

# Reflections on ethics in Indigenous health research in Chile

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Reflexiones sobre la ética en la investigación de la salud de la población indígena en Chile

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Reflexões sobre a ética na pesquisa em saúde indígena no Chile

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## Abstract

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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

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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

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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 health 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 disci-

pline, 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 world-views, 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 reconsid-

eration 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 constant-

ly 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 Nahuelpán 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 (Stigman & 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 health 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 commu-

nity-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 be-

tween 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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