Ethics of medical research in Aboriginal and Torres Strait Islander populations

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Abstract. Conducting ethical health research in Aboriginal and Torres Strait Islander populations requires an understanding of their unique cultural values and the historical context. The assimilation of Indigenous people with the broader community through colonial policies such as the dispossession of land and forcible removal of children from their families in the Stolen Generation, deprived entire communities of their liberty. Poorly designed research protocols can perpetuate discriminatory values, reinforce negative stereotypes and stigmas and lead to further mistrust between the Indigenous community and healthcare professionals. The manuscript offers a fresh perspective and an up-to-date literature review on the ethical implications of conducting health research in Aboriginal and Torres Strait Islander communities.

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How does the quest for evidence-based medicine paradoxically undermine the autonomy and wellbeing of Indigenous people?

Conducting ethical health research in Aboriginal and Torres Strait Islander populations requires an understanding of their unique cultural values and the historical context. As described by Moran (2005), the assimilation of Indigenous people with the broader community through colonial policies such as the dispossession of land and forcible removal of children from their families in the Stolen Generation, deprived entire communities of their liberty (Moran 2005). Although the Australian Government issued a formal apology to Aboriginal and Torres Strait Islander people for this targeted discrimination, contemporary racism continues to permeate throughout society. Indigenous people experience significantly lower socioeconomic status, lower health literacy, shorter life expectancies, higher rates of child and maternal mortality and higher unemployment rates (Vos et al. 2009). Poorly designed research protocols can perpetuate discriminatory values, reinforce negative stereotypes and stigmas and lead to further mistrust between the Indigenous community and healthcare professionals (Cochran et al. 2008).

As discussed by Humphrey (2001), the historical imbalance in power dynamics between colonialisists and Aboriginal and Torres Strait Islander people increases the importance of conducting health research in accordance with local Indigenous values and culture rather than subscribing to the aims and values of the respective researchers or research institutions (Humphrey 2001). Widespread distrust of scientists and medical professionals among Aboriginal and Torres Strait Islander people may make it difficult to develop equal and open research collaborations with Indigenous communities (Kingsley et al. 2010). Despite these challenges, research initiatives offer an opportunity to facilitate partnerships between Indigenous people and the scientific community. Meadows et al. (2003) gathered qualitative health data on Aboriginal women living on and off reserves, demonstrating the opportunities for fostering partnerships with Indigenous populations through their analysis (Meadows et al. 2003). In a study conducted by Aboriginal and non-Aboriginal health researchers, Kingsley et al. (2010) conducted a qualitative analysis of the importance of ancestral connections via semi-structured interviews and focus groups, successfully outlining the methodologies of an effective collaborative approach to Indigenous health research (Kingsley et al. 2010).

Autonomy and informed consent

The principle of autonomy and need for informed consent is core to the ethical conduct of health research, and has particular nuances in Indigenous populations (Glass and Kaufert 2007). Gillon (1985) defined autonomy as a combination of liberty and agency, with individuals having the capacity to think, rationalise and make their own decisions without coercion from outside influences. It is important to first recognise the power relations between health researchers and research participants, the latter typically being in a more vulnerable position due to a relative lack of knowledge regarding the risks and benefits of the studies to which they are consenting.
(Zion et al. 2000). This is particularly relevant in Indigenous communities, where the power imbalance and knowledge differential between Western researchers or research institutions and Indigenous participants may entrench the sense of mistrust and vulnerability that has persisted from Australia’s colonial history (Sherwood 2010). Ensuring informed consent is thus critical to ethical health research (Weijer and Emanuel 2000). While autonomy and informed consent are also pertinent issues in research conducted in other minority groups such as immigrants and refugees, these populations are not First Nations groups and are not affected by the same historical context; thus, different mechanisms and voices need to be used to advocate for groups other than for the Indigenous population.

In Aboriginal and Torres Strait Islander populations, different cultural and spiritual values may require the consent process to be adapted in order to ensure research participants have gained a comprehensive understanding of the risks, benefits and aims of studies before their involvement. Russell et al. (2005) undertook a pilot cross-sectional survey of 20 Aboriginal and 20 non-Aboriginal women in Alice Springs with information about a vaccine trial presented to Aboriginal participants by an Aboriginal researcher using verbal, visual and written information that was specifically designed to be culturally appropriate. While questionnaires of participant recall demonstrated no significant differences in level of understanding of the risks and benefits of the trial between the groups, it did identify comparative difficulty with particular concepts in the Aboriginal group and preferred delivery modes of visual flipcharts and presentation by Aboriginal healthcare workers (Russell et al. 2005). This suggests that tailoring the informed consent process to Indigenous populations remains beneficial.

Governance and evidence-based medicine in Indigenous health research

The question of governance in Indigenous health research has significant ethical and legal implications. Peak Indigenous health bodies such as the National Aboriginal Community Controlled Health Organisation, Australian Institute of Aboriginal and Torres Strait Islander Studies and the Aboriginal Health and Medical Research Council of New South Wales have advocated for local Indigenous communities to decide the ethical implications of Indigenous health research rather than other non-Indigenous organisations or ethics committees (Couzos et al. 2005). Such an approach is in keeping with the principle of autonomy by empowering Indigenous people to be in control of health data and facilitating research projects related to their own communities (Maddison 2009). The emphasis on empowering Indigenous people is also in alignment with community-based ethics, recognising the needs of local Indigenous communities to maintain autonomy.

Conversely, lack of regulatory oversight in a shift away from evidence-based approaches governed by national, state or local ethics committees may contribute to poor research methodology and inadequately constructed projects. Currently, research projects and clinical trials in Indigenous health are legally required to submit to the same processes for ethical approval as research in non-Indigenous contexts; however, they are subject to additional rigorous standards for research in Aboriginal and Torres Strait Islander populations (Humphrey 2001; National Health and Medical Research Council (NHMRC) 2017). While the guidelines are intended to safeguard Indigenous people from high-risk and culturally inappropriate health research, they may act as a barrier to facilitating and advancing medical research in Indigenous communities.

Importantly, appropriate governance of research processes is key to ensuring transparency (Goodyear et al. 2007). Standard methods of assessing the validity of public health research involve health metrics and evidence-based principles. Evidence-based medicine is an approach to clinical practice in which decisions are made based upon evidence from well-designed, high-quality clinical trials (Rosenberg and Donald 1995). This type of data is rarely able to accurately quantify benefits such as enhanced spirituality, kinship and experiential learning, which are core to Indigenous health and wellbeing (Guerin et al. 2011). The question then arises as to how we evaluate the efficacy of health interventions in Indigenous communities. Would it be unjust to hold research conducted in Aboriginal and Torres Strait Islander populations to different standards than the rest of the population? Developing different standards for validating research protocols in Indigenous contexts may raise issues of inequity if other vulnerable populations do not also receive specific attention. Furthermore, undertaking research is an expensive process, for which funding from government sources is typically required. Many organisations require demonstrated benefits of potential projects and quantifiable data according to evidence-based principles in order to secure research funding (Hales 2006). This may perpetuate a culture of financial dependency upon Western funding sources in cases where Indigenous researchers or communities are initiating projects.

Community-based ethical perspectives

From a community-based ethical perspective, research collaborations should be tailored to maximise aspects of cultural security and empower Indigenous people (Jamieson et al. 2012). This contrasts with the traditional approach to research, which is focussed on biomedical models of health care. The community-based approach to conducting ethical health research is reflected in various policies and guidelines. National Health and Medical Research Council (NHMRC) guidelines...
for Aboriginal and Torres Strait Islander populations have been established to ensure congruency with community values, focusing on spirituality, integrity, reciprocity, respect, equality, survival protection and responsibility (Maddocks 1992). For example, the NHMRC’s ‘Keeping Research on Track’ is designed specifically for Aboriginal and Torres Strait Islander communities that are considering conducting health research, and thus provides a method for enabling the community to be meaningfully embedded in all aspects of the research process (NHMRC 2018).

Some researchers suggest that research endeavours undertaken in Aboriginal and Torres Strait Islander populations should either be Indigenous-led or involve significant collaboration with Indigenous leaders to ensure they abide by the ethical values of the local community. Couzos et al. (2005) described the methodology of a landmark Aboriginal community-controlled randomised controlled clinical trial of treatments for chronic suppurative otitis media, demonstrating that participatory Indigenous-led research can be of a high scientific standard without compromising the cultural values and integrity of the Aboriginal and Torres Strait Islander communities being studied. Rigney (2003) refers to increasing numbers of Indigenous scholars as the rise of ‘contemporary Australian Indigenous intellectualism’ and emphasises the need for such Aboriginal and Torres Strait Islander people to play key roles in self-determination and decision-making regarding the ownership of knowledge in Indigenous research.

In the international context, in the first reported study by an Indigenous person with Indigenous perspectives utilising methodologies established by Indigenous people in Indigenous contexts, Bull (2010) reported a qualitative study of the perspectives of local Innu, Inuit and Inuit-Metis people in Canada on the role of authentic research collaborations and the optimal approaches to achieving authenticity in research with Aboriginal populations. The study supported holistic methodologies and Indigenous leadership in developing ethical guidelines and protocols for research in Indigenous communities (Bull 2010). In New Zealand, Smith (2013) has been at the forefront of developing Indigenous research methodologies, and there has been an increasing shift towards utilising Kaupapa Maori research frameworks in Indigenous health research. Specifically, the Kaupapa Maori framework provides guidance on researching in Kaupapa Maori contexts via eight ethical principles, which advocate for building healthy relationships with research participants based upon mutual respect, trust and maintaining dignity.

Human rights ethical perspectives

From a human rights perspective, Aboriginal and Torres Strait Islander people are a vulnerable population warranting additional resources and government support (Mann 1997). This perspective could be used to advocate for increased funding for health research targeted at improving health outcomes specifically in Indigenous communities. Conversely, from a utilitarian view, health resources should be devoted to research that will have the greatest effect for the largest number of people (West 2004). Given that Aboriginal and Torres Strait Islander people comprise a minority of the Australian population, this could be perceived as an irresponsible distribution of health resources. The view of justice by Rawls (2009) considers all individuals as equally deserving, basing distribution of resources on a needs basis. Perspectives of distributive and comparative justice reflect the limited resources of the health system, and could be used to support additional funding for Indigenous health research given the significantly lower health status of Aboriginal and Torres Strait Islander populations compared with the broader community (Crough 2002).

Conclusions

Various stakeholders, including Indigenous people, economists, public health experts and politicians play an important role in ensuring the ethical conduct of Indigenous health research. Facilitating equal relationships with research participants that promote their dignity, respect and autonomy is critical to conducting ethical health research in Indigenous communities. There are various ways in which research institutions can work towards practically achieving this, including conducting culturally appropriate education and training for research staff, abiding by national guidelines on the ethical conduct of Indigenous health research, creating culturally appropriate protocols to guide institutional research practices where necessary, and arguably most importantly, by conducting health research in conjunction with and ideally led by Indigenous leaders and scholars. Ultimately, respect for the cultural values and autonomy of Aboriginal and Torres Strait Islander communities needs to occur in conjunction with the pursuit of advancing high-quality scientific knowledge in Indigenous health research.

Conflicts of interest

The author declares no conflicts of interest.

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Research ethics in Indigenous communities


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