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Leashes and Lies: Navigating the Colonial Tensions of Institutional Ethics of Research Involving Indigenous Peoples in Canada

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Abstract

Ethical standards of conduct in research undertaken at Canadian universities involving humans has been guided by the three federal research funding agencies through the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (or TCPS for short) since 1998. The statement was revised for the first time in 2010 and is now commonly referred to as the TCPS2, which includes an entire chapter (Chapter 9) devoted to the subject of research involving First Nations, Inuit, and Métis peoples of Canada. While the establishment of TCPS2 is an important initial step on the long road towards decolonizing Indigenous research within the academy, our frustrations—which echo those of many colleagues struggling to do research “in a good way” (see, for example, Ball & Janyst 2008; Bull, 2008; Guta et al., 2010) within this framework—highlight the urgent work that remains to be done if university-based researchers are to be enabled by establishment channels to do “ethical” research with Aboriginal peoples. In our (and others’) experience to date, we seem to have been able to do research in a good way, *despite*, not *because* of the TCPS2 (see Castleden et al., 2012). The disconnect between the stated goals of TCPS2, and the challenges researchers face when attempting to navigate how individual, rotating members of REBs interpret the TPCS2 and operate within this framework, begs the question: Wherein lies the disconnect? A number of scholars are currently researching this divide (see for example see Guta et al. 2010; Flicker & Worthington, 2011; and Guta et al., 2013). In this editorial, we offer an anecdote to illustrate our experience regarding some of these tensions and then offer reflections about what might need to change for the next iteration of the TCPS.

Keywords

Indigenous research, community-based participatory research, research ethics boards; relational ethics

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Leashes and Lies: Navigating the Colonial Tensions of Institutional Ethics for Research Involving Indigenous Peoples in Canada

Doing Research “In a Good Way” Because of or Despite the TCPS2?

Ethical standards of conduct in research undertaken at Canadian universities involving humans has been guided by three federal research funding agencies (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], and Social Sciences and Humanities Research Council of Canada [SSHRC]) through the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (or TCPS for short) since 1998; the statement was revised for the first time in 2010 and is now commonly referred to as the TCPS2 (CIHR, NSERC, & SSHRC, 2010). In the original version, short shrift was given to research involving Indigenous¹ peoples despite growing critiques² of their decades-long involvement as “exotic subjects of study.” A year after the TCPS became policy, Linda Tuhiwai Smith (1999) published her seminal book, *Decolonizing Methodologies: Research and Indigenous Peoples*, emblematic of a growing movement at the grassroots level and a new generation of scholars, Indigenous and non-Indigenous allies alike, saying enough is enough: Indigenous peoples have been “researched to death” and need avenues for “researching back to life” (see Brant Castellano, 2004). In response to these critiques, one of the federal research funding agencies, the CIHR, undertook lengthy consultations with Indigenous peoples, communities, and organizations as well as university-based researchers concerning how best to do health research ethically with this population. CIHR produced a well-received policy document in 2007 (CIHR, 2007). Soon after, it became clear that the TCPS needed updating. As a result (though some have criticized the process, arguing that insufficient Indigenous community engagement or researcher consultation took place), the TCPS2 included an entirely new chapter (Chapter 9) devoted to the subject of research involving First Nations, Inuit, and Métis peoples of Canada (CIHR, NSERC, & SSHRC, 2010). The intention of this new chapter has been to provide a distinct framework for university-based Research Ethics Boards (REBs) to evaluate research protocols and ensure that they meet the three guiding principles of the TCPS2: respect, concern for welfare, and justice—as they apply in the unique context of research involving Indigenous peoples in Canada.

On paper, the TCPS2 looks good. In its preamble, it respects the jurisdiction of Indigenous communities over research, stating: “*It is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves [emphasis added]*” (p. 105); and encourages researchers to undertake community-based and participatory approaches (i.e., shared decision-making, relationships established before research is undertaken, bi-directional capacity building, etc.) (see Castleden, Sloan Morgan, & Lamb, 2012). However, following its acknowledgement of jurisdiction, it does not give any guidelines to REBs or researchers in terms of how to navigate the tensions that arise when the ethical guidance of Indigenous peoples contradicts that of a university REB. At the end of the day, the issue appears to

¹ In Canada, Indigenous peoples are the original inhabitants of the land; according to the Canadian Constitution, they are identified through the use of an umbrella term “Aboriginal,” which includes First Nations, Inuit, and Métis. Following Alfred (2009), we use “Indigenous” as a means of acknowledging the inherent rights and responsibilities of the original peoples of Turtle Island (North America) that flow from their unique relationship to their traditional territories. We use the term “Aboriginal” when quoting official documents, and when describing the interface between Indigenous groups and institutions of the Canadian settler-state.

² See, for example, the Royal Commission on Aboriginal Peoples (RCAP, 1996).

become one of researcher compliance—with the *academy* as opposed to the ethical directives given by Indigenous peoples themselves. Specifically, as stated in TCPS2: “To be eligible to receive and administer research funds from the [Tri-Council] Agencies, institutions must agree to comply with a number of Agency policies [i.e., TCPS2] set out as schedules to an Agreement between the Agencies and institutions” (CIHR, NSERC, & SSHRC, 2010, p. 5). Should a researcher comply with ethical guidance offered by Indigenous research partners that contravenes that of their university-based REB implementing the TCPS2 (or other policies), the researcher is at risk of losing their project funding. In short, they risk their careers in the academy, especially if they are pre-tenure, and their Indigenous partners risk losing the benefits of the potential research processes and outcomes that would be taking place in their communities. Given these circumstances, the Indigenous jurisdiction that the TCPS2 acknowledges would seem, therefore, to be token at best; the colonial academy, represented by the REB, retains ultimate decision-making over the research process.

While the establishment of the TCPS2 is an important step on the long road towards decolonizing Indigenous research within the academy, our frustrations—which echo those of many colleagues struggling to do research “in a good way” (see, for example, Ball & Janyst, 2008; Bull, 2008; Guta et al., 2010) within this framework—highlight the urgent work that remains to be done if university-based researchers are to be enabled by establishment channels to do “ethical” research with Indigenous peoples. In our³ (and others’) experience to date, we seem to have been able to do research in a good way, and at times this has been *despite*, not *because* of, the TCPS2 (see Castleden et al., 2012). The disconnect between the stated goals of the TCPS2 and the challenges researchers face when attempting to navigate how individual, rotating members of REBs interpret the TPCS2 and operate within this framework begs the question: Wherein lies the disconnect? A number of scholars are currently researching this divide (see for example Flicker & Worthington, 2011; Guta et al., 2010; Guta, Nixon, & Wilson, 2013). In this commentary, we offer an anecdote to illustrate our experience regarding some of these tensions and then offer reflections about what might need to change for the next iteration of the TCPS.

“Just Got Another Round of F#*&ing Revisions Back from the REB!”

One of the challenges in (and strengths of) doing community-based participatory research (CBPR), particularly with Indigenous communities as described above, is the length of time needed to build the foundations of a collaborative undertaking, namely building trusting relationships, and a common vision for research that responds to community needs and priorities. This opening phase is paramount if real power sharing is to take place; yet, it falls largely outside of established funding structures. In our case, we were able to overcome that initial hurdle thanks to our long-standing and on-going relationships with our First Nation research partners that pre-dated the actual research project by several years. A research focus was established through a series of exploratory discussions with community leaders, harvesters,

³ Both authors are non-Indigenous scholars. The first author has 10 years of experience engaging in community-based participatory research (CBPR) involving Indigenous peoples and has submitted ethics applications to three Institutional REBs. The second author has 15 years of experience engaging in CBPR involving Indigenous peoples and has submitted ethics applications to three institutional REBs; she has also served on an Institutional REB, assisted with the development of the TCPS2 Tutorial associated with Chapter 9, has been an invited speaker at several academic conference on the topic of ethical research involving Indigenous peoples in Canada, and has a research trajectory in this area.

and members of the elected band council over the winter and spring of 2013. Funding was secured that summer, and planning with a band-appointed community liaison began in the fall of 2013. A Research Advisory Circle was established early in January 2014, and together we began collectively defining the roles and ethical responsibilities of the Circle, refining the goals of the project, as well as the logistics of carrying it out. By March 2014, we were ready to go to the University REB, as well as the ethics board of the Indigenous nation in question (a process, which in this context, happens in parallel), with our application to approve our research design and protocols. We submitted our application and three weeks later the significant energies that we should have channeled into the community to maintain this exciting momentum (when the real work needed to start in terms of recruitment, training, mentorship, and planning) instead got channeled into interfacing with the university REB when we received a 5-page letter requesting major revisions, and attention to minutia that seemed, at least to our minds, could only rightly be made in collaboration with our partners as the project rolled out in real-time. This, despite the fact we received ethics clearance from the Indigenous REB within a month of our submission.

In total, it required three rounds of revisions with the university REB over 100 days, which resulted in our project, centered on land-based activities that were entirely dependent on seasonality and guide availability, being postponed for a full year. Were we not under the gun, rushing to obtain ethics clearance in order to begin the project in time with the season, we might have picked the battle of demanding the REB respect the jurisdiction of our Indigenous research partners and their REB; that is, to not “override or replace ethical guidance offered by Aboriginal peoples themselves” (CIHR, NSERC, & SSHRC, 2010, p. 105). Instead, we begrudgingly engaged in what Guillemin and Gillam (2004) have described as “procedural ethics” that seemed to be steeped in a positivist tradition of sanitized laboratories that adhere to a linear scientific method.⁴ One characteristic of the research design that finally won REB approval was an overly-exhaustive, six-page consent form (complete with a table of activities giving time breakdowns to the half-hour), committing us to a project design so detailed it completely disempowered the ability of our partners to guide the evolution of the research over time, effectively stripping the power we had wanted to reside with our Research Advisory Circle. Should our First Nations partner want us to make any changes while the project was underway, we would have had to request permission from the university REB to do so,⁵ reducing the Circle to a token advisory role—a move our partners have rightly pointed out undermines the larger political goals of decolonization and Indigenous resurgence with which they see our research aligned.

⁴ See Guillemin and Gillam (2004) for a more detailed discussion of the biomedical origins of university REB processes. See Denzin (2009) for a rich discussion of the peer-review system (including REBs), which he argued is not an apolitical endeavor; Denzin considers the need for space to include moral and ethical criteria in the evaluation of research rigour, and the need to resist “the pressures for a single gold standard” (p. 152).

⁵ Specifically, the REB formally reminds researchers of their on-going responsibilities after an REB has given its approval, one of which is: “Prior to implementing any changes to your research plan, whether to the protocol or consent form, researchers must submit them to the Research Ethics Board for review and approval. This is done by completing a Request for Ethics Approval of Amendment to an Approved Project form (available on the website) and submitting three copies of the form and any documents related to the change. Please note that no reviews are conducted in August” (personal communication).

A Short Leash Can Lead to Lies: Reflections on Indigenous Autonomy versus Institutional Oversight

While we appreciate the need for ethical oversight on academic research involving human participants, the length of leash the university affords Indigenous peoples to determine research conducted with their people, on their territory, is highly problematic. As university-based researchers, we find ourselves in a "catch-22" where we are "damned if we do" the minutia (privileging academic protocols over respect for Indigenous jurisdiction and community autonomy) or "damned if we don't" (thus not getting REB approval to proceed with our research). Such a scenario leaves us with two choices: (a) either lie to the university and provide them with an overly detailed and culturally inappropriate research plan while going about "business as usual" with our community partners, or (b) completely disempower our partners by imposing university regulations on them. The latter is a deal-breaker for the CBPR researcher. The former risks getting reprimanded, having grant funding revoked, or even being fired for breaking the TCPS2 "code of conduct," especially for someone on the tenure-track. Both Israel and Hay (2006) and Martin (2007) proposed a third option, which we echo here, calling on researchers to critically engage with the regulatory bodies and the structures that govern ethical authority within research.

It is absolutely critical for a university REB to compel university researchers to think through the details and potential ethical dilemmas of their research—even in light of the fact that CBPR projects will necessarily deviate from the initial plan on paper. The REB application process ensures we have solid, well thought-out research designs and provides the REB with what they need to evaluate whether our intellectual inquiry meets the minimum ethical standards of the TCPS2; that is it: (a) respects human participants and the communities they are a part of, (b) demonstrates concern for welfare, and (c) treats people fairly and equitably. More importantly, from the perspective of CBPR, the REB process serves as a checkpoint; it is the place where we are to demonstrate that we have clearly articulated our research agenda to our community partners in the opening phase of our relationship. It is a place for us to produce the tools our partners need to make informed decisions about whether or not to enter, or continue, a research partnership with us, as well it subjects those tools to the scrutiny of peer-review (the hallmark of maintaining high standards of quality research from the perspective of the academy). Perhaps most importantly, it provides our Indigenous partners with tools they can use to hold us accountable vis-à-vis the colonial university structures that govern our world.

Clearly, we support the goals of our institutional REBs to prevent the kind of harmful, disempowering, tokenizing, and pathologizing research that has gone on in the past. But as decolonizing CBPR researchers, we want more than that. We want our REBs to ensure that the kind of community-driven, capacity-building, empowering research that Indigenous communities, Indigenous scholars, and non-Indigenous scholar allies are demanding becomes the norm (Brant Castellano, 2004; Kovach, 2009; Smith, 1999; Wilson, 2008)—and we want the REB process to *enable* the kind of CBPR methodologies such an approach often entails, not *disable* them. From the perspective of ethics, as it is understood in CBPR and in Indigenous research, the REB process *should* be a site of empowerment for Indigenous partners within the research enterprise. A central goal of CBPR involving Indigenous peoples (and most, if not all, decolonizing approaches to research) is to radically shift, if not invert, the balance of power between the academy and Indigenous research partners—and to meaningfully acknowledge Indigenous partners as *nations*, not stakeholder groups—with jurisdiction over research in their communities and

on their traditional territories (see Kershaw, Castleden, & Laroque, 2014). This lies at the heart of CPBR methodologies and is inseparable from the larger political goals of Indigenous self-determination, autonomy, and decolonization that align with our work.

Our thesis is thus: If ethical research with Indigenous peoples hinges on shifting the balance of power, the focus of the REB process should be on evaluating the strength of researcher-community partnerships and structures of mutual accountability that have been established, while acknowledging the jurisdiction of the nation in question and deferring to their authority—especially in cases where an Indigenous REB (or the equivalent) is established.⁶ While it is appropriate and useful for an REB to evaluate the general parameters of a research design, the details belong to the people on the ground. It is unrealistic to expect Indigenous community partners involved in academic research to divert their time and resources from the urgent needs and priorities in their communities in order to take on yet another colonial battle to engage in a lengthy negotiation process with a university REB, which (perhaps unknowingly) is questioning their jurisdiction over research conducted with their people on their territory.

The existing university REB process assumes a researcher-driven model, and hinges on individual consent of research “subjects” obtained via the individual informed consent form. However, CBPR is defined by its attempt to invert this power dynamic: Vulnerable “subjects” become research “partners” who, ideally, are driving the process. Such a scenario implies a much different level of responsibility for an REB, and calls for a much different criteria of evaluation in determining ethical oversight. While individual consent in Indigenous CBPR research is important, obtaining the relevant collective approval to conduct research is perhaps even more so.⁷ In such a case, the REB’s focus should then become evaluating the degree of collective ownership over the research, the power-sharing mechanisms and mutual structures of accountability established, the cross-cultural competency of the research team, their knowledge of and respect for local protocols, the arrangements for Indigenous control and ownership over data that have been negotiated,⁸ and the ways the research results will be shared and mobilized in ways that involve and are relevant to both partners. In other words, the REB’s focus should shift to evaluating how researchers demonstrate an understanding of and operationalize what Kirkness and Barnhardt (2001) have called the “four Rs” of Indigenous research: respect, reciprocity, relevance, and responsibility.

⁶ The Akwesasne Research Advisory Committee (see <https://reo.mcmaster.ca/download/akwesasne.pdf>) and Mi’kmaw Ethics Watch (<http://www.cbu.ca/mrc/ethics-watch#.VQBiuGb9um0>) are both interesting examples of Indigenous organizations established to provide ethical oversight and review applications to conduct academic research with their respective nations.

⁷ The notion of collective approval is often interpreted to mean approval of the Chief and Council in a First Nations context, but there are communities within communities that also have leadership processes and protocols; the TCPS2 does recognize this but many researchers (and this includes some REB members) have a flawed understanding as to how to navigate the appropriate “approval” in terms of how to conduct themselves and their research with First Nations (see, for example, Campbell, Castleden, Francis, Strickland, & Denny, in press).

⁸ See Schnarch (2004) for a discussion of the widely recognized benchmark for data ownership and storage within Aboriginal research established by the former National Aboriginal Health Organization (NAHO).

The Master's Tools Can Only Do So Much

In forging ethical university-based research partnerships with Indigenous peoples, is it surprising that the tools the university gives us to work with are not suitable for the task at hand? Perhaps it is worth asking ourselves, to paraphrase the now famous words of the late Audre Lorde (1984/2007), how realistic is it for us to expect that the master's tools will dismantle the master's house? REBs are structures and processes deeply embedded in a colonial institution. They were established for good reason: to protect human participants from harm in academic research. But they were also established to evaluate individual researchers (in the classic atomized, rational, self-interested Western understanding) with positivist research designs (that happen in controlled laboratory-like settings). This early process has lingering affects, allowing for the production of "knowledge" in a very particular, Western, colonial sense (knowledge that can be abstracted and extracted from its context and web of relationships), with individual ownership protected via academic Intellectual Property "Rights" (embedded within the legal structures of the settler-state), and with little concern for the incumbent responsibilities and relational accountability (Wilson, 2008) such "knowledge" entails. Given all of this, is it realistic to expect that REBs—who are subject to the terms and conditions of the federal funding agencies and who are charged with upholding the principles of the TCPS2 in researchers' everyday practice—are in a position of self-awareness, ability, or autonomy to not only permit, but to enable, decolonizing methodologies?

We must not let go of a decolonized academy as a political goal; this includes engaging with and challenging our REBs jurisdictional authority. To do so would ignore the countless demands from our colleagues and Indigenous community partners to work together to create and guard a space for Indigenous resurgence within the academy. Decolonizing the REB review process is a work in progress; it bears recognizing that it is a project with significant gains many of our colleagues have worked long and hard to achieve—both by participating in the TPCS2 process, and by serving on REBs, one of the most time-consuming but fundamentally important university-based administrative committees. At the end of the day, however, even the best-designed "houses" need to be populated by people with the cultural competency and/or lived experience to run them.⁹

Recognizing Jurisdiction, Creating Space for Indigenous Resurgence

Coming back to the notion that the TCPS2 is not intended to override or replace ethical guidance offered by Indigenous peoples themselves, we noted in our review of Chapter 9's contents there is a section tucked towards the end of a section entitled "Interpreting the Ethics Framework in Aboriginal Contexts" (CIHR, NSERC, & SSHRC, 2010, p. 109), referring to research involving Indigenous

⁹ The second author's ongoing research in this area suggests that REBs are starting to be populated with at least one content or process expert in CBPR involving Indigenous peoples. At the same time, this has been identified as a major limitation for many institutionally-based REBs and points to the contradictions and challenges involved in decolonizing university-based research with Indigenous peoples in a context where the overwhelming majority of researchers leading and scrutinizing research are non-Indigenous and have little to no lived experience working with Indigenous peoples.

peoples in *other* countries.¹⁰ Here the TCPS2 indicates that the guidance articulated in its policy may be usefully applied in other jurisdictions with the caveat that “it is critically important, however, to seek local guidance in the application or adaptation of the policy” (p. 110). It struck us that, here in Canada, what the TCPS2 fails to fully address (and perhaps many REB members fail to understand) (see for example Godlewska, Moore, & Bednasek, 2010), is we are dealing with *nations within a nation*. And while the REB can offer us, as researchers bound to institutional policies and procedures, guidance on ethical practice for research involving Indigenous peoples, it also has to acknowledge that when we cross jurisdictions into Indigenous territories, we are entering more than a community, we are entering places where the aim is decolonization—a project that implicates the very power structures REBs both operate within and operationalize. At the end of the day, who best determines the ethical practice of academic research involving Indigenous peoples in Canada? Indigenous peoples, period. Thus, when examining Indigenous CBPR projects for ethical rigour, we suggest the REB process should be concerned primarily with ensuring researchers have created meaningful power-sharing arrangements with their Indigenous partners, not regulating and limiting their decision-making authority.

¹⁰ While it is beyond the scope of this commentary to provide an analysis of the policy environments and institutional ethics review procedures that govern Indigenous CBPR outside of Canada, it is worth noting that similar tensions have been described by researchers doing CBPR with Indigenous people in Australia (Couzos, Lea, Murray, & Culbong, 2005), and CBPR with other populations in both the US (Martin, 2007) and internationally (Israel & Hay, 2006).

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