Reflections on ethics in Indigenous health research in Chile

PUBLICACIÓN ANTICIPADA EN LÍNEA
Este artículo ha sido aprobado para su publicación por el Comité Editorial de la Revista Latinoamericana de Bioética, teniendo en cuenta los conceptos emitidos por los pares académicos evaluadores del artículo. La publicación se hace anticipada en formato PDF provisional, de acuerdo con la última versión enviada por los autores, sin que aún se haya realizado la corrección de estilo ni la diagramación. El DOI se encontrará asignado más no activado, la activación se realizará cuando se publique el PDF final.

Esta versión puede ser citada, descargada, distribuida y usada, pero recuerde que este es un documento provisional y puede diferir del PDF final.

Citación provisional:

Fecha de recepción: Enero 10 de 2018
Fecha de evaluación: Mayo 5 de 2018
Fecha de aceptación: 18 de mayo de 2018
Publicación en línea: 21 de mayo de 2018
Authors:

Angeline Ferdinand, MPH
Public Health Researcher
University of Melbourne, Australia
a.ferdinand@unimelb.edu.au

Ana María Oyarce, PhD (abd)
Professor
Doctor of Anthropology
University of Chile
aoyarce@med.uchile.cl

Margaret Kelaher, PhD
Professor
Doctor of Public Health
University of Melbourne
mkelaher@unimelb.edu.au

Ian Anderson, PhD
Professor
Doctor of Public Health
University of Melbourne
i.anderson@unimelb.edu.au
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
Background

Academia and Indigenous peoples

Historically, research carried out in Indigenous contexts has been associated with processes of 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 or dehumanising treatment towards them (Cervini, 2011; Dobbin, 2015; Grekul, Krahn, & Odynak, 2004; Kukkanen, 2006; Nahuelpán M, 2013). The domination of 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, undermining 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 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 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 by which these determinants affect Indigenous health are interconnected and reinforce each other, leading to stress, maladaptive coping mechanisms and social fragmentation (King et al., 2009).

In 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 undertaken in this field; serious questions have been raised by Indigenous communities, leaders and scholars regarding the utility of the work being done and whether Indigenous communities, bearing the brunt of the risks and burden of research, are receiving adequate benefit (K. Mohindra, 2016; K. S. Mohindra, 2015). This has led to the perception within Indigenous communities that Indigenous health research has primarily been undertaken as a way to further the careers of academics, rather than for the purpose of improving Indigenous health outcomes (Tuhiwai Smith, 2012). For these reasons, there
exists a distrust towards academics and academia as a whole, rooted in long-standing experience that indicates 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 centre 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 transdisciplinary field with diffuse borders that encompass bioethics in research with human beings, public policy and health and human rights, among others (Gordon; Silber, 1982). The current article is located at the intersection of these areas and presents as a central focus 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. Achieving these goals will require that the academy profoundly change its relationship with Indigenous communities and peoples.

The decolonisation of research engages with the history that exists between researchers and Indigenous peoples and seeks to reorient this relationship in a way that supports the rights of Indigenous peoples to self-determination, sovereignty and control over their own histories and knowledges. Linda Tuhiwai Smith (2012) positions it as a direct response to the harm experienced by Indigenous communities due to 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 for the use of non-Indigenous individuals and organisations, as Indigenous people and communities wield the tools of research to serve their own needs and purposes, imbuing research processes with their values, perspectives, priorities and epistemologies.

Smith’s Decolonizing methodologies is explicitly aimed towards Indigenous scholars, leaders and communities, and problematises the role of the non-Indigenous scholar undertaking research in Indigenous contexts. In 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 y Speed (2008) examine in depth the challenges and possibilities in 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 come to 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 interrogates the way knowledge and meanings are constructed, as well as examining the influence of the relative positions of the researcher and participants within the social, political and historical context. Guillemin and Gillam (2004) argue that reflexivity in research represents “ethics in practice,” or grappling with the day-to-day ethical issues that arise in the course of research practice, 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 Indigenous context as being practiced on three levels: self-reflexivity, that is, how the individual recognises their own biases, assumptions and ways of working. This reflexivity is tied to the second type, which is interpersonal reflexivity, that is, the ways in which the research works with or
collaborates with others, incorporating 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 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, 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, 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 (Tunón, Kvarnström, & Lerner, 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 focus of the documents align with the principles of biomedical ethics, including free and informed consent, respect, benefit and justice, and focus primarily on the relationship between 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 emphasised strongly principles that stem from a health equity or human rights perspective, such as the involvement of local stakeholders in priority setting, community benefits before and after the research, capacity-building and research partnerships.

Logically, thinking regarding ethics in Indigenous health research is not static and continues to evolve worldwide. Examination of the ethics of Indigenous health research outside of the researcher-participant relationship continues to expand, considering the role of funding bodies, publication methods and other aspects of the research process. For example, there are 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); as well as 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 in the experience of Indigenous health research of the principal author (ASF) in Temuco, Chile and in Indigenous health in Australia. In Chile, many conversations were undertaken with Mapuche leaders about the relationship and expectations of the communities and academic researchers, as well as about the utility of Indigenous health research. These conversations were complemented by discussions with Chilean academics reflecting on their own research practice.
In that time, 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 via academic journals or theses, leaving 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—went only to furthering researchers’ careers. The Mapuche historian Héctor Nahelpán describes 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 M, 2013).

Within Chile there remains a lack of evidence needed for the development of appropriate health services for Indigenous peoples. This refers not only to epidemiological data, but also 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 ethical 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 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. This necessitates reflexivity, thought and effort to be put towards re-orienting academia’s relationship with Indigenous communities.

This paper therefore aims to support the reflection on the construction of a conceptual and methodological framework to undertake ethical research in 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 mainly on the role of academic and non-Indigenous institutions 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**

Chile demonstrates a lack of formal guidance 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. This includes a publication regarding the inclusion of vulnerable participants in scientific research, which includes only a 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 with human beings. Law 20.120, Regarding scientific research in 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, including 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 in 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 G et al., 2014; Universidad de Chile).
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; identification of relevant Indigenous values and the incorporation of these values into research; and the roles of academic and community partners and other stakeholders. Rather, it is largely left to the individual researcher and Indigenous organisation or community to reach an agreement on these issues with possibly little common language for doing so.

The development of guidelines either undertaken by Indigenous organisations or in collaboration with them and the adoption of such guidelines into universities’ and research institutions’ ethical processes may therefore serve a number of uses: First, to encourage research that is designed from the beginning stages 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 receive approbation before proceeding will ensure that researchers begin the process of designing projects with ethical principles in mind. Second, to strengthen an academic framework that adheres to expectations that researchers
fulfil their ethical obligations towards Indigenous communities and to provide mechanisms for enforcing such expectations. Under this system, researchers have the benefit of clearly communicated expectations regarding appropriate research conduct from their institutions. Finally and relatedly, embedding ethical guidelines and related structures provide the basis for 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 in strong and clearly defined principles and also provide actionable indicators for ethical practice. In 2013, the Australian National Health and Medical Research Council (NHMRC) undertook an evaluation of their documents relating to ethics in Aboriginal and Torres Strait Islander health research. Within Australia, all University-based researchers are obligated to comply with the principles in the document *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2004* (National Health and Medical Research Council, 2003). One of the main findings of the evaluation was that participants felt that the values espoused in this document could be strengthened through the provision of good and bad practice examples 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 in showing the particularities of local issues and what ethical practice looks like in these instances.
Principles of ethical Indigenous health research may be seen as 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 in 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 as identified by Tunón et al broadly align with the principles of biomedical ethics, with basic research practices represented 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 relying on a basis of individualistic and Western analytical thought (Hedgecoe, 2004; León Correa, 2009). This conceptualisation of ethics has proven to be insufficient to address 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 reference the decolonisation of research framework and a community-based understanding of human rights. In these writings, ethical Indigenous health research is primarily held to be research that respects and upholds Indigenous peoples’ rights to self-sovereignty and autonomy and is characterised by accountability and reciprocity (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—that is, 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 document through discussion of how they should inform research practice. *Te Ara Tika* stands out regarding the presentation of 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* set 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 supports 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, where 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 of delivering 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 the ethical obligations of stakeholders 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 incorporating 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, reflecting the diversity of opinion and viewpoints on this 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 the 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 the use of 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 undertaken 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 federally-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).

In considering the case of Chile, a number of interrelated questions regarding 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. To accomplish 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 for training members of institutional ethics committees in relation to ethical issues in Indigenous research from the perspective of Indigenous communities, 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 to adhere to established ethical norms should be included.

Using international examples as a starting point, the next section presents a number of possibilities for the development and execution of guidelines for ethical Indigenous health research in Chile, each with their advantages and challenges:

1. An initial set of guidelines is developed at the national level, such as 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 obligated to comply with these guidelines. While this would have the advantage of 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 here.

3. The development of guidelines undertaken by Indigenous organisations, reflecting those values and principles of particular importance and relevance to them. In cases of framework development led by Indigenous organisations and communities, there will need to be subsequent consideration 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 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 one in particular. Option four in particular could be used in conjunction with the other three options in order to improve responsiveness of research to local concerns, increase control of communities over research that affects them and strengthen the incorporation of diverse Indigenous values and perspectives. That is, ethical approval processes could be conducted at 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 for shaping research has been criticised as being insufficient for conceptualising a more inclusive and responsive dynamic between researchers and Indigenous communities (Humphery, 2001). In addition to the use of ethical guidelines, there is therefore also a need for more explicit involvement of Indigenous people and communities at all stages of the research process.

**Collaborative partnerships and community-led research**

Examining academic 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 space to occur through the incorporation of Indigenous- and community-led approaches and the centering of Indigenous perspectives, values and priorities as well as the creation of institutional structures that facilitate such research to take place (Tuhiwai Smith, 2012). For research undertaken through 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 through 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 to 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 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 research is more relevant and corresponds to community priorities and facilitates the positioning of Indigenous communities as the experts on what does and does not work in their context.

Working in partnership with Indigenous communities can also facilitate the production of good research through the generation of ongoing relationships and fostering trust and understanding between the different parties, thereby increasing individuals’ and
communities’ willingness to be involved and 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 at all stages of the research and the right of communities 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 towards the utility of the research that would be generated from the investment of approximately 8 million USD 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 M, 2013).

There is no single model of 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 cyclical framework of five phases: Pre-research, where interpersonal relationships are established; community consultation; community entry, where research partnerships are established; research; and research dissemination. This model centres 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 community and have encompassed a re-imagining of research funding mechanisms, re-establishing data governance protocols and shared responsibilities for research design, data collection, interpretation and dissemination. For example, one health initiative was driven by Indigenous communities in Canada (Musqueam) and Ecuador (Quichua), 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 of 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 model 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. 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, while necessary for the undertaking of ethical Indigenous health research, can be a burden 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 that work with Indigenous communities to incorporate culturally appropriate methods in their practice.

For these reasons, the establishment of sustainable collaborations between academic institutions and Indigenous communities and organisations may be difficult, particularly in the initial phases where 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 indicated previously, in order for community-based and -directed research based in mutual collaboration to be carried out, research funding must prioritise these projects and principles. Funding guidelines should ensure that the timelines of Indigenous health research are adequate for the establishment of 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 is apparent within 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 exists a long and continuing history of tension and conflict between Indigenous communities and non-Indigenous academic researchers, which is reflective of complexities that exist 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 to illuminate the current status of Indigenous health and the needs faced by Indigenous communities, 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.
In this case, 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 for the establishment of 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 a particular context.

The establishment of 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 accountable to adherence. Genuine research partnerships and collaboration between academic institutions and Indigenous organisations and communities are critical for ensuring 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 involved communities is situated within a context where 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 development of the field there has been a push towards a social bioethics that is able to converse with a diversity of 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, the implementation of processes to respond to those ethical dimensions that are 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.

Acknowledgements

The authors would like to express their profound thanks to those people that have generously and respectfully provided comments and feedback on this work, including Andrés Cuyul, Jorge Neira, Catalina Quiñones and Reynaldo Neira. The material for this article is based on work supported by the Australian Government through the National Health and Medical Council Postgraduate Scholarship and the Endeavour Postgraduate Scholarship.
References

Australian Institute of Aboriginal and Torres Strait Islander Studies, & The Lowitja Institute. (2013). Researching the right way: Aboriginal and Torres Strait Islander health research ethics: A domestic and international review. Retrieved from Canberra, Australia:

Australian Institute of Aboriginal and Torres Strait Islander Studies, & The Lowitja Institute. (2014). Evaluation of the National Health and Medical Research Council documents: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research 2004 (Values and Ethics) and Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005 (Keeping research on track). Retrieved from Canberra, Australia:


Comisión Nacional de Investigación Científica y Tecnológica. (2014). Participantes de investigación científica en situación de vulnerabilidad: Desafíos y resguardos especiales. 9° Taller de Bioética organizado por Comité Asesor de Bioética FONDECYT de CONICYT. Retrieved from Santiago, Chile:


Couzos, S., Lea, T., Murray, R., & Culbong, M. (2005). 'We are not just participants - We are in charge': The NACCHO ear trial and the process for Aboriginal community-controlled health research. Ethnicity & Health, 10(2), 91-111. doi:10.1080/13557850500071038


First Nations Centre. (2007a). *Considerations and templates for ethical research practices*. Retrieved from Ottawa, Canada:


León Correa, F. J. (2008). De los principios de la bioética clínica a una bioética social para Chile. [From clinical to social bioethics in Chile]. *Revista Medica De Chile, 136*(8), 1078-1082. doi:10.4067/s0034-98872008000800018


National Health and Medical Research Council. (2003). *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. Retrieved from Canberra, Australia:


