While this legislation has not been implemented successfully and has recently been recognised as a breach of Treaty obligations,[53] the case of New Zealand illustrates the utility of Constitutional recognition and an established treaty in the development of Indigenous health policy. In contrast, the cases of Australia and Canada, which do not have Constitutional recognition, exhibited weaker and more piecemeal legislative structures.[61]

Brazil and Chile also fall in line with this pattern. In Brazil, the right to health for all people was enshrined under the 1988 Constitution, as well as the rights of Indigenous peoples to the use of their lands and retention of their languages and cultures.[43] Subsequently, the differentiated health care subsystem for Indigenous people and the cultural right to health care were born within the national health care reform movement.[81] Despite the support of international instruments ILO 169 and the UNDRIP, Chile's national legislative and policy framework is inadequate to support sustained engagement and shared decision-making with Indigenous peoples regarding their health needs. Of the four countries, Chile has the weakest national infrastructure in this regard. Of note, Chile is the only country in Latin America that does not have Constitutional recognition of its Indigenous peoples or their rights (apart from Costa Rica).[82]

Distinctions between policy and practice

The purpose of this study was to analyse national-level policy and legislation, rather than taking into account policy implementation or real-world practice. However, it is important to note that the difference between Indigenous health policy and practice can be substantial.

Of the four countries, Brazil exhibited the strongest national frameworks regarding recognition of Indigenous health needs and Indigenous engagement; however, the Indigenous health subsystem has been heavily and consistently criticised for a lack of accountability to and representativity of the Indigenous communities, as well as failing to ensure that decisions made through such processes are implemented. From its establishment, the SASISUS presented management problems and outsourcing of Indigenous health care services and delivery to NGOs, low levels of quality and coverage,[38,83] as well as an inefficient monitoring information system of Indigenous health conditions.[84] While the concept of interculturality or cultural appropriateness forms the backbone of Brazil's Indigenous health policy, including the differentiated health care model and the PNASPI, there is a lack of clarity around the term, which has also been identified as being ethnocentric.[85,86] In this regard, the SASISUS model was established to increase inclusivity of the health care system, but remains operationally normative[85] and reproduces the hegemony of biomedical knowledge in health care practices for indigenous people.[87,88]

As can be seen, New Zealand has a strong basis for the engagement of Māori people in health and for the recognition of Māori values, priorities and needs in the form of the Treaty of Waitangi. However, there has been some indication that engagement with and recognition of Māori people is being dismantled. In 2006, senior management in the Ministry of Health instructed staff to remove all references to the Treaty from health policy.[89,90] Following this, a review of 49 public health strategies and plans published between 2006 and 2016 found that none of the documents

made mention of the Māori text of the treaty and 75% made no reference to the English version.[89] Given the importance of the treaty in establishing Crown obligations to protect Māori health and affirm Māori sovereignty, its implicit rejection in the development of health policies signals a reluctance to engage with these principles. Moreover, the Waitangi Tribunal inquiry and subsequent first report into Primary Care for Māori has outlined the deficits in government policies in relation to reducing health inequities and adhering to their Treaty of Waitangi obligations.[53] This inquiry also found that the government did not collect sufficient quantitative or qualitative data to inform decisions about health policy for Māori and as a result these inequities persisted without a clear understanding of the problems underlying Māori health inequity. A failure to monitor performance of primary health sector with regard to Māori health also contributes to this inequity.[53]

In Australia, the situation is rather different--despite the lack of formal national policy or legislation to this effect, various mechanisms do exist to support Aboriginal and Torres Strait Islander engagement at multiple levels of policy and service development. In particular, the Aboriginal community controlled health care sector is recognised as essential to not only health care provision, but in shaping Indigenous health policy and research.[91,92] Nevertheless, these mechanism structures are generally not based in legislature and fall short of sharing decision-making responsibilities. Rather, the impetus for Aboriginal and Torres Strait Islander engagement relies on established norms and ethics regarding practice in Aboriginal and Torres Strait Islander health.[93]

Limitations of the study

There are three main limitations to this study. First, this research considers only policy as it exists on paper, and does not fully consider any discrepancies that may exist between the written policy

and real-world implementation. While this decision was made for ease of comparison, it is acknowledged that in some cases this gap is significant. Secondly, we present here only national-level policy, not local or regional. Particularly in Brazil, New Zealand and Australia, a large proportion of the responsibility for Indigenous health policy is held at regional levels. The policies presented here are therefore an underrepresentation of the full Indigenous health policy environment. Finally, while significant effort was made to ensure all relevant pieces of policy and legislation were identified within the four countries, the study is not a systematic review. It may therefore be that some elements of national-level Indigenous health policy in the comparator countries have inadvertently been missed.

Conclusions

In recent years, there has been an increased trans-national influence on Indigenous policy, bolstered by the recognition that Indigenous peoples worldwide are facing similar challenges and hold similar goals with respect to health. The creation of international policy frameworks has been important in shaping a shared understanding that Indigenous peoples have the right to participate in the formation and implementation of health policy and programs to address their health needs. However, the adoption of international agreements does not necessarily directly lead to the relevant principles being reflected in national legislature and policy, although it may reflect the 'soft transfer' of those ideas and standards. At the same time, while a national legislative and policy framework may be created to support the engagement of Indigenous peoples, this may not necessarily translate into practice. Developing approaches that improve cohesion between international policy, national policy and practice in Indigenous engagement in health is therefore vital. The inclusion of countries outside of Australia, Canada, New Zealand and

the United States in cross-country comparative Indigenous health research may be useful in providing guidance to strengthen these links.

Declarations

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Not applicable

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

AF and LP developed the manuscript idea. AF, LP and ML carried out the search strategy and wrote sections of the manuscript for each of the countries as follows: AF: Australia and Chile; LP: Brazil; ML: New Zealand. All authors provided critical feedback and helped shape the research, analysis and manuscript.

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Appendix 5: Outputs arising from the research

Reports

- Ferdinand A, Kelaher M, Oyarce AM, Paradies Y, Anderson I. Institutional perspectives on Mapuche community participation in health. Melbourne, Australia: University of Melbourne, Centre for Health Policy, 2016.
- Ferdinand A, Kelaher M, Oyarce AM, Paradies Y, Anderson I. Mapuche community participation in health: The case of Makewe Intercultural Hospital. Melbourne, Australia: Centre for Health Policy, University of Melbourne, 2017.
- Ferdinand A, Kelaher M, Oyarce AM, Paradies Y, Anderson I. Mapuche community participation in health: The case of Boroa Filulawen Intercultural Health Centre. Melbourne, Australia: Centre for Health Policy, University of Melbourne, 2017.

Conference presentations

- Ferdinand A, Pedrana L, Kelaher M, Trad, L, Oyarce AM. Improving indigenous health care from a comparative critical perspective: Lessons from Brazil, Chile, Australia and New Zealand. International Workshop on Public Policy. Pittsburgh, United States; 2018.
- Ferdinand A, Kelaher M, Oyarce AM. Indigenous autonomy through community participation: Tensions and conflicts. International Workshop on Public Policy. Pittsburgh, United States; 2018.
- Ferdinand AS, Kelaher M. Independence and control in Indigenous community participation in health. International Conference on Public Policy. Singapore; 2017.
- Ferdinand AS, Oyarce AM, Paradies Y, Kelaher M. Balancing international experiences and local contexts in Indigenous health. Association of Pacific Rim Universities (APRU) Global Health Workshop. Sydney, Australia; 2016.
- Ferdinand AS, Oyarce AM, Paradies Y, Kelaher M. Balancing international experiences and local contexts in Indigenous health. International Union for Health Promotion and Education (IUHPE) Conference. Curitiba, Brazil; 2016.

- Ferdinand AS. Balancing international experiences and local contexts in Indigenous health. Health Services Research Association of Australia and New Zealand Conference 2015. Melbourne, Australia; 2015[†]
- Ferdinand AS. Intercultural models of Aboriginal health care: What can we learn from international experiences? Melbourne School of Population and Global Health Postgraduate Student Conference. Melbourne, Australia; 2014.
- Ferdinand AS. Intercultural models of Aboriginal health care: What can we learn from international experiences? Menzies Centre for Health Policy, University of Sydney Emerging Health Research Conference. Sydney, Australia; 2014.

[†] Highly Commended as part of the Best Conference Abstracts by an Early Career Researcher Award

Invited presentations

- Ferdinand AS. Independence and control in Indigenous community participation in health. Indigenous health in a global context. University of Melbourne. Melbourne, Australia; 2018.
- Ferdinand AS. Chile's Mapuche people: The role of intercultural health practices. University of Melbourne. Melbourne, Australia; 2017.
- Ferdinand AS. Independence and control in Indigenous community participation in health. Indigenous health in a global context. University of Melbourne. Melbourne, Australia; 2018.
- Ferdinand AS. Indigenous community health in the Sustainable Development Goals. The Chile-Global Seminar. Melbourne, Australia; 2017
- Ferdinand AS. Ética de investigación en comunidades Mapuche. Hospital Makewe. Temuco, Chile; 2016.

Academic articles

- Ferdinand A, Lambert M, Pedrana L, Trad L, Paradies Y, Kelaher M. Indigenous engagement in health: Lessons from Brazil, Chile, Australia and New Zealand. International Journal for Equity in Health 2019; In press.

- Ferdinand A, Oyarce AM, Kelaher M, Anderson I. Reflexiones sobre la ética de la investigación en salud indígena en Chile (Reflections on ethical Indigenous health research in Chile). Revista Latinoamericana de Bioética (Latin American Journal of Bioethics) 2018, 18 (35-2).