

SECOND ASIA-PACIFIC REGIONAL MEETING for NATIONAL ETHICS/BIOETHICS COMMITTEES

*Reducing Inequities through Solutions-Orientated Bioethics*

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## Indigenous Populations and Equity – Articles Summary

### Indigenous research ethics

#### **(Anderson & Cidro 2019)**

This research describes the themes that emerged when two Indigenous scholars interviewed their Indigenous university-based colleagues who work in Indigenous health. These interviews uncovered four critical themes that were prominent and related specifically to understanding research ethics in Indigenous health research specifically.

- These themes included research in relationship, creating partnerships and negotiating across systems, self-determination applied to research, and community-engaged research.

#### **(Bainbridge et al. 2013)**

This paper explores the opportunities and challenges for developing an ethics of practice when conducting community-based research with Aboriginal people in Australia. Findings included:

- Research must implement strengths-based approaches to realise ethically sound research
- Research should prioritise the relevance of the research to the daily lives, needs and aspirations of those with whom they work; and in doing so, remain cognisant of their own philosophical position and context in which the research is located.

#### **(Blanchard et al. 2017)**

This article identifies challenges and strategies for collecting qualitative data on the perceptions of direct-to-consumer (DTC) Genetic Ancestry tests (GAT) among diverse Indigenous communities.

- Highlights the need to conduct genetics-related research with Indigenous communities in culturally and methodologically appropriate way
- Priority areas include issues related to participant recruitment and tribal advisory boards, challenges of self-identification as a recruitment mechanism, and the necessity of including Indigenous researchers in all aspects of the research process.

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**(Bond, Foley & Askew, 2015)**

This paper describes the Inala Aboriginal and Torres Strait Islander Community Jury for Health Research, and evaluates its usefulness as a model of Indigenous research governance within an urban Indigenous primary health care service from the perspectives of jury members and researchers.

- The jury processes facilitated transformative research practice among researchers and resulted in transference of power from researchers to the jury members, to the mutual benefit of both.
- Ethical Indigenous health research practice requires an engagement with Indigenous peoples and knowledge at the research governance level, not simply as subjects or objects of research

**(Brunger & Wall 2016)**

The authors examine the question of whether and how research ethics guidelines and associated assumptions about the value of community engagement may be grounded in, and inadvertently reinforce, ongoing colonialist relations of power.

- community engagement—if done uncritically and in service to ethics guidelines rather than in service to ethical research—can itself cause harm by leading to community fatigue, undermining the community’s ability to be effectively involved in the research, and restricting the community’s ability to have oversight and control over research
- the laudable goal of engaging communities in research requires careful reflection on the appropriate use of resources to operationalize meaningful collaboration.

**(de la Barra, Redman & Eades 2009)**

This paper describes the policy changes made by the National Health and Medical Research Council (NHMRC) from 1997 to 2002 to improve funding of Aboriginal health research, examines catalysts for the policy changes, describes the extent to which policy changes were followed by new models of research and, outlines issues for Indigenous health policy in the future.

- The need for research to better address health disparities in Indigenous people has been widely recognised.

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- Policy changes have made some progress in supporting better research models particularly in improving engagement with Indigenous communities. However, there remains a need for further reform to optimise research outcomes for Indigenous people from research.

**(Dyall et al 2013)**

This paper documents the research approach taken involving different groups of Māori people and organisation in the design and implementation of the feasibility project, designed to pave the way for the large longitudinal study on advanced ageing by Māori and non-Māori.

- Māori like other indigenous populations worldwide suffer from chronic health conditions which reduce their quality of life and cause premature death.
- There is now growing awareness of the ongoing harm of institutionalized racism.
- The researchers engaged a registered Māori translator who had tribal links to one of the researched areas and he was recommended by the Māori Language Commission to translate the questions, the participant information form, and the consent form.
- In cooperation, the researchers developed the bilingual questionnaire to a level of acceptability across several different tribes and determined how the research would be conducted best with Māori by Māori; Kaupapa Māori.

**(Fitzpatrick et al. 2016)**

When conducting research with Indigenous populations consent should be sought from both individual participants and the local community. This paper aims to search and summarise the literature about methods for seeking consent for research with Indigenous populations.

- In five studies based in Australia, Canada and The United States of America the consent process with Indigenous people was objectively evaluated.
- Some Indigenous organisations provide examples of community-designed resources for seeking consent and describe methods of community engagement, but none are evaluated.
- International, national and local ethical guidelines stress the importance of upholding Indigenous values but fail to specify methods for engaging communities or obtaining

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individual consent. In the 'Grey literature' concerns about the consent process are identified but no solutions are offered.

- Consultation with Indigenous communities is needed to determine how consent should be sought from the community and the individual, and how to evaluate this process.

**[\(Goodyear-Smith, Jackson, & Greenhalgh 2015\)](#)**

This paper explores how implementation science research, especially when using participatory and co-design approaches, raises unique challenges for research ethics committees. Such challenges may be poorly addressed by approval and governance mechanisms that were developed for more traditional research approaches such as randomised controlled trials.

- Implementation science commonly involves the partnership of researchers and stakeholders, attempting to understand and encourage uptake of completed or piloted research.
- Ethics committees should acknowledge and celebrate the diversity of research approaches, both formally (through training) and informally (by promoting debate and discussion)
- Ground rules should be established for co-design applications (e.g. how to judge when 'consultation' or 'engagement' becomes research) and communicated to committee members and stakeholders.
- Benefits of power-sharing should be recognised and credit given to measures likely to support this important goal, especially in research with vulnerable communities. Co-design is considered best practice, for example, in research involving indigenous peoples in New Zealand, Australia and Canada.

**[\(Guillemin et al. 2018\)](#)**

Relationships of trust between research participants and researchers are often considered paramount to successful research; however, we know little about participants' perspectives. This paper examines whom research participants trusted when taking part in research.

- In contrast to Indigenous participants, non-Indigenous participants placed their trust in research institutions because of their systems of research ethics, their reputation and prestige.

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- Researchers working in non-Indigenous contexts need to be cognizant that the trust that participants place in them is closely connected with the trust that participants have in the institution.

**(Guillemin et al. 2016)**

This paper examines the accounts of Australian Indigenous and non-Indigenous research participants in terms of how and why they agree to take part in research.

- It is important for researchers to understand the motivations and decision-making processes of participants who take part in their research. This enables robust informed consent and promotes research that meets the needs and expectations of the community.
- It is particularly vital when working with Indigenous communities, where there is a history of exploitative research practice.
- There were stark differences between Indigenous and non-Indigenous research participants in terms of why and how they decided to participate in research. For Indigenous participants, taking part in research was primarily to benefit their communities rather than for personal interests. Indigenous participants often started from a position of caution, and showed a considered and deliberate process of decision making.

**(Hing, Breen & Grodon, 2010)**

This paper details how the researchers, as 'cultural outsiders', conducted a large gambling survey in an Indigenous Australian community that adhered to Indigenous ethical protocols and values while differing from some standard survey practices.

- There has been a growing discussion on the necessity for research involving Indigenous peoples to be approached from within an Indigenist paradigm rather than from a western colonial tradition.
- The relationship between Indigenous communities and the research community has evolved through many phases, and various models have been used successfully.
- This involves the explicit recognition and commitment to respect for Indigenous cultural values and principles. The models also promote local relationships to ensure that the nuances of judgement and practice necessary to promote trustworthiness and trust are created and

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maintained. They also illustrate the important aspects of accountability and transparency in standards, processes and structures

**(Hudson & Russell 2008)**

The relevance of the Treaty of Waitangi to research ethics is discussed and this paper suggests a revised interpretation of the treaty principles to incorporate the range of ethical issues that Māori have expressed as important.

- Researchers, when engaging with Māori communities, are in a process of relationship building and this process can be guided by the principles of the Treaty of Waitangi, partnership, participation and protection.
- The importance of relationships as the foundation for equitable partnerships and development within Indigenous communities is promoted strongly by Indigenous academics.
- The suggested revision of the treaty principles in relation to research ethics is necessary to ensure that issues of reciprocity, equity and benefit-sharing are an explicit part of the negotiation process between researchers and Māori communities.

**(Jamieson et al. 2012)**

This article sets out the 10 principles relevant to health research among Indigenous Australian populations reflected in the many documents related to working and researching with Indigenous Australians; for example, the National Health and Medical Research Council (NHMRC) ethical guidelines for research among Aboriginal and Torres Strait Islander people.

The principles include:

1. Addressing a priority health issue as determined by the community.
2. Conducting research within a mutually respectful partnership framework.
3. Capacity building is a key focus of the research partnership, with sufficient budget to support this.
4. Flexibility in study implementation while maintaining scientific rigour.
5. Respecting communities' past and present experience of research.

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6. Recognising the diversity of Indigenous Australian populations.
7. Ensuring extended timelines do not jeopardise projects.
8. Preparing for Indigenous leadership turnover.
9. Supporting community ownership.
10. Developing systems to facilitate partnership management in multicentre studies.

**(Kendall et al. 2011)**

In this article the authors describe events that have led to more appropriate research methods in Australia, and the resulting changes in the research community.

- Evidence-based approaches to health care have been difficult to achieve in Indigenous populations across the world, a situation which has contributed to the significant health disparities found in this group.
- One reason for the inadequacy of evidence-based health interventions is that empirical knowledge tends to be organized around professional disciplines that are grounded in Western ways of knowing.
- The principles that have guided Australian research policy development might not yet be fully matured, but the improvements we have experienced over the last several decades have gone a long way toward acknowledging the significant disparities that affect Indigenous people and the role of researchers in addressing this issue.

**(McWhirter & Eckstein 2018)**

This study initiates the required evidence base through an audit of informed consent practices for medical research in the Australian state of Tasmania to assess the need for, and current uptake of, supplementary consent strategies.

- Allowing persons to make an informed choice about their participation in research is a pre-eminent ethical and legal requirement. Almost universally, this requirement has been addressed through the provision of written patient information sheets and consent forms.

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- Researchers and others have raised concerns about the extent to which such forms—particularly given their frequent lengthiness and complexity—provide participants with the tools and knowledge necessary for autonomous decision-making.
- Concerns are especially pronounced for certain participant groups, such as persons with low literacy and Indigenous persons.
- Multimedia strategies have the potential to usefully supplement current consent practices in Australia; however, information is needed about the need for supplementary consent practices, along with drivers for and barriers against adoption.

**(Pyett 2009)**

In this paper, one Indigenous and two non-Indigenous public health researchers reflect on our combined experience of over thirty years in Aboriginal health, in order to develop some practical guidelines, particularly for researchers working with urban Indigenous population groups.

- The practical guidelines suggested in this paper may assist public health researchers to conduct ethical health research that is planned and carried out in a culturally appropriate way and that will benefit urban Aboriginal people.
- While not intended to be prescriptive, the authors believe that the lessons learned in Victoria will be applicable to other urban Indigenous contexts around Australia.

**(Tupara 2012)**

This article describes the findings of a retrospective qualitative case study of the decision experiences of members of three Māori kin groups (whānau) who have been participants in genetic research (in New Zealand).

- The study found four Māori constructs embedded in the participants' decision processes. Hui, rangatiratanga, manaakitanga, and kotahitanga.
- The results confirm philosophical, theoretical, and anecdotal discussions indicating that Maori utilize unique conventions in decision making, which is relevant to health researchers because of the important link between decision making and informed consent.

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## **Indigenous bioethics**

### **(Chennells 2014)**

This thesis explores how cross-border access to human genetic resources, such as blood or DNA samples, can be governed to achieve equity for developing countries. In drawing its conclusions, the thesis resolves a highly pressing topic in global bioethics and international law. Originally, it combines bioethical argument with jurisprudence, in particular reference to the law of equity and the legal concepts of duress (coercion), unconscionable dealing, and undue influence.

- Benefit sharing is crucial to avoiding the exploitation of developing countries in genomic research.
- With functioning research ethics committees, undue inducement is less of a concern in genetic research than in other medical research (e.g. clinical trials).
- Concerns remain over research involving indigenous populations and some recommendations are provided.

### **(Camargo 2013)**

This paper shows the role of the solidarity principle in relation to right to health of Colombian aboriginal peoples, analysing the Universal declaration of the rights of aboriginal peoples and the Declaration on Bioethics and Human Rights.

### **(Du Pelssis & Fairbain-Dunlop 2010)**

This article reviews the responses of participants in a number of different gatherings on ethics-related issues in the Pacific. It explores the importance of Pacific ideals of collective rights and the need to recognise the value of indigenous knowledge systems, particularly the way this knowledge has been collectively produced, shared and used.

- The impact on Pacific peoples of developments in genetic science and the actions of researchers and companies working in the life sciences have prompted increasing discussion about the politics and ethics of knowledge.
- What is distinctive about particular Pacific cultures, what is shared by Pacific people and the negotiated spaces between indigenous thinking and western science are highlighted in this

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introduction to articles that offer Pacific challenges to established thinking on the ethics of knowledge production.

- Ethics systems and processes were, and still are, central to every aspect of the life of Pacific indigenous communities. Although not documented, and long disregarded in the privileging of western ideas about ethical practice in the post-contact period, Pacific ethics processes integrate epistemological, pedagogical and methodological considerations.

**(Evans 2012)**

This paper provides part of an analysis of the use of the Maori term whakapapa in a study designed to test the compatibility and commensurability of views of members of the indigenous culture of New Zealand with other views of genetic technologies extant in the country.

- Four levels of curiosity are identified, in the Maori data, which penetrate more or less deeply into the psyche of individuals, affecting their health and wellbeing.
- These phenomena are compared with non-Maori experiences and considerable commonalities are discovered together with a point of marked difference
- Research into Maori conceptions of whakapapa as genealogy has revealed various levels of genetic curiosity, which are shared more generally with non-Maori people. It has been noted that these can be ordered in a way that marks a growing significance of such information in the lives of people with respect to their health and wellbeing.
- These levels of curiosity call for increasing levels of care both in the formation of health policy and in the provision of clinical services.

**(Fitzgerald et al. 2019)**

This article undertakes a close reading of the parliamentary debates associated with the topic of embryo cryopreservation in Aotearoa New Zealand. The authors argue that there is a lack of transparency over the ethical reasons for enforcing a maximum storage limit.

- Authors illustrate that the avoidance of embryo accumulation and related conflict was only achieved by the denial of indigenous spiritual and cultural concerns, while also shifting the ethical burdens of disposition on to clinic staff and those members of the public who protested against enforced cryopreserved embryo disposal.

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- The Pākehā cultural concept of 'tidy housekeeping' emerges as a presumed ethical and social good in the New Zealand situation. This is despite abundant literature documenting the suffering created through forced decision-making upon disposition.

**(Illklic & Paul 2009)**

This article discusses the ethical issues as illustrated by the Human Genome Diversity Project (HGDP). This investigation focuses on the confrontation of culturally diverse images of humans and their cosmologies within the framework of genome diversity research and the ethical questions it raises.

- The goal of the HGDP was to reconstruct the history of human evolution and the historical and geographical distribution of populations with the help of scientific research. An important part of this genome diversity research consists in taking blood and tissue samples from indigenous populations
- In addition to complex questions pertaining to research ethics such as informed consent and autonomy of probands, genome diversity research also has a cultural–philosophical, meta-ethical, and phenomenological dimension which must be taken into account in ethical discourses
- The limits of current guidelines used in international genome diversity studies, following this up by a formulation of theses designed to facilitate an appropriate inquiry and ethical evaluation of intercultural dimensions of genome research.

**(Kotalik & Martin 2016)**

This paper raises the possibility of constructing a bioethics grounded in traditional Aboriginal knowledge. As an example of an element of traditional knowledge that contains strong ethical guidance, we present the story of the Gifts of the Seven Grandfathers.

- Contemporary bioethics recognizes the importance of the culture in shaping ethical issues, yet in practice, a process for ethical analysis and decision making is rarely adjusted to the culture and ethnicity of involved parties.
- Further engagement with a variety of indigenous moral teachings and traditions could improve health care involving Aboriginal patients and communities, and enrich the discipline of bioethics.

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**[\(Kowal, Greenwood & McWhirter 2015\)](#)**

This article presents a review of the role of blood in Australian Aboriginal cultures. It discusses the range of meanings and uses of blood in traditional culture, including their use in ceremonies, healing, and sorcery.

- For Aboriginal Australians, blood has held—and continues to hold—diverse meanings, the significance of which varies across space and time.
- This review provides a starting point for researchers to have productive conversations with communities, illustrating the utility of drawing on anthropological literature to address bioethical questions.
- The findings provide an empirical basis for researchers and bioethicists to develop culturally grounded strategies to boost the participation of Aboriginal Australians in biomedical research.
- Further exploration in community engagement and for further research into contemporary understandings of blood to better inform current practice, to augment past anthropological evidence, and to complement the emerging literature from indigenous populations elsewhere

**[\(Miller et al 2015\)](#)**

This article describes the use and effectiveness of the participatory action research (PAR) framework to better understand community members' perceptions and risks of pandemic influenza.

- Findings included the importance of working in a multidisciplinary team with Aboriginal and Torres Strait Islander researchers; the complexities and importance of obtaining multi-site human research ethics approval processes; the importance and value of building the research capacity of both experienced and novice researchers in PAR; the need to use localised sampling protocols; and the process of undertaking a collective research process and enacting action research and feedback.
- The participatory approach used in this study has the potential to be applied to vulnerable populations in other countries.

**[\(Rotimi & Marshall 2010\)](#)**

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This paper uses national and international projects to illustrate the growing complexities of scientific and ethical issues in genomics and their implications for informed consent.

- Social and ethical issues associated with the process of informed consent for genomic research are challenging for research participants, investigators and policy makers.
- Policy and guidelines need to be revised quickly in response to the continually evolving enterprise of genomic research as new knowledge is generated and technologies advance
- Working with indigenous groups concerns the need, in some cases, for community approval or 'consent', depending on local governance and political authority. Examples of policies for ethical conduct in research that demonstrate respect for the concerns and rights of indigenous

**(Walajahi, Wilson & Hull 2019)**

This study aims to fill the gaps in empirical work on this issue and characterize how genetic ancestry companies.

- Direct-to-consumer (DTC) genetic ancestry companies have rapidly increased in popularity, with top testing services maintaining genetic databases of several million consumers. articulate indigenous identity through their marketing strategies.
- Many companies claim to be able to determine Native American heritage, claims that are not supported by the state of the science and may have significant cultural and political consequences for US tribal communities.
- Genetic ancestry company claims regarding genetic ancestry, personal identity, and cultural membership are problematic and challenge how US tribal nations currently identify and create potential obstacles for tribal sovereignty.

## **Indigenous public health / global ethics**

**(Matthews 2019)**

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This article describes the problem of Indigenous ethnocide and explores its ethical implications. It highlights the implications of colonialism and ethnocide (or cultural genocide) for ethical decision-making. It problematises the role of law in health ethics.

**(Mohindra 2015)**

This paper describes the current evidence base on indigenous health in low- and middle-income countries (LMICs), and proposes practical strategies for undertaking future research, and concludes by describing how global health researchers can contribute to improving the health of indigenous populations.

- In low- and middle-income countries (LMICs)—when there are available data—a ‘health divide’ exists between indigenous and non-indigenous populations living in the same society.
- Pursuing research is clouded by the prior negative experiences that indigenous populations have had with researchers.

The paper outlines the following proposals for future research:

- Shifting to an indigenous lens – calling for the use of indigenous theoretical frameworks, [perspectives and ‘ways of knowing’. An indigenous lens is a progressive indigenous viewpoint that recognises historical and cultural oppression.
- Understanding the local with indigenous populations – research should promote self-determination, mobilisation and transformation.
- Getting a grasp on the global forces that influence indigenous health – the health divide persists within and across countries, suggesting a need for scrutiny of global-level forces.

## **Indigenous clinical ethics**

**(James, Cameron & Usherwood 2009)**

This study at an urban Aboriginal medical service aimed to explore how confidentiality is understood in a community controlled Aboriginal health service, with a view to informing the training of general practitioners.

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- The medical ethic of confidentiality is usually taught from a western ethical perspective based on the Hippocratic oath.
- Perspectives on confidentiality in this community included issues of social justice, the importance of public demonstrations of confidentiality, and the challenge of protecting all relationships when staff have multiple roles.
- Incorporation of community perspectives into the teaching of confidentiality may help doctors to understand the responsibilities of practising confidentiality in certain communities.

**(McWhirter, Nicol & Savulescu 2015)**

This paper explores how the potential benefits of genomics can be more equitably distributed with minimised potential harm.

- The perceived difficulties associated with genetic research involving Aboriginal and Torres Strait Islander people mean that they have largely been excluded as research participants. This limits the applicability of research findings for Aboriginal and Torres Strait Islander patients.
- Emergent use of genomic technologies and personalised medicine therefore risk contributing to an increase in existing health disparities unless urgent action is taken.
- The authors recommend the following five actions:
  1. Ensure diversity of participants by implementing appropriate protocols at the study design stage;
  2. Target diseases that disproportionately affect disadvantaged groups;
  3. Prioritise capacity building to promote Indigenous leadership across research professions;
  4. Develop resources for consenting patients or participants from different cultural and linguistic backgrounds; and
  5. Integrate awareness of issues relating to Indigenous people into the governance structures, formal reviews, data collection protocols and analytical pipelines of health services and research projects.

**(Harding 2013)**

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This paper argues that the globalisation of nursing and the internationalisation of nursing education have led to Western values being embedded into nursing curricula in nations where the cultural values and beliefs may be based in quite different philosophies.

- There is a need for critical examination of assumptions underpinning ethics education in nursing and proposes that the principles of cultural safety need to be incorporated into ethics education to create a culturally safe ethic for both nurses and patients in a multicultural healthcare environment.

## **Bibliography**

Anderson, K., & Cidro, J. (2019). Decades of Doing: Indigenous Women Academics Reflect on the Practices of Community-Based Health Research. *Journal of Empirical Research on Human Research Ethics*, 1556264619835707.

Bainbridge, R., Tsey, K., Brown, C., McCalman, J., Cadet-James, Y., Margolis, S., & Ypinazar, V. (2013). Coming to an ethics of research practice in a remote Aboriginal Australian community. *Contemporary nurse*, 46(1), 18-27.

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- Blanchard, J. W., Tallbull, G., Wolpert, C., Powell, J., Foster, M. W., & Royal, C. (2017). Barriers and Strategies Related to Qualitative Research on Genetic Ancestry Testing in Indigenous Communities. *Journal of Empirical Research on Human Research Ethics*, 12(3), 169-179.
- Bond, C., Foley, W., & Askew, D. (2016). "It puts a human face on the researched"—A qualitative evaluation of an Indigenous health research governance model. *Australian and New Zealand Journal of Public Health*, 40(S1), S89-S95.
- Camargo, D. R. B. (2013). Solidarity, international human rights declarations and bioethics: the case of the right to health of aboriginal Colombian peoples. *Acta Bioethica*, 19(1), 9-19.
- Chennells, R. S. (2014). Equitable access to human biological resources in developing countries: Benefit Sharing Without Undue Inducement (Doctoral dissertation, University of Central Lancashire).
- Crowden, A. (2016). Indigenous health care, bioethics and the influence of place. *The American Journal of Bioethics*, 16(5), 56-58.
- de la Barra, S. L., Redman, S., & Eades, S. (2009). Health research policy: a case study of policy change in Aboriginal and Torres Strait Islander health research. *Australia and New Zealand health policy*, 6(1), 2.
- Du Plessis, R., & Fairbairn-Dunlop, P. (2009). The ethics of knowledge production—Pacific challenges. *International Social Science Journal*, 60(195), 109-114.
- Dyall, L., Skipper, T. K., Kēpa, M., Hayman, K., & Kerse, N. (2013). Navigation: Process of building relationships with kaumātua (Māori leaders). *The New Zealand Medical Journal*, 126(1368), 2010-2019.
- Evans, D. (2012). Whakapapa, genealogy and genetics. *Bioethics*, 26(4), 182-190.
- Fitzgerald, R. P., Legge, M., Rewi, P., & Robinson, E. J. (2019). Excluding indigenous bioethical concerns when regulating frozen embryo storage: An Aotearoa New Zealand case study. *Reproductive biomedicine & society online*, 8, 10-22.
- Fitzpatrick, E. F., Martiniuk, A. L., D'Antoine, H., Oscar, J., Carter, M., & Elliott, E. J. (2016). Seeking consent for research with indigenous communities: a systematic.
- Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). Co-design and implementation research: challenges and solutions for ethics committees. *BMC medical ethics*, 16(1), 78.
- Guillemin, M., Barnard, E., Allen, A., Stewart, P., Walker, H., Rosenthal, D., & Gillam, L. (2018). Do research participants trust researchers or their institution?. *Journal of Empirical Research on Human Research Ethics*, 13(3), 285-294.

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Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H., & Rosenthal, D. (2016). "We're checking them out": Indigenous and non-Indigenous research participants' accounts of deciding to be involved in research. *International journal for equity in health*, 15(1), 8.

Harding, T. (2013). Cultural safety: a vital element for nursing ethics. *Nursing Praxis in New Zealand*, 29(1).

Hing, N., Breen, H., & Gordon, A. (2010). Respecting cultural values: conducting a gambling survey in an Australian Indigenous community. *Australian and New Zealand journal of public health*, 34(6), 547-553.

Hudson, M. L., & Russell, K. (2009). The Treaty of Waitangi and research ethics in Aotearoa. *Journal of Bioethical Inquiry*, 6(1), 61-68.

Ilkilic, I., & Paul, N. W. (2009). Ethical aspects of genome diversity research: genome research into cultural diversity or cultural diversity in genome research?. *Medicine, Health Care and Philosophy*, 12(1), 25-34.

James, J., Cameron, S., & Usherwood, T. (2009). The practice of confidentiality in an Aboriginal medical service: What do GPs need to know?. *Australian family physician*, 38(10), 837.

Jamieson, L. M., Paradies, Y. C., Eades, S., Chong, A., Maple-Brown, L. J., Morris, P. S., ... & Brown, A. (2012). Ten principles relevant to health research among Indigenous Australian populations. *Medical Journal of Australia*, 197(1), 16-18.

Kendall, E., Sunderland, N., Barnett, L., Nalder, G., & Matthews, C. (2011). Beyond the rhetoric of participatory research in indigenous communities: Advances in Australia over the last decade. *Qualitative Health Research*, 21(12), 1719-1728.

Kotalik, J., & Martin, G. (2016). Aboriginal health care and bioethics: A reflection on the teaching of the Seven Grandfathers. *The American Journal of Bioethics*, 16(5), 38-43.

Kowal, E., Greenwood, A., & McWhirter, R. E. (2015). All in the blood: A review of Aboriginal Australians' cultural beliefs about blood and implications for biospecimen research. *Journal of Empirical Research on Human Research Ethics*, 10(4), 347-359.

Matthews, R. (2019). Health ethics and Indigenous ethnocide. *Bioethics*.

McWhirter, R., Nicol, D., & Savulescu, J. (2015). Genomics in research and health care with Aboriginal and Torres Strait Islander peoples. *Monash bioethics review*, 33(2-3), 203-209.

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McWhirter, R. E., & Eckstein, L. (2018). Moving forward on consent practices in Australia. *Journal of bioethical inquiry*, 15(2), 243-257.

Miller, A., Massey, P. D., Judd, J., Kelly, J., Durrheim, D. N., Clough, A. R., ... & Siggers, S. (2015). Using a participatory action research framework to listen to Aboriginal and Torres Strait Islander people in Australia about pandemic influenza. *Rural and Remote Health*, 15, 1-10.

Moodie, S. (2010). Power, rights, respect and data ownership in academic research with indigenous peoples. *Environmental research*, 110(8), 818.

Pyett, P., Waples-Crowe, P., & Van Der Sterren, A. (2009). Engaging with Aboriginal communities in an urban context: some practical suggestions for public health researchers. *Australian and New Zealand Journal of Public Health*, 33(1), 51-54.

Rotimi, C. N., & Marshall, P. A. (2010). Tailoring the process of informed consent in genetic and genomic research. *Genome Medicine*, 2(3), 20.

Tolich, M. (2002). Pakeha" paralysis": Cultural safety for those researching the general population of Aotearoa. *Social Policy Journal of New Zealand*, 164-178.

Tupara, H. (2012). Ethics and health research: Decision making in Aotearoa New Zealand. *AJOB Primary Research*, 3(4), 40-52.

Walajahi, H., Wilson, D. R., & Hull, S. C. (2019). Constructing identities: the implications of DTC ancestry testing for tribal communities. *Genetics in Medicine*, 1.