

Research ethics, informed consent and the disempowerment of First Nation peoples

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Abstract

Recently, Indigenous commentators have begun to analyse the way in which institutional Research Ethics Boards (REBs) engage with Indigenous researchers and participants, respond to Indigenous peoples' concerns with academic research activities, and scrutinise the ethics proposals of Indigenous scholars. Of particular concern for Indigenous commentators is that the work of REBs often results in the marginalisation of Indigenous approaches to knowledge construction and dissemination, especially in relation to the vexed issue of informed consent. Based on analysis of the results of research with Indigenous researchers and research participants, this paper argues that institutionalised REBs' preference for 'universal' and 'individualised' approaches for determining ethical research conduct marginalises Indigenous approaches to ethical research conduct. The paper concludes by calling for a decolonisation of REB processes through recognition of the validity of communal processes for attaining the informed consent of Indigenous research participants.

Keywords

First Nations, research ethics boards, informed consent, decolonisation

Introduction

Recently, Indigenous commentators have begun to analyse the way in which institutional Research Ethics Boards¹ (REBs) engage with Indigenous researchers and participants, respond to Indigenous peoples' concerns with academic research

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activities, and scrutinise the ethics proposals of Indigenous scholars. Of particular concern for Indigenous commentators is that the work of REBs often results in the marginalisation of Indigenous approaches to knowledge construction and dissemination (Piquemal, 2000; Tauri, 2014). Informed by research with Indigenous researchers and research participants, this paper critically analyses the processes employed by REBs to assess the ethical validity of Indigenous-led research. The paper begins with an overview of the author's experience of the REB process through his attempt to obtain ethics clearance for his doctoral research on Indigenous justice. This experience led to research with Indigenous researchers and research participants on their experiences and views of REB-related processes. Based on analysis of the results of this research and engagement with the extant literature, it will be argued that institutionalised REBs' preference for 'universal' and 'individualised' approaches to judging the merit of ethics applications often results in the marginalisation of Indigenous approaches to knowledge construction, particularly in relation to the vexed issue of informed consent.

The author's experience of the research ethics board process

In November 2009, the author submitted the requisite research ethics application for his proposed doctoral research to the REB at the institution where he was enrolled for his doctoral studies. In preparation for submission, the author had read the background documents provided by the institution's REB on the application process. Afterwards, the author carried out a thorough community engagement process to ensure the development of protocols deemed to be 'ethical' and 'tika' (the 'right way') by his Māori and Canadian Indigenous research participants. The engagement process took place over a 16 month period via phone, email and two visits to the region of Canada where part of the research project was to take place. For the New Zealand component of the project, the author built on extensive research and engagement with Māori communities over the previous 15 years working in the academy, by seeking advice on appropriate research ethics from three prominent Māori researchers.

In contrast to Indigenous research protocols (AIATSIS, 2012; Mi'kmaw Ethics Watch, 2000), the REB concerned employed a standardised, formulaic process for assessing the ethicality of a researcher and their project. It was evident from even a cursory glance at the relevant background documents issued by the REB, supplemented by communications between the author, his supervisor and members of the committee, that the focus of their ethics deliberations were less concerned with protecting potentially vulnerable research subjects, and instead on managing the 'risk' this, or any other project, provides to the reputation of the institute it represents. The REB in question had already rejected a previous version of the proposal

submitted in August 2009, in which the author had critiqued the REB's privileging of individual-focused protocols for obtaining informed consent from research participants. Subsequently, the author carried out further discussions with advisors and research participants before resubmitting the application in November of that year. The revised submission offered a dual-consent process designed to enable the researcher to avoid behaving 'unethically', as that term was interpreted by Indigenous research participants in particular. The following extract from the ethics application outlines the compromise offered by the author and his supervisor to the REB concerned:

All individual participants in the research will be informed of the purpose of the research either verbally, or through receipt of a written copy of the PIS [project information sheet], which will be offered to them prior to the primary researcher reading out the document.... The process required by... University will be explained to all participants, who will be informed that the requirements of the institution privileges informed consent evidenced through written, signed documents... research participants will be provided an opportunity at this stage of the process to respond to the request for written confirmation. If they consent to signing the informed consent forms, then these will be distributed to them for their analysis and signing. If they do not consent to the [REB] process then the primary researcher will acknowledge this fact in their research notes from that particular session.

This extract demonstrates that collaboration with Indigenous participants was central to the development of the researcher's ethics protocols. For example, the strategy of identifying one person to confirm group consent to participation in the research, if the REB needed to seek confirmation, was suggested by two Canadian advisors after consultation with members of Elders' Councils. How this selection would be made was to be determined by the members of the group, or determined by Elders prior to engagement. Given its stated preference for individual informed consent processes, the REB's rejection of the compromise was not unexpected, and for months thereafter it continued to try to force its individual-focused informed consent process upon the researcher and his Indigenous research participants. Many more months were lost attempting to alter the approach taken by the REB, before his supervisor finally received formal sign-off for the research to proceed in April 2010.

The research context

In response to a contested decision made by an REB in relation to his research ethics submission for his PhD, the author included questions in his study related to the development of research ethics protocols for research involving Indigenous peoples. The questions were designed to enable the researcher to 'enquire of First Nation academics, researchers and service providers, their thoughts on the issues that arose from the debate between the author and the REB'. Of particular interest

were their views on the ethics protocol developed by the author and key Indigenous advisors (in both New Zealand and Canada), and the informed consent protocol demanded by the REB. The research involved individual interviews and focus groups with Indigenous participants in both jurisdictions. In all, 12 individual interviews and four focus groups (involving 24 participants) were completed between November 2010 and October 2013. Questions were posed to participants regarding the ethics review process, including what they thought of the REB's finding that the ethics protocols they had assisted in developing for the project violated the principles the REB considered essential for carrying out ethical research with Indigenous peoples. The views and experiences of research participants form the basis for the analysis provided in the second part of this paper.

In order to ensure anonymity, participants' comments are coded depending on the method used to engage with them and their geographical location. For example, focus groups are coded as CFG1 or CFG2 (Canadian focus group 1 and/or 2), while focus group participants are given a random number, an identifier known only to the researcher and the participant (for example, CFG14 for a Canadian participant, or MFG145 for a Maori participant). Individual interviewees were randomly allocated a code based on the jurisdiction the interview took place in, plus ethnicity (for example, a Māori interviewee might be delegated the 'code' MII3 – Māori, individual interview 3).

In order to contextualise our analysis of the views and experiences of research participants of the ethics board processes, however, it is essential that we ground it within the developing Indigenous critique of academic, institutionalised research ethics processes.

Indigenous critique of Research Ethics Boards

A common theme in recent Indigenous critique of academic research has been the role of REBs in the colonising project of Western research, which contributes to the continued marginalisation of Indigenous peoples (Absolon, 2008; Glass and Kaufert, 2007; Smith, 1999; Wax, 1991). Indigenous critique of REBs covers a broad range of issues, including (but not exclusively):

- **Universalism:** characterised by a preference of REBs for deciding the ethicality of research projects utilising processes derived from Eurocentric notions of 'right (research) conduct', and essentialist notions of what does/does not constitute ethical research conduct (Battiste and Youngblood Henderson, 2000; Ermine, 2000; Wilson, 2004).
- **Lack of expertise:** many REBs demonstrably lack adequate disciplinary, epistemological, methodological expertise in Indigenous research/issues, and knowledge of the socio-political context of Indigenous peoples, and yet

their decisions greatly impact Indigenous scholars and their research participants (Smith, 1997; Tauri, 2014).

- **Formulism:** an over-reliance on standardised, ‘tick-the-box’ analyses that mask the complexity of the social context within which research takes place and confines Indigenous philosophies and practices to a narrow sub-set of standardised, heavily proscribed protocols (Hammersley, 2006).
- **Individualism:** privileging autonomous research participants, which leads to informed consent processes that problematise collective decision-making and informed consent protocols (Ellis and Earley, 2006; Glass and Kaufert, 2007; Piquemal, 2000; Wax, 1991).

For the sake of brevity this paper will focus on the impact that the concepts and related practices of individualism and universalism are having on Indigenous researchers and Indigenous research participants. More specifically, we are particularly interested in how these concepts impact Indigenous research practice ‘in the real world’ including the vexed, complex issue of informed consent.

Universalism, individualism and institutional empowerment

Indigenous scholars and Indigenous research participants have identified universalism as an especially problematic issue arising from their engagement with REBs (Menzies, 2004; Tauri, 2014). In the REB context, the operationalisation of universalism is often based on the ideological belief that, with a little tweaking to make them situationally and culturally responsive, ‘Western’ social research methods, methodologies and ethics protocols can be made applicable to any and all social and cultural contexts (Youngblood Henderson, 1997). The ideological underpinnings of universalism are highlighted by Battiste and Youngblood Henderson who argue that ‘[i]t suggests one main stream and diversity as a mere tributary.... [t]ogether mainstreaming and universality create cognitive imperialism, which establishes a dominant group’s knowledge, experience, culture, and language as the universal norm’ (Battiste and Youngblood Henderson, 2000: 134). Similarly, Minnich describes universalism as a process through which ‘one category/kind comes to function almost as it were the only kind, because it occupies the defining centre of power... casting all others outside the circle of the “real”’ (Minnich, 1990: 53).

Participants in the author’s research were also critical of the universalising nature of the processes employed by New Zealand REBs that they had experience of, as the following comments demonstrate:

Even the HRC [Health Research Council], a key research body aligned with government, recognises the need to engage – engage not consult, with Maori participants for research. They, at least on paper, recognise that difference actually means something; it means that different

people, communities, like Maori, have valid ways of doing research that organisations need to respond to. This lot [the REB to whom the researcher reported] seem to think that following a script is the best way.... Well, it is probably the easy way for them (CFG27).

And

I don't understand the attitude of the ethics committee; according to the protocols on its website, it requires that you consult with us on the appropriate way of doing your research. And yet, despite working with us to develop an agreed way [of doing the research], it says you have to follow a script. But that also means that the way we prefer is wrong! (CFG13)

The views and experiences of participants reveal that the universalism inherent to institutionalised ethics process is based on a fundamental myth, namely that 'white knowledge' is *the* only knowledge worthy of consideration. Its dominance of the academic research ethics process, especially informed consent is, as Best (cited in Ermine, 2000) describes it '...a dictatorship of the fragment' (Ermine, 2000: 62) that is based on the culturalist presumption that ethical research is best achieved through Eurocentric, formulaic processes. Halloway et al. argue that the dominance of universalism as a guiding principle of contemporary REB practice is due in part to a 'view of ethics based upon the mistaken assumption that morality can be bracketed off from other aspects of human life (such as emotions) and reduced to generalisable rules of conduct' (Halloway et al., 2005: 148). In light of this, let us now turn to the limitations and impact of universalism, in particular how it manifests in the practice of gaining informed consent in the research context.

Individualism, informed consent and indigenous disempowerment

The standard consent process, common amongst New Zealand REBs and across Western jurisdictions, is for participants to sign a printed form to demonstrate that they have been informed of the purpose of the research and their role in it. The preference for individual, signed consent is a reflection of the evolution of research ethics from a bio-medical model (Fadan and Beauchamp, 1986). While REB protocols often stipulate that other 'indicators' of consent are legitimate, such as the Medical Research Council of Canada, National Sciences and Engineering Council of Canada and Social Sciences and Humanities Research Council of Canada (2003) written validation of the use of verbal consent in particular circumstances, the experience of the author and other Indigenous researchers is that this is rarely accepted, and most definitely discouraged.

Fine et al. discuss the ways in which 'the consent form sits at the contradictory base of the institutionalisation of research' (Fine et al., 2000: 113–114). It is a 'crude tool – a conscience – to remind us of our accountability and position [in

effects].... Stripping us of our illusions of friendship and reciprocity [with our research participants]’. Or, as Smith expressed the underlying issues for Indigenous scholars:

One concern of Indigenous communities about the informed consent principle is about the bleeding of knowledge away from collective protection through individual participation in research, with knowledge moving to scientists and organisations in the world at large. *This process weakens Indigenous collectively shared knowledge* (Smith, 2005: 99, emphasis added).

The risks to Indigenous researchers of adhering to REBs’ universalising, individual-focused ethics protocols was a key theme of many research participants, one of whom argued that:

What is ethical about putting a piece of paper in my face? In the face of an elder who has invited you to speak to him about whatever? To the community? He has given consent and not likely on his own. If I tell you yes, then it is yes. It means I know you, I trust you; give me that paper and I’ll tell you no because you don’t understand. Why would I trust you with something else, something more important? (CFG16).

while another stated that:

...the ethics board, in rejecting our way of research, of giving consent or engaging, is practicing old order research, where white academics know best for Indians and people of colour how to do ethical research (CFG17).

And, relatedly, as an Elder associated with a Maori research organisation stated:

What’s the point of that piece of paper [on being shown the individual informed consent sheet demanded by the REB]? I don’t own the knowledge, nor does he [another participant sitting to his right]. You are asking for a community’s process of gathering knowledge, in this case, a research organisation... we collectively create that information (MFG11).

Participants’ responses to the REB process described previously, especially with regards informed consent, lends weight to Lykes’ contention that:

The informed consent form which I introduced as a mechanism for ‘protecting the subjects’ of the research project, was instead a barrier and forced me to confront the chasm between the needs and demands of research conducted within the boundaries of the university and the systems of trust and mistrust and of sharing and withholding that were already part of this collaboration (Lykes, 1989: 178).

According to Juritzen et al., ‘the rule-bound obtainment of consent involves a risk of making the process routinised and mechanical’ (Juritzen et al., 2011: 644). Thus rendered, the process of obtaining informed becomes one that is exemplified by an overbearing focus on the *individual research subject*, which in turn often results in

'inadequate attention to the needs of communities' and to the complexities of knowledge construction and dissemination (Wilkinson, 2004: 6). The National Health and Medical Research Council of Australia highlighted this point when it argued that:

In many non-Western societies, and in some communities within Western societies also, the rights and autonomy of the individual are complicated and constrained, to a greater or lesser extent, by those of related individuals and groups with specific authority over that individual. Thus researchers need to be aware of individuals' rights within specific local and national socio-cultural contexts.... A constant awareness of this variety will be necessary to ensure that the application of the ethical values by which research is assessed continues to respect that variety (National Health and Medical Research Council, 1999: 5).

One of the key failings of REBs with respect to Indigenous research is their reliance on the principle of individualism as a governing motif within their adjudication process (see Tauri, 2014). This principle comes through in the privilege shown to the concepts of individual negotiation, informed consent and 'risk', to the extent that few REBs 'ask about community or societal level risks and benefits' (Reid and Brief, 2009: 83). This point leads us to the crux of issue upon which this paper is based, best summarised by Butz, who writes that:

Conventional informed consent guidelines as exemplified by the [Canadian] Tri-Council Policy Statement presuppose an individuated liberal humanist research subject that is incommensurate with the subjectivities of our actual research participants as they experience them, and as the theoretical perspectives upon which much qualitative research is based conceptualise them (Butz, 2008: 241).

Numerous texts developed by Indigenous researchers identify the types of informed consent processes deemed legitimate by Indigenous peoples. For example, Piquemal carried out ethnographic research with Canadian First Nations on the topic of developing codes of research conduct; and '[o]ne recurrent theme in what I heard is that free and informed consent is an ongoing process based on notions of authority and collectiveness and on a principle of confirmation' (Piquemal, 2000: 49). In contrast:

...codes of research ethics designed by centralised science councils, emphasising review processes exclusively controlled by university – or hospital-based research ethics boards were not designed to accommodate the alternative models and power relationships inherent in participatory frameworks favoured by Aboriginal communities (Glass and Kaufert, 2007: 29).

The tension between Eurocentric notions of informed consent and Indigenous positions is recognised by Canadian First Nations, as expressed in the draft Canadian Institute of Health Research Guidelines which state that '[r]esearchers should recognise that the principle of individual autonomy may be limited by the

interests of the Aboriginal community as a whole'. But what is an Indigenous researcher and his/her research participants to do when institutional REBs themselves do not adhere to or recognise Indigenous principles of 'right' research conduct, especially when:

As the university's regulating body with the power to approve or deny research endeavors, conformity and adherence to IRB prescribed guidelines is ensured. This conformity creates a set of cultural norms that serves the interests and reflects the values of the IRB and the academy. Cultural norms are thereby nonevents when researchers fail to question the ways that power is diffused through their multiple manifestations, such as in constructing consent forms (Knight et al., 2004: 397).

Lastly, Haggerty outlines the weakness of the REBs' over-reliance on the biomedical approach to informed consent when he states that:

Consent forms can unnecessarily colour interview or ethnographic situations, transforming encounters that are routinely more informal and exploratory into an unnecessarily official and legalistic exchanges. These apprehensions are particularly germane to research on large groups of people (Haggerty, 2004: 404).²

This now brings us to the countervailing (Indigenous) position on informed consent; namely, the need to decolonise institutionalised REB processes.

A rationale for Indigenous, communal informed consent

In rationalising the ethics of community-informed consent, so prevalent in Indigenous contexts, Glass and Kaufert argue that '[g]roup leadership is more likely to know risks/benefits for members of the group as individuals *and* as a community than are people from outside the community' (Glass and Kaufert, 2007: 33, emphasis theirs). Furthermore, Piquemal further underlines the 'ethics' of enabling culturally and socially-specific forms of consent when he describes how:

Three years ago, I was granted both oral and written permission to study narratives, storytelling, and traditional ways of learning as they applied to a specific Native community in Alberta. The elders of the school involved in my research gave me oral approval; the director of the school gave me written consent. Even though the written authorisation may be regarded as official, the acquisition of the elders' permission constituted the first and most important step of my research. *The oral approval may be defined as cultural approval...* (Piquemal, 2001: 71, emphasis added).

Furthermore, Coram relates that recognising communal forms of informed consent is essential for empowering Indigenous research participants: '[t]he provision of oral consent may be consistent with *decolonising methodology* through the

incorporation of an informed consent process that is culturally sensitive' (Coram, 2011: 44). At the same time she reiterates that '... [o]ral consent does not diminish the obligation of the researcher to obtain consent in an ethical manner' (Coram, 2011: 44), except in such cases where it is the Indigenous community that decides the parameters within which 'ethics' is measured. As one of the research participants pointed out:

This REB we are talking about, I had a look at their protocols; it says to engage, to seek advice. But then its decision basically is saying that that was a waste of time, that the protocol we want, that we consider is right, is wrong. Let's be clear, we don't need a bloody piece of paper to tell you how to behave, to ensure you conduct yourself properly, or to give you the ok to go ahead [with the research] (MFG14).

The author sought to replicate an informed consent process as designated by Indigenous participants. This was undertaken by, firstly, establishing relations, ensuring participant input into all aspects of the research design, establishing community ownership of data, analysis and reporting, and identifying what the research can 'give back' to the community in return for the privilege of carrying out research with them. Key to this protracted but necessary process was obtaining consent via the establishment of a trust-based, negotiated relationship for, as Bull powerfully argues, the 'consent process for any research involving humans is complex and requires more than obtaining a signature' (Bull, 2010: 17). According to my participants, what was neither necessary nor important was individual, paper-based consent (see Bull (2010) for a description of a similar process in relation to Indigenous peoples in the Labrador region of Canada). In a bid to satisfy the REB, however, the author decided to 'play the game' by offering participants the standard, individualised paper-based informed consent process described previously.

The author offered to designate a noted community member to 'witness' the delivery of relevant research information and the granting of informed consent at the communal, verbal agreement, a similar process to that advocated by Coram, who writes that:

The provision of an oral undertaking, as a reflection of indigenous oral tradition, could be deemed in 'good faith' and the equivalent of written consent. It could also play an important ethical role in the negotiation of consent if accompanied, for example, by the inclusion of a witness who is prepared to act as a signatory (Coram, 2011: 44).

By offering a dual-process, however, one could adjudge the author to have sought to placate the REB, potentially at the expense of a process considered to be ethically appropriate and empowering for the participants. As Butz argues:

When it is assumed that the problem of voluntary informed consent is solved by asking participants individually to sign written consent agreements regardless of the research context,

then a fully communicative appreciation of the adjectives *voluntary* and *informed* are subordinated to the instrumental purposes of the monitoring and controlling attached to the noun *consent* (Butz, 2008: 251; emphasis his).

Butz further underlines the impact of ‘giving in’ when he states that, ‘[i]t is our research participants who bear the effects of the careless assumptions that institutionalised research makes about who they are and how they want to interact with researchers’ (Butz, 2008: 252), and furthermore that:

...the conventional individuated and vertically structured consent process that is assumed as the norm in most REB policies takes a rich – and richly contested – set of obligations and entitlements that currently link community members to one another in a socially and culturally meaningful way, and translates them into an inflexible, contractual, and vertical relationship between individuated research subjects and the researcher (Butz, 2008: 254).

In summary, the processes prevalent in REBs in the New Zealand context ‘normalise’ the ‘autonomous researched individual’ inherent to the liberal democratic tradition that sanctifies individual rights and freedoms. This ‘fetish of individualism’, as Van den Hoonaard describes it, offers especial problems for the Indigenous researchers and their communities because its ‘individualistic tradition may be quite foreign to other cultures where collectivism prevails and where individual rights are defined by the collective. In such cases, the seeking of individual consent may be an affront to the larger group’ (Van den Hoonaard, 2001: 22).

Concluding remarks

Battiste and Youngblood Henderson write that, ‘[m]ost existing research on Indigenous peoples is contaminated by Eurocentric prejudice [and] ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality’ (Battiste and Youngblood Henderson, 2000: 132–133). It is my contention that if we are to negate Eurocentric hegemony over knowledge development and dissemination, we must challenge the processes the academy has constructed to facilitate its domination through the institutionally-centred REBs; after all:

The real danger of codes of ethics lies in their potential to silence those voices that do not fit with the current dominant view of ethical research standards and behaviour. If we are complicit in this silencing, as researchers, we are behaving unethically (Ferdinand et al., 2007: 540).

All too often, REBs privilege the ‘liberal’, Eurocentric conceptualisation of the autonomous research subject as the focus of their deliberations on ‘right research’, which leads in turn to an over-reliance on formulaic ethics processes. These processes marginalise the importance of the ‘difference’ that occurs in the

social context within which ‘real world’ research takes place. Furthermore, these practices potentially marginalise Indigenous researchers and Indigenous research participants by putting them at risk of violating the ethics protocols of both the institution to which they have applied for ethical consent, and/or the Indigenous communities where their research takes place, as the experiences of Indigenous scholars and research participants reported here attest. The institutionalised ethics procedures may even be read as a politics of containment that at once renders invisible the importance of relationships in Indigenous research, while asserting the right of the institution to determine the ‘correct’ way that research should be conducted.

Nowhere is this issue more apparent than in the process that marks the hegemony of the principles of universalism and individualism within REB processes. Simply following REB processes, in particular those related to informed consent, does not, of itself, *produce an ethical researcher*. Indeed, as Butz (2008), Van den Hoonaard (2001), the author and his research participants demonstrate, it often means the opposite. It does though, however, mean that you have acted as a ‘right’ member of the academy, by conforming to its preferred, standardised, individual ethics process; a conformity that Knight et al. argue, ‘...creates a set of cultural norms that serves the interests and reflects the values of the IRB and the academy’ (Knight et al., 2004: 397).

And lastly, as Indigenous scholars we must resist the hegemony of institutionalised REBs, lest we perpetrate the environment described by Bradley in which these institutionally derived and focused entities ‘can, and often do, silence the voices of the marginalised and perpetuate an academic political economy and a traditional top-down research and professional model that quantify and objectify human lives by keeping them nameless, faceless and voiceless’ (Bradley, 2007: 341).

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Notes

1. It should be noted that the title by which institutional ethics review boards are known can vary depending on geographic location, for example in the US they are often referred to as Research Ethics Committees (RECs) and Institutional Review Boards (IRBs), while in Canada they are designated Research Ethics Boards (REB)s or General Research Ethics Boards (GREBs). The term REB is used here to refer to all committees of this kind.
2. Van den Hoonaard (2002: 11) recounts a situation that demonstrates the ridiculous situations that can arise from the marriage of inflexibility of REBs, lack of experience of research context and/or discipline knowledge of REB members, with regards to gaining

informed consent in the social context, when he recounts how the REB at his university instructed a post-graduate student to 'look away' when/if her planned participant observation brought her into contact with individuals who had not explicitly consented to being studied.

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