

# Shifting practise: recognizing Indigenous rights holders in research ethics review

Shifting  
practise

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## Abstract

**Purpose** – For many Indigenous nations globally, ethics is a conversation. The purpose of this paper is to share and mobilize knowledge to build relationships and capacities regarding the ethics review and approval of research with Indigenous peoples throughout Atlantic Canada. The authors share key principles that emerged for shifting practices that recognize Indigenous rights holders through ethical research review practice.

**Design/methodology/approach** – The NunatuKavut Inuit hosted and led a two-day gathering on March 2019 in Happy Valley-Goose Bay, Newfoundland and Labrador, to promote a regional dialogue on Indigenous Research Governance. It brought together Indigenous Nations within the Atlantic Region and invited guests from institutional ethics review boards and researchers in the region to address the principles-to-policy-to-practice gap as it relates to the research ethics review process. Called “Naalak”, an Inuktitut word that means “to listen and to pay close attention”, the gathering created a dynamic moment of respect and understanding of how to work better together and support one another in research with Indigenous peoples on Indigenous lands.

**Findings** – Through this process of dialogue and reflection, emergent principles and practices for “good” research ethics were collectively identified. Open dialogue between institutional ethics boards and Indigenous research review committees acknowledged past and current research practices from Indigenous peoples’ perspectives; supported and encouraged community-led research; articulated and exemplified Indigenous ownership and control of data; promoted and practiced ethical and responsible research with Indigenous peoples; and supported and emphasized rights based approaches within the current research regulatory system. Key principles emerged for shifting paradigms to honour Indigenous rights holders



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through ethical research practice, including: recognizing Indigenous peoples as rights holders with sovereignty over research; accepting collective responsibility for research in a “good” way; enlarging the sphere of ethical consideration to include the land; acknowledging that “The stories are ours” through Indigenous-led (or co-led) research; articulating relationships between Indigenous and Research Ethics Board (REB) approvals; addressing justice and proportionate review of Indigenous research; and, means of identifying the Indigenous governing authority for approving research.

**Research limitations/implications** – Future steps (including further research) include pursuing collective responsibilities towards empowering Indigenous communities to build their own consensus around research with/in their people and their lands. This entails pursuing further understanding of how to move forward in recognition and respect for Indigenous peoples as rights holders, and disrupting mainstream dialogue around Indigenous peoples as “stakeholders” in research.

**Practical implications** – The first step in moving forward in a way that embraces Indigenous principles is to deeply embed the respect of Indigenous peoples as rights holders across and within REBs. This shift in perspective changes our collective responsibilities in equitable ways, reflecting and respecting differing impetus and resources between the two parties: “equity” does imply “equality”. Several examples of practical changes to REB procedures and considerations are detailed.

**Social implications** – What the authors have discovered is that it is not just about academic or institutional REB decolonization: there are broad systematic issues at play. However, pursuing the collective responsibilities outlined in our paper should work towards empowering communities to build their own consensus around research with/in their people and their lands. Indigenous peoples are rights holders, and have governance over research, including the autonomy to make decisions about themselves, their future, and their past.

**Originality/value** – The value is in its guidance around how authentic partnerships can develop that promote equity with regard to community and researcher and community/researcher voice and power throughout the research lifecycle, including through research ethics reviews that respect Indigenous rights, world views and ways of knowing. It helps to show how both Indigenous and non-Indigenous institutions can collectively honour Indigenous rights holders through ethical research practice.

**Keywords** Research, Ethics, Research ethics, Data sovereignty, Indigenous research ethics, Inuit governance

**Paper type** Research paper

### **The “Naalak Gathering”: enacting, encouraging and embodying the ethical space**

Elder and scholar, Willie Ermine, articulated the concept of ethical space to denote a space of engagement that is essential in research involving Indigenous peoples (2007). He builds on the work of Roger Poole (1972), who examined the space between two opposing societies when they are required to work together to address an issue. Ermine adapted Poole’s framework for human dialogue to conceptualize the relationship between Indigenous and non-Indigenous peoples, highlighting the necessity of integration (of world views, methods, perspectives). In research, this integration is often fraught with conceptual and pragmatic challenges that have yet to be resolved as it relates to ethics review for research with Indigenous peoples. Though the ethical space is often considered abstract or theoretical, this paper will illustrate how a physical gathering can enact, encourage and embody the ethical space when committed people gather together.

On 20 and 21 March 2019, Inuit from NunatuKavut hosted the “Naalak Gathering: A regional dialogue on Indigenous Research Governance” that was funded in part by the Social Sciences and Humanities Research Council. It brought together Indigenous nations within the Atlantic Region and invited guests from university and college’s research ethics review boards (REBs) and researchers (shown in the following list: “Participating Organizations at the Naalak Gathering”). “Naalak” is an inuttitut word that means “to listen and to pay close attention”. Inuit organizers chose this word after many years of working in research ethics and noting the crucial component of listening that is required by both the researchers who work in Indigenous communities and the REBs who oversee them. The vision was to create a dynamic moment of respect and understanding of how to work better together and support one another in research with Indigenous peoples on Indigenous lands. The aim was to better animate ethical and responsible conduct of research with Indigenous nations, and to better understand how to respond to the tensions emerging as the policies and practise of research continue to shift (Bull *et al.*, 2019).

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Participating organizations at the “Naalak Gathering”:

- NunatuKavut Community Council
- Nunatsiavut Government
- Qalipu First Nation
- Mi’kmaq Ethics Watch
- Mekap’sk Mi’kmaq Band
- Atlantic Policy Congress of First Nation Chiefs
- Centre for Addiction and Mental Health
- Cape Breton University
- College of the North Atlantic
- Dalhousie University
- Memorial University of Newfoundland – Grenfell Campus
- Memorial University of Newfoundland – Labrador Institute
- Memorial University of Newfoundland – St John’s Campus
- Mount Saint Vincent University
- Newfoundland and Labrador Health Research Ethics Authority
- Nova Scotia Community College
- St Thomas University
- University of Prince Edward Island
- Urban Aboriginal Knowledge Network – Atlantic

Grounded in the ideals of Indigenous sovereignty in research, the *Nalaak* gathering honoured the leadership and expertise of Indigenous communities in setting the tone for the how, why and what research is done on their lands and with their people. The gathering provided an opportunity to move forward in relationships and collaborations across Atlantic Canada. There was a commitment to decolonizing research practices, including respecting and supporting the autonomy of Indigenous nations and territories in their right to self-determine in research. The “Naalak Gathering” embedded an Indigenous approach to research, whereby the community identified a research priority, sought and held the funding, and invited people from academic institutions to join as co-investigators and collaborators. The *Nalaak* gathering was unique in that the target audience was the ethics boards themselves (REB members, chairs and administrators of universities, colleges and hospitals), which intended to increase the likelihood of influencing policy and practice change at local and regional levels. For example, it may be that an REB at a university could post principles and guidelines for researchers and REB members about how to do Indigenous research in a good way, including recognizing Indigenous peoples as rights holders, highlighting the need for community leadership and engagement in developing, approving and conducting the research, and for ongoing processes associated with these principles (including the complexities in data stewardship and related access and dissemination).

For NunatuKavut Inuit, and many other Indigenous nations globally, “ethics” is an ongoing conversation and, yet, many of the REB processes and guidelines that are put in place at academic institutions are procedural, finite and legalistic (Bull, 2019a). There are rarely checks and balances in place to ensure that the ongoing process of enacting ethical

research is followed, and often there are no or insufficient means to ensure that the relational elements of research are incorporated into ethical protocols – or even that these ethical protocols can grow and evolve in partnership with Indigenous communities and governments. To address the principle-to-policy-to-practise gap, the “Naalak Gathering” exemplified and magnified the ethical space through open dialogue among institutional ethics boards and Indigenous research review committees by: acknowledging past and current research practices from Indigenous peoples’ perspectives; supporting and encouraging community-led research; articulating and exemplifying Indigenous ownership and control of data (including existing options for data sharing and research agreements); promoting and practising ethical and responsible research with Indigenous peoples; and supporting and emphasizing Indigenous rights and relational-based approaches within the current research regulatory/administrative system.

Relational ethical space at the gathering encouraged knowledge as relationships in action through physical, spiritual and procedural ways that balanced opportunities for listening and voicing, seeing and showing, feeling and practising ideas and ways to challenge self and others to understand, to think and to do better. The physical location of the work within the NunatuKavut territory oriented a set of ethical relational processes that wrapped around the workshop including a formal welcoming from the President of the NunatuKavut Community Council, setting up a Labrador Tent, a blessing of the work by lighting the Kullik, and inclusion of traditions as part of the workshop including cultural performances, a feast, and a Big Land Adventure.

The physical space grounded participants in the community for a meaningful connection to the work. That is part of relational ethics, being physically related to a place. The spiritual practices similarly served to orient the group to what it means to be searching for a right path that listens with the heart as well as the mind. Procedurally ethical relationships were at the core of how we started, with an opening of the workspace with introductions of who was there and why they had come to the meeting including who they represented in their presence. An important ethical, collaborative learning process is to animate participation while minimizing risk for sharing difficult issues. We value sharing difficult or “sticky” issues because that is precisely how we learn what needs attention. To encourage a low-risk sharing, we created a “Sticky Questions” section and invited participants to place their ideas on sticky notes at the tables and to post them during breaks or at the end of the day. We used the phrase “add your sticky questions to the sticky notes” as a process to animate emergent thoughts. These thorny issues were compiled collectively throughout the two days. Together we began to imagine better ethics review processes and practices within the context of indigenous-led research and Indigenous sovereignty as it relates to research. From that collaborative questioning we learned that some things are going well, and some challenges remain. We discuss some of the fundamental principles and practices emerging from our dialogue towards this re-imagining later.

The process next created an opportunity for each of the nations present at the gathering to share their reflections with regard to ethical research including their policies, procedures, protocols and practices. Two further circles gave ample opportunity for discussion and reflection as representatives of REBs and then researchers had an opportunity to share. These three sharing circles set the stage to have deeper understandings for the Table/Tent Talks to determine key questions, considerations and challenges as the first day’s closing process and setting the stage for the second day of learning. Promotion of learning was also animated by the use of a graphic recording of the work (Bull *et al.*, 2019). As the conversations hit upon important ideas and insights, the group would see images and connections emerge as powerful reminders of our collective knowledges and responsibilities. These images were helpful for participants to remember what had already been voiced, to add their reflections and insights and to recall connections to earlier points.

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The second day built upon the first both through the graphic displays still present in the room and also by a fourth circle of emerging and promising practices followed by more collaborative Table/Tent talks to reflect on key solutions, opportunities and wise, emerging, or promising practices that could inform policy and practice recommendations. Not only did the group work and elaborate on the ideas from the circle sharing, they also took time with the “Sticky Questions” at the end of the two days in an open group forum – collaboratively reflecting on the questions and creating larger group understandings of the issues, potential opportunities for better ways of approaching the problems and an acknowledgement of the remaining challenges. Thus, not only did the “Naalak Gathering” create the ethical engagement of nations as rights holders to collaborate with institutions and researchers for sharing knowledge, it also animated deeper ways of understanding and sharing perspectives that opened up the possibility for creating and innovating. This paper aims to share and mobilize knowledge from the “Naalak Gathering” to build relationships and capacities regarding the ethics review and approval of research with Indigenous peoples.

### **It is about timing, not time**

There are several reasons why the “Naalak Gathering” was timely and necessary. The primary reason, and which provided an underlying foundation, is that Indigenous peoples are resurging and reasserting rights to control their own stories, which define who they are, and to represent and shape their present lives into a future with a past that is their own. It is increasingly clear that it is not up to academic REBs to approve (or deny) Indigenous research for Indigenous communities (Bull, 2019a). Recognizing that Indigenous peoples are rights holders and have authority over the how, when, where or why their stories are told leads to new collective responsibilities around equitable processes in support of Indigenous governance of research within, of, and on their lands and with their communities.

From a more proximate and regulatory/administrative perspective, the timing is critical because key guidance and policy documents and processes are emerging and/or under revision. The “Tri-Council Policy Statement (Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), & Social Sciences and Humanities Research Council of Canada (SSHRC), 2010-2014) on Ethical Conduct for Research Involving Humans”, including Chapter 9 – Research Involving the First Nations, Inuit and Métis Peoples of Canada, is almost nine years old. Similarly, OCAP® is 20 years old, and the NunatuKavut Community Council Research Advisory Committee (NCC RAC) has been operational over more than a dozen years and is currently reviewing and updating their research policies and protocols. In 2018, Inuit Tapiriit Kanatami “National Inuit Strategy on Research” was released. REBs are grappling with how to apply TCPS2 Chapter 9 in practice, and current training on TCPS does not adequately address how to do some of the complex practices it encourages. For example, TCPS Chapter 9 identifies that there may be complex Indigenous governance structures but gives little guidance on how to navigate that complexity. Many REBs are not sufficiently aware of jurisdictional considerations required in Indigenous research, and even for those who may be, it is not clear to REBs which Indigenous community or body has jurisdiction or governance authority over research, and how to ensure their engagement and consent has been obtained by researchers (Moore, 2015). REBs in Atlantic Canada who participated in the “Naalak Gathering” recognized that they needed to do a “listening tour” to learn from Indigenous peoples how best to respect and acknowledge them as rights holders.

The approach for the “Naalak Gathering” was based on research relationships that span a dozen years, led by NunatuKavut Inuit, researchers and the NCC RAC. Their self-determined leadership favours community-based participatory methods, informed by Inuit values and ethics. This wholistic approach integrates multiple ways of knowing in a co-learning model with shared benefits. This act of reciprocity seeks to enhance

understanding and capacity of institutional REBs in Atlantic Canada as a step towards ensuring adequate ethical review and clearance of research with Indigenous peoples while promoting Indigenous data sovereignty.

### **Decolonizing research ethics review**

Research is not a new idea for Indigenous peoples who have always studied to live and thrive, but colonization and Euro-centric institutions typically do not recognize and appreciate Indigenous knowledges or sciences (Wilson, 2008). Likewise, Euro-centric institutions have not honoured or respected Indigenous peoples as rights holders, yet Indigenous ways of knowing and being are integral to researching in “a good way” with(in) Indigenous communities. In recent centuries, Euro-centric institutions have enshrined a world view that compartmentalizes and alienates the power of research from Indigenous communities, which in turn also undermines Indigenous communities and voices (Smith, 1999). This Euro-centric framing and marginalization has implications for the way in which REBs at universities and other institutions situate Indigenous peoples and define, administer, review and approve Indigenous research (Bull, 2019a).

Given a legacy of colonial research by western institutions, and the detrimental impact upon Indigenous peoples and communities, Indigenous peoples have been reclaiming and (re) asserting their rights to make decisions that impact them, including decisions about research happening on their lands (Bull and Hudson, 2018). In the case of NunatuKavut Inuit, this has taken the form of actively understanding decolonizing processes that work best for them and their communities in relation to decision making, and has meant the decolonizing of self, and of expectations on relationships with external researchers, academics, partners, etc. In matters of self-determination (whether in research ethics or otherwise), decolonization and resurgence cannot be separated in the pursuit of Indigenous freedom and autonomy (Corntassel, 2012). Resurgence comes from the community. Community-specific decolonizing practices and processes are born out of the local knowledge, interests, goals and needs that are specific to that community and driven by their local context (Hudson, forthcoming). In research relationships, decolonization means that Indigenous peoples and communities ask the questions they want and lead the research on their terms, shifting the power imbalance between Indigenous nations or communities and institutions (Cunsolo and Hudson, 2018). The move to balance does not mean that institutions of higher learning and the knowledge they bring become obsolete. Rather, it means that their role in decolonization and in relation with Indigenous peoples is to support the leadership and autonomy of Indigenous communities to lead research on their terms and in renewed ways.

Several governmental and institutional shifts have transpired in recent years that seek to address the way that research is “done” in Indigenous communities and with Indigenous peoples. For example, connecting the link between education and reconciliation, the Truth and Reconciliation Commission Report (2015) clearly articulates that the onus is on academic institutions to change the way they do research and engage Indigenous communities (Call to Action 65, p. 8). Yet, the report does not set out or provide a mechanism for accountability for academic institutions in doing this work. Examples exist whereby well-intentioned institutions take it upon themselves to “do better” and to change the way that research is initiated, conceived and undertaken with Indigenous peoples, communities and nations (Brunger *et al.*, 2014). A history of colonial education and deeply rooted western institutional practices, however, continues to dominate and challenge the way that many institutions and individuals engage with Indigenous peoples and communities in research.

A specific example of how the “Naalak Gathering” engendered these shifts comes from the province of Newfoundland and Labrador. As a part of the small group discussions, an REB administrator from Newfoundland and Labrador’s Health Research Ethics Board

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(HREB) engaged with Indigenous research advisory committee (RAC) administrators and discussed possible improvements to the reporting structure that operates between REBs and RACs in that province. It was noted that, while communication regarding applications for new projects functioned more or less effectively, amendments to projects post-approval were not being communicated in many cases. It was noted that sometimes changes were requested by Indigenous RACs that were never communicated to institutional REBs, changes were being communicated to REBs that were never communicated to RACs and so on. RAC and REB members discussed a possible future reporting structure to improve communication regarding post-approval project changes including monthly reporting to RACs. This was put into action in May 2019 when the HREB and local RACs began monthly meetings to discuss emerging and ongoing challenges and opportunities.

Decolonization involves revealing not only how Euro-centric bias operates but also excavating how that worldview is perpetuated in research institutions and practice, wherein Indigenous rights and ways of knowing continue to be systematically supplanted, denigrated and dismissed. Decolonizing research requires shifting the policies and practices of research ethics within academic institutions and, importantly, within research communities (Brant-Castellano, 2004; Tuhiwai Smith, 1999). The shift towards decolonizing research ethics is already underway through leadership from Indigenous researchers – many of whom have been working to re-imagine the right ways of being in relationship with Indigenous communities and in honouring Indigenous sacred teachings and principles (Bull, 2010; Ermine, 2007; Hart *et al.*, 2017). The Seven Grandfather teachings of Love, Honesty, Humility, Truth, Respect, Bravery and Wisdom represent one perspective of how to be in right relation in conducting research or any other form of knowledge process (Flicker *et al.*, 2015). The OCAP® principles of ownership, control, access and possession represent good ways of respecting community sovereignty over data collection processes, their information and how it can be used (Schnarch, 2004). Notably, the OCAP® principles are specifically first nations developed, but many Indigenous peoples do use the underlying principles in their research governance frameworks. The four Rs of respect, relevance, reciprocity and responsibility represent other good ways of engaging in research with Indigenous peoples (Kirkness and Barnhardt, 1991). Importantly, research and ethics are relational and collective in Indigenous contexts. Therefore, both individual and collective consent is required, and ethical considerations ought to include both as well. This collective component is essential because of Indigenous peoples' inherent right to determine the research that happens with their peoples and on their lands.

As researchers begin or continue to adopt decolonizing approaches, support is required from academic institutions such that authentic partnerships can develop that promote equity with regard to community and researcher and community/researcher voice and power throughout the entire research lifecycle (Bull, 2010; Simonds and Christopher, 2013). However, there are persistent gaps in institutional research ethics processes wherein principles promoting decolonization are far from adequately considered or included (Morton Ninomiya and Pollock, 2017). For instance, such principles are rarely, if ever, explicitly embedded in standard institutional ethics application forms. Few REBs provide guidance documents on principles for Indigenous research that they expect or require researchers and board members to follow. Many REBs still do not ask questions about Indigenous inclusion in research. It is unclear to what extent REBs consider such principles in their review of applications for Indigenous research, but at best, it is inconsistent across REBs and generally far from sufficient (Bull, 2019a). What we find instead, within these forms and processes, is another set of beliefs, values and practices that govern how research is conducted within Euro-centric paradigms. Gontcharov (2016) describes the current regulatory system in Canada to be a bureaucratic exercise fraught with notions of institutional liability rather than participant protections, as research ethics was/is intended. Indigenous peoples as rights holders and

respect for their ways of knowing and being are not explicitly recognized or embedded. As institutions strive to be in right relation with Indigenous nations, they need to embody principles and practices that signal a shift to a more inclusive and equitable world view and practice. Riddell *et al.* (2017) published “Laying the Groundwork: A practical guide for ethical research with Indigenous communities”, which can be a helpful starting point for people who are just beginning this work. Paramount in the shift to right relations and decolonizing research ethics is the recognition by both Indigenous nations and academic institutions of their respective and collective responsibilities.

### **Collective responsibility**

Research and ethics practices are rooted in and respond to Indigenous self-determination. The decolonizing of research ethics cannot and should not be led by academic institutions or their REBs. However, REBs are at the intersection of shifting world views and disrupting processes that entail collective responsibilities, and they too have a role to play in the decolonizing process. Reconceptualization of ethics is embedded within the broader Canadian context of the Truth and Reconciliation Commission’s Calls to Action, in which Indigenous communities are acknowledged as existing as nations that have sovereignty and governance over their peoples and their lands through Aboriginal and Treaty Rights and Indigenous Law (TRC, 2015). A resurgence of Indigenous rights to research is emerging as Indigenous nations continue to assert their inherent rights to self-government and ultimately, self-determination with federal, provincial and territorial governments in Canada. Reconceptualization of research ethics to an Indigenous rights based worldview that respects Indigenous peoples, land, community, knowledge, rights, sovereignty and governance is part of this shifting process and practise. Indigenous communities and Indigenous researchers and scholars are pushing for this shift, which is putting a strain on the apparatus of the system/institution (which includes REBs), and some are seeing the need and obligation to respond to this indigenous-led shift (Bull, 2019a).

Situated in the middle, REBs have an essential role to play in decolonizing research through associated “right” ethical practices, yet they cannot lead this process. The REBs are at the intersection of ethical principles and practices and positioned at the nexus of researchers, communities, university administration and the broader research system comprised of funding and other institutional and governance bodies such as Indigenous RACs, Tri-Council and environment, health and education institutional ethics bodies, among others. In this context, the REBs may be seen as an intermediary among all these processes, as part of a larger system that needs to adjust course towards a decolonized research process that honours Indigenous rights holders on their lands. Mi’kmaq scholar, Carla Moore and her colleagues identify that despite the vast policies and guidance on research ethics for health research with Indigenous peoples, “understanding between communities and campuses and within and across campus jurisdictions, are necessary to better understand the nuances of ethical Indigenous research and the disconnects between policy (ies) and practice(s)” (Moore *et al.*, 2017, p. 13).

While acknowledging these broader shifts and influences, more proximate principles and practices nonetheless emerge wherein both Indigenous communities and institutional REBs have central roles and responsibilities that warrant their collective attention. Collective responsibilities around ethical principles and practices for Indigenous research entail more equitable processes for creating/designing, reviewing/approving and doing research in a good way. Since the early 2000s, many Indigenous communities and nations have created their own research and ethics review processes (Fitzpatrick *et al.*, 2016). As self-determining peoples, many Indigenous communities, governments and organizations are (re)claiming control over research through a number of highly effective community consent contracts (e.g. research agreements, research partnerships) and ethical review processes and protocols



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(e.g. community REBs, RACs, Elders council directives, Band council resolutions) (Brunger *et al.*, 2015; Fitzpatrick *et al.*, 2016). On the other hand, some Indigenous communities, governments and organizations have less evolved and/or sophisticated research governance processes in place, have different priorities and/or have not yet developed community consent processes or standard contracts for research review purposes. Regardless of Indigenous communities' priorities or research processes, it is imperative that academic REBs recognize them as rights holders.

Thus, it is incumbent upon REBs to know or to learn the ethical and legal dimensions of research with Indigenous peoples, as well as the structures and processes they have in place (or emerging) for Indigenous reviews, permissions and consents in various Indigenous contexts and jurisdictions (Bousquet and Williams-Jones, 2015; Bull, 2019a). Being versed in these dimensions entails REBs understanding of principles and good practices of Indigenous research, and the particular processes of engagement and consent of the Indigenous peoples involved. While the fundamental guiding principles and good practices from the "Naalak Gathering" pertain across the Atlantic region, the particular processes and context of the specific Indigenous peoples vary across communities and regions and must also be acknowledged, understood and respected. As noted earlier, there are several robust systems of Indigenous research governance in the Atlantic region, many of whom participated in the "Naalak Gathering" and shared emerging, promising and preferred practise.

### **Principles and practices of ethical engagement**

The "Naalak Gathering" raised important policy implications for institutions of higher education, REBs and even the Secretariat on the Responsible Conduct of Research for future consideration in the TCPS (Bull *et al.*, 2019). The summary report and subsequent materials have been shared with the Secretariat. Through dialogue at the gathering, the understanding of Indigenous peoples as rights holders and what this means in terms of institutional research principles, policies and practices were recognized and enhanced, along with the deepened realization that this also entails broader systematic changes, beyond REBs. The collective responsibilities around these changes require equitable principles and practices, involving Indigenous governing bodies and REBs, and institutions and processes beyond them, including discipline specific training of researchers for ontological complexity and, further, into community/settler understandings of what it means to work as Treaty people in Nation-to-Nation relationships.

The "Naalak Gathering" opened the space to broaden the scope of understanding on the part of REBs and researchers as informed by movements within both Indigenous communities and academia and embracing better ways to honour and respect right relations. During the "Naalak Gathering", we heard examples of policies and processes from the NunatuKavut Community Council, the Nunatsiavut Government, the Mi'kmaw Ethics Watch, Qalipu First Nation, and the Mekap'sk Mi'kmaq Band. Indigenous communities at the "Naalak Gathering" described and discussed their experiences in research by offering examples of both excellent and poor research/review practices and explained their respective research governance systems in detail, focusing on their own resiliency and resurgence in research governance and sovereignty.

There are several key elements that were discussed at the "Naalak Gathering" that can be helpful for researchers, communities and REBs in the conduct of research/review with Indigenous peoples. This section briefly identifies six of these principles and practices by encouraging actionable items for both researchers and REBs.

### **Indigenous rights holders**

Legal scholars, such as Olthuis, Kleer and Townshend (2012), assert that "Aboriginal peoples have always maintained their right to be sovereign or self-governing" (p. 29) As such,

Indigenous communities are rights holders, not stakeholders. They have sovereignty over their lives, lands, communities and stories. As rights holders, Indigenous peoples are the leaders and decision makers about research within their communities and on their land. Due to a history of harm to Indigenous peoples and communities, research with and by Indigenous peoples is becoming standard practice, instead of research on or about them (Battiste, 2016). This shift is influenced and has been reshaped over time by movements within both Indigenous communities and academia to develop policy on research ethics for research involving Indigenous peoples. As noted by the United Nations Declaration on the Rights of Indigenous Peoples, the conduct of ethical research cannot be separated from discussions and applications of research governance. Regardless of who is undertaking the research – whether a seasoned or novice researcher, Indigenous or settler, and known or unknown to the specific community – permission to conduct research in any Indigenous nation or territory is required, and community consent is an ongoing conversation. The shift to recognizing Indigenous peoples as rights holders, with a right to governance over research, brings with it and changes the inherent collective responsibilities for Indigenous communities and academic/institutional REBs. Bull (2019b) notes that for Inuit and many other Indigenous peoples, “research ethics is not separate from ‘how-you-live-your-life’ ethics, and therefore, research is about being and becoming an able human” (p. 1). Participants at the “Naalak Gathering” reiterated that relational and reflexive research is crucial.

### **Enlarging the sphere of ethical considerations**

In our conversations at the “Naalak Gathering”, it was clear that operating within the ethical space the principle of an enlarged ethical sphere will put us on a good path towards addressing contentious issues including the authority to research within a territory or with Indigenous peoples. Accordingly, there is a need for ethical considerations and approvals in research that are cognizant of connections to the land. For example, if researchers want to do research related to fish, plants or animals within an Indigenous community, permission from the respective Indigenous community is required, just as it would be for research pertaining to humans. This way of relating to and understanding place within research extends the sphere of Indigenous considerations in institutional research ethics beyond the social science, humanities and health REBs, to those overseeing animal, physical or natural science research (Wilson, 2008). Furthermore, it requires embedding in research and ethics the reality that Indigenous perspectives delineate no clear divide between people, plants, animals and the land: all are connected. Research on non-humans is intimately connected to Indigenous peoples and their identities, relations, lives, livelihoods, stories and responsibilities. Therefore, all projects within Indigenous territories – regardless of whether focused on humans or non-humans, living or inanimate – all things require ethics oversight in line with Indigenous rights and principles.

### **“The stories are ours” – Indigenous-led (or co-led) research**

Within a decolonizing ethic, the principles of Indigenous research will be revealed in how the ethical process reflects the community relationship process (Tuhiwai Smith, 1999). Ideally, Indigenous research should be Indigenous-led, or at minimum co-led. In the situation where the researcher is from the community, using a relationship to co-create their project with other rights holders, the researcher and their team would work through a research project design and an ethics clearance/approval process with the community. In some communities, this may be with an RAC, or in others with the Band Council or counsel of Elders. Only after community permissions, agreements or contracts are obtained would the academic REB processes be pursued. Researchers from outside the community need to do additional relationship building to co-create the research question and work through an ethical engagement process with the community ethics review body and process prior to any

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institutional REB review process. There is variance in how researchers engage with communities and their approvals processes, and with institutional REBs. However, no researcher should seek (or be granted) institutional REB clearance without having first spent considerable time building relationships with the community; finding out who can speak on behalf of the community as a nation; developing a research design and contract, including a data sharing agreement, with the community; and obtaining necessary community approvals. Nation-to-Nation work includes research that is respectful of clear boundaries and clear agreements.

### **Relationships between Indigenous and REB approvals**

There are issues that come up when the academic REB is seen as the final arbiter of ethics. For example, there are times when it is the responsibility of the REB to deny or not grant clearance/approval of applications for research with Indigenous peoples; this is appropriate when the proposed research does not reflect Indigenous rights and principles of good research and right relations and/or when no collective consent has been granted. Such times would include, for example, denial of any research application that does not demonstrate clearly how the research has been created in relationship not only with a particular community, but also how the Nation or governing authority has given approval and how the community will benefit. It is not up to an REB to decide who the rights holders are, but an REB can ensure the researcher has demonstrated that they know and have received permission for their study (Bull, 2019a). The researcher must demonstrate to the REB that they know and that they have the documentation that shows an engaged and detailed relationship of how data are acquired, shared, analysed, stored, stewarded and brought back to the community. No research should be approved or conducted without the appropriate collective and individual consent.

### **Justice and proportionate review of Indigenous research**

Some REBs treat Indigenous communities as “groups who have, at times, been treated unfairly and inequitably in research”, or as “groups whose circumstances cause them to be vulnerable or marginalized”, and thus “may need to be afforded special attention in order to be treated justly in research”, as described in relation to the core principle of “justice” in TCPS2 (p. 10). So, some REBs apply a higher level of scrutiny to research with Indigenous peoples in an attempt to ensure adequate protection of Indigenous participants from research-related harms, including injustices and breaches of respect. In some cases, this higher level of scrutiny entails full board review (instead of delegated review). Unfortunately, this full review may at times create impediments and place unwarranted constraints, and at the same time perpetuate a perception of Indigenous peoples as “vulnerable” (Bull, 2019a).

At times full REB review may be warranted, such as in cases where the research itself is high risk, and/or the community does not have its own review processes in place. In other cases, it is highly inappropriate and insultingly infantilizing in effect. Specifically, to require full REB review for those research protocols that have been approved by Indigenous peoples or organizations serves to enact colonization by re-creating damaging narratives whereby Indigenous peoples are reflected as a special population, identifying them as vulnerable, and discrediting their decision-making authority and autonomy. The TCPS2 does not direct REBs to treat Indigenous communities as special or vulnerable groups, and Indigenous research does not necessarily need increased scrutiny or full REB review.

### **Identifying the Indigenous governing authority for approving research**

In practice, each researcher needs to know the community they wish to engage in research. Therefore, the researcher is in the best position to identify, with the community, the most

appropriate governing authority within or for the community or communities. The REB should not be tasked with determining who the community is and who speaks for it. At times, this can cause discomfort for REBs, who may feel they are then reliant upon “trusting” that the researcher has indeed identified and obtained the appropriate approval, from the right person or the right group (Brunger and Bull, 2011). The discussions at the “Naalak Gathering” reiterated these common struggles regarding authority for research approvals.

In the case of Labrador, the three Indigenous nations are represented by their respective Indigenous government/governing organizations, and they have established research processes to guide research in their communities. We learned that this is not the case across the Atlantic provinces, and it is a challenge to REBs in the region. There were many questions and discussions related to “what to do?” in the absence of clear governing research authorities in Indigenous communities. Should researchers be pursuing research that has not been sought out by a specific community themselves? Are there supports or opportunities to engage communities who are less equipped and/or with less clear governance authority to see if they may be interested in pursuing research?

There is general agreement that, to demonstrate due diligence, the REB should require and check to ensure that an approved research agreement between the researcher and the community is attached to the REB application. This is a particularly contentious issue at institutions that have a stand-alone research legal office that is responsible for contracts. In many cases, the REB does not assert jurisdiction over the creation and execution of these contracts, yet they have an ethical obligation to ensure that researchers have done this work. The legal office can maintain its responsibility for the content of the agreement, and the REB maintains its responsibility for confirming the existence of it and for the conduct of it. The contract should include components such as partnership agreements, memorandum of understanding, data sharing agreements, the goals of the research, decision-making tree, confidentiality agreements, timelines/research plan and dissemination plan (academic and community). It is not the responsibility of the communities to have these in place; the researcher must do and lead this work, and the REB must ensure that it is done.

### **Moving forward, together**

Together as Indigenous and non-Indigenous researchers and REB members, we commit and want to understand how to move forward in recognition of Indigenous peoples’ inherent right to self-determine research with their people and on their lands. We do this by disrupting mainstream dialogue around Indigenous peoples as “stakeholders” in research and by promoting and supporting Indigenous governance of research.

There may be some benefit across the Atlantic region to explore the idea of creating a principled model for Indigenous research governance that is open to Indigenous communities that have not (yet) developed their own processes yet might like to do so. We are not interested in creating a pan-Indigenous approach across the region, but rather, providing examples of processes and tools that may be helpful to communities in the process of developing their own. We can all support each other’s individual and collective efforts without asserting ourselves and our ways or detracting from locally relevant protocols and practices.

What we have been reminded of during the “Naalak Gathering” is that it is not just about academic or institutional REB decolonization: there are broad systematic issues at play. Other guiding, over-arching principles include doing research in a “good” way – research priorities and aims emerge from the community, ideally as Indigenous led; Indigenous research methodologies are embraced; community is engaged throughout the research, in its development, collection of information, analysis and communication of results; and, the community has ownership and stewardship of the data. A good way

includes supporting Indigenous communities in taking governance of research ethics (review and approval/clearance). No research should be approved by REBs without the approval of or clearance by the appropriate Indigenous research governance authority. It is the responsibility of REBs to learn that Indigenous communities are the experts in themselves and have autonomy and authority to make decisions that impact them directly. Pursuing these/our collective responsibilities works towards empowering communities to build their own consensus around research with their people and on their lands. Indigenous peoples are rights holders and have governance over research, including the autonomy to make decisions about themselves, their future and their past; all people engaged throughout the research enterprise has a responsibility to ensure that such governance is respected and upheld.

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