

Bridging the
Policy-Practice Gap:
In Search of a New Model of
Indigenous Research Ethics
Review at Queen's University

FINDINGS REPORT

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# Compiled by

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#### **EXECUTIVE SUMMARY**

This report summarizes the findings of the qualitative research which explored options for designing a new Indigenous research-related ethics review model at Queen's. The research methods included an online survey questionnaire distributed to Queen's faculty members who collaborate with Indigenous communities, and remote, in-depth interviews with key internal knowledge holders (Indigenous and settler researchers, students, staff supporting Indigenous initiatives, REB members, ethics office staff), and external experts (members of the Tri-Agency Reference Group for the Appropriate Review of Indigenous Research and SSHRC's Indigenous Advisory Circle).

The following sections outline the main recommendations provided by the campus community members and external experts who have generously contributed their insights to this report.

# Proposed models of Indigenous research ethics review

The model that garnered the strongest support from the participants is a separate Indigenous research ethics review process, with an independent REB holding the authority to grant or refuse ethics clearance and renew, propose modifications to, or terminate any proposed or ongoing research involving Indigenous peoples. The second most preferred option is a model relying on the expertise of Indigenous research ethics advisors – experts hired to advise the researchers and REBs on ethical issues in relation to research conducted with Indigenous communities. Several participants advocated for creating a separate ethics committee or a panel formed specifically to review Indigenous-related research with a mandate to advise the GREB/HSREB, but without the decision-making power. A small number of participants highlighted the value of an integrated model with robust Indigenous representation on the existing boards, and an option to invite ad hoc advisors representing diverse Indigenous communities and areas of expertise. A few participants proposed models situated outside of the university such as the creation of a provincial Indigenous REB or local community-based Indigenous research hubs with the authority to review ethics applications.

The participants consistently stated that whatever model is chosen, it should involve Indigenous people who are knowledgeable about Indigenous research methodologies or have extensive experience conducting research in partnership with Indigenous communities as well as the expertise in both relational and procedural ethics.

# A relational ethics review process

A common thread running through the qualitative analysis was the need to create a wholistic ethics review process that focuses on transparency while prioritizing relational ways of being and knowing over litigious and overly bureaucratic approaches. The participants were concerned that the communication between the researcher and the REBs tends to be one-sided, requiring the researcher to provide detailed information without fully understanding the rationale behind the reviewers' comments and feedback. There is a need for greater clarity. A mechanism that could potentially facilitate dialogue, transparency and relationality is a conversational ethics review allowing the applicant to participate in the review meetings, with both sides available to address any problematic issues or provide relevant explanation. Although researchers may attend REB meetings most applications do not go to full board review. A verbal, relational ethics review could also bring other benefits such as less time spent on revisions and reduced back and forth between the boards and the applicants. This recommendation stems from the concern that the system currently in place, and designed to follow the ethical principles and the articles set out in the TCPS2, is not aligned with Indigenous ways of knowledge sharing and can be alienating, overwhelming and adversarial. While one-on-one support is available from ethics compliance advisors, the researchers don't know who the reviewers are due to confidentiality issues.

# Greater accountability

An important component of the ethics review process is greater accountability with clearly outlined responsibilities of the REBs, university, researchers, and communities. The onus is currently placed on researchers to provide detailed justification in terms of the need to follow community protocols and comply with ethical guidance provided by Indigenous people themselves. Some participants perceive the main purpose behind the current ethics review as protecting the university from potential liability and securing a steady flow of funding. These administrative "drivers" and frameworks may violate Indigenous research protocols, e.g., when the timeline for spending the funding doesn't recognize shifting community priorities, when modifications to the research plan are not allowed or when the community refuses to follow rigid templates for securing informed consent. The participants advocated for a more flexible model – one that would address the tension between the current requirements in terms of framing research descriptions (or using rigid templates) and the community processes and protocols.

# **Nested mentoring**

The researchers spend a lot of time interacting with the e-submission interface, which can be especially alienating and difficult to navigate for students and early career scholars. Being positioned as just another reference number in a massive ethics application filing system situates this method of research ethics review in harsh contrast to a relational, in-person interaction between individuals committed to ensuring that research is done in a good way.

One way of addressing this issue, in addition to establishing an oral ethics review, is to create and formalize a centralized nested mentorship network focused on capacity and community building and led by a group of advisors dedicated to supporting less experienced applicants in working through their ethics applications. Students and researchers in training would participate in relevant courses and activities while relying on a support system and building a community of ethical researchers. Some mentorship resources are already in place through the supports received by students from their Unit REBs.

# 1. RESEARCH OBJECTIVES

This project is a joint initiative of the Office of Indigenous Initiatives and the Vice-Principal Research Portfolio. It explores the institutional ethics structures and protocols at Queen's University in hopes of bridging the policy-practice gap to address the needs of Indigenous communities and the researchers who collaborate with them, and to help enact better partnerships. The main goal of this study was to design a new Indigenous research-related ethics review model at Queen's, drawing upon recommendations articulated by internal stakeholders at Queen's as well as the members of the Tri-Agency Reference Group for the Appropriate Review of Indigenous Research and members of SSHRC's Indigenous Advisory Circle. Specific objectives are listed below:

- 1. Explore the current ethics review practices across Canadian universities and beyond.
- 2. Critically assess the existing REB processes at Queen's with respect to wise practices in review of Indigenous research proposals.
- 3. Examine the needs, challenges and recommendations of Indigenous and allied faculty, Knowledge Keepers, students and REB members at Queen's in relation to the current institutional process of Indigenous research ethics review.
- 4. Identify the key gaps between the existing criteria of ethics review addressed in the research description and the actual ethical challenges arising in Indigenous research conducted under the auspices of Queen's.
- 5. Design a new Indigenous research-related ethics review model at Queen's, drawing upon recommendations articulated by the campus community members.

Our research goals were not limited to identifying the desired modifications in the language of ethics applications and they extended beyond the changes in protocol to include wise practices surrounding the post-secondary ethics review of Indigenous research in broader terms. For example, issues of interest included capacity building around ethical practices and prioritizing ethics review conducted by an Indigenous research governance body.



# 2. METHODOLOGY AND DATA GOVERNANCE

This research was supported by the Office of Indigenous Initiatives, and we have received approval and feedback from Queen's Indigenous Council and the Indigenous Knowledge, Curriculum and Research Working Group. Both the Indigenous Council and the Working Group were consulted to ensure continuous research oversight for this project and the findings were sent to the interview participants for validation. The overall guidance for our research was provided by the principles of OCAP®: Ownership, Control, Access and Possession (First Nations Information Governance Centre, 2018) and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2, Chapter 9, Research Involving the First Nations, Inuit and Métis Peoples of Canada (Government of Canada, 2018). The decisions about data governance were made jointly by the members of the research team from the OII and the Vice-Principal Research Portfolio, following the guidance and leadership of the OII. Data is stored securely on a VPR Portfolio encrypted laptop by Research Advisor, Equity, Diversity, Inclusion and Indigenization (EDII). After five years, data will be destroyed securely.

The first phase of this research comprised a short review of scholarly and grey literature regarding the university-based ethics review of Indigenous research proposals, and it was summarized in the first section of the report. The review was followed by qualitative research focusing on the recommendations of Indigenous and allied research community members at Queen's. An online survey questionnaire was distributed to faculty members who collaborate with Indigenous communities, and we also conducted remote, in-depth interviews with the key internal knowledge holders (Indigenous and settler researchers, students, staff supporting Indigenous initiatives, REB members and ethics office staff). To complement our environmental scan of the current ethics review practices across Canadian universities, we have also interviewed several members of the Tri-Agency Reference Group for the Appropriate Review of Indigenous Research and SSHRC's Indigenous Advisory Circle. We applied the conversational method in our interviews (Kovach, 2010), using open-ended interview questions to prompt a collaborative dialogue and a co-creation of knowledge between the participants and the researcher.

The analyzed material encompassed 23 interview transcripts and responses from 10 survey questionnaires, including incomplete or partial responses. A thematic analysis of the data (Braun & Clarke, 2013) with the use of NVivo qualitative analysis software was conducted to identify the overarching themes. The list of initial codes was created deductively using the interview and survey questionnaires. New codes were added as the analysis progressed and the codes were grouped into themes which are summarized in the findings section below.

While this report provides some basic quantitative data about the percentage of participants who supported a particular model of Indigenous ethics research review, the findings are predominantly qualitative and aimed at presenting a comprehensive needs assessment and a variety of critical perspectives on how to improve the existing institutional processes.

# 3. INDIGENOUS RESEARCH ETHICS REVIEW AT QUEEN'S AND OTHER UNIVERSITIES

In response to the Truth and Reconciliation Commission's final report and the calls to action, the Canadian universities have taken significant steps to advance inclusive relationships between Indigenous and non-Indigenous peoples, and to create culturally validating educational and research environments. As the research landscape shifts and evolves, many post-secondary institutions have also come to re-examine their current practices of ethics review.

"Extending the Rafters" – the final report of Queen's University Truth and Reconciliation Commission Task Force (2016) – asserts the rights of Indigenous communities and individuals to be equal partners and beneficiaries in culturally-appropriate research that addresses the needs of Indigenous peoples. The report highlights the importance of building reciprocal relationships with Indigenous communities, grounded in meaningful consultations and informed consent. One of the key recommendations of this report is to ensure that researchers and members of REBs are appropriately trained on guidelines for ethical conduct of Indigenous research, with a special focus placed on community engagement as a core ethical requirement.

Queen's has two Ethics Boards with the authority to review research proposals involving human participants: Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB), which reviews health science research, and the General Research Ethics Board (GREB), which focuses on research in the areas of humanities, social science, science, engineering, and administration. Currently, there is no ethics review body formed specifically to evaluate Indigenous-related research.

In terms of the Boards' composition, GREB's SOP 201.001 indicates that the Board will include "at least one member who is either a researcher who is knowledgeable of First Nations, Métis, Inuit (FNMI) issues or an FNMI member of an identifiable Aboriginal community/Native Centre, or non-Aboriginal member closely associated with FNMI community" (2016, p.4). Similarly, HSREB's SOP 201.003 states that when the review of research on topics related to Indigenous peoples or affecting Indigenous communities is regularly required, the board's membership "should include a member with relevant and competent knowledge and expertise in Indigenous cultures, or the inclusion of an ad hoc advisor for occasional review" (2022, p.3).

Queen's ethics review of research involving Indigenous peoples is guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2, Chapter 9, Research Involving the First Nations, Inuit and Métis Peoples of Canada (Government of Canada, 2018). Both GREB and HSREB application forms require Queen's researchers to refer to this chapter and to explain the process for community engagement (or the omission of this step) when conducting research with Indigenous communities. Applicants are also required to demonstrate that they have obtained the necessary community approvals. In 2021, following consultations with the OII and researchers engaged in partnerships with Indigenous communities, the ethics office created a new section of the GREB Standard Ethics Application Form, dedicated to Indigenous and community-based research. The new section includes questions about community engagement, Indigenous codes of research practice, community research priorities, data governance considerations and knowledge dissemination.

TCPS2, Chapter 9 provides a general framework for the conduct of research grounded in or engaged with First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals, however it is not intended to replace ethical guidelines offered by Indigenous peoples and their governing bodies. While many researchers across Canada seem to find considerable merit in Chapter 9, a lot of questions remain regarding its interpretation and specific applications in different cultural contexts, for example with respect to navigating complex Indigenous governance structures (Bull, 2019).

At the same time, Indigenous communities are implementing their own processes for research ethics review which tend to focus on the following three intertwining themes: (1) balancing individual and collective rights; (2) upholding culturally grounded ethical principles; and (3) self-determined research processes, methods, and knowledge translation (Hayward et al., 2021). Several Indigenous organizations and ethics bodies have developed guiding documents that offer insights into ethical conduct of research in specific contexts. Some examples include the principles of OCAP®: Ownership, Control, Access and Possession (First Nations Information Governance Centre, 2018), the Mi'kmaw Ethics Watch Research Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaw People (2000), the USAI Research Framework (Ontario Federation of Indigenous Friendship Centres, 2012), the Manitoulin Anishinaabek Research Review Committee's Guidelines for Ethical Aboriginal Research (2003), Principles of Ethical Métis Research (National Aboriginal Health Organization, 2011), and the National Inuit Strategy on Research (Inuit Tapiriit Kanatami, 2018).

The diversity of cultural protocols and the need to meaningfully engage with multiple Indigenous research jurisdictions in certain types of Indigenous research, combined with the requirements to comply with the university ethics policies provides for a complex research ethics environment, with a variety of relational accountabilities and different perspectives on ethics review. A recent study in Canadian Indigenous research-related context highlights the importance of flexibility in reviewing research and the need for contextual considerations such as the experience of the researcher, the nature of research and the community to be involved, and the volume of applications reviewed by the REB (Langer, 2019). Personal and professional identities as well as insider/outsider experiences of researchers also factor into community-based research with Indigenous peoples (Innes, 2009; de Leeuw et. al, 2012, Marsh et. al, 2015). For Indigenous scholars research often entails fulfillment of extended kinship responsibilities to a specific community (Cidro & Anderson, 2020). These individuals may not view themselves as outsiders whose ethical obligations in terms of research oversight are fulfilled primarily through their roles as university-based researchers. Navigating multiple roles such as an academic, a grant-holder and a member of an Indigenous community can be difficult to reconcile (Cidro & Anderson, 2020), especially in the context of an ethics review which often requires scholars to position themselves outside of the community they conduct research with.

A common issue raised by the scholarship on the research ethics systems, and one that's especially relevant in Indigenous research contexts, is the gap between the formal research ethics review based on the description of the proposed ethics protocol and the ethical challenges emerging in the actual research practice (van den Hoonaard, 2014; Stiegman & Castleden, 2015 Gontcharov, 2016; Bull, 2019), which leads researchers to ponder whether the ethics applications designed by the post-secondary institutions are "asking the right questions." For example, some scholars postulate expanding the sphere of ethical considerations pertaining to Indigenous research beyond human participants to include the place-based, relational processes with respect to land, animals, plants and other beings within Indigenous territories: "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" (Bull et al., 2019). Furthermore, researchers and community activists have highlighted the need to invert the researcher-driven power dynamic that defines community members as "vulnerable subjects" and replace the language describing Indigenous populations as inherently "high-risk" with characterizations that may refer to individuals or groups in "high-risk or vulnerable social circumstances" (Stiegman & Castleden, 2015; Bull, 2019). Other challenges in fulfilling university ethics review protocols include the need to navigate rigid REB standards and heavy procedural requirements, particularly those associated with obtaining written consent from Indigenous communities. This requirement can be perceived as offensive and thus negatively impact relationship building because alternative, culturally grounded protocols for obtaining informed consent (e.g., a ceremony, tobacco offering) may already exist in the communities (Davison et al., 2006).

The environmental scan of institutional websites reveals different ethics review models of Indigenous research (or combinations of models) emerging at universities in Canada and beyond. A few of them are listed below:

- 1. Double review model with an ethics body formed specifically to review Indigenous-related research. At some universities, an existing body, e.g., the Office of Indigenous Initiatives, plays the role of an initial reviewer and community engagement facilitator. For example, Aboriginal Research Advisory Circle (ARAC) at Brock University completes a culturally-informed review of all research applications that fall under the guidance of Chapter 9 TCPS2, which is then followed by the REB's review using ARAC's input.
- 2. Enhanced ethics application model. An additional ethics form or an expanded application section must be filled for the purpose of research involving Indigenous peoples.
- 3. Pre-review model. Consultation with an Indigenous community is required prior to the development of a research proposal and a consultation form is reviewed by a Research Consultation Committee to ensure the project is aligned with the needs of Indigenous communities. The process takes place before any ethics review body is engaged and it is followed by the full ethics review.
- 4. A model relying on the expertise of Indigenous ethics advisors who may be asked by the researcher and by the university REB to provide advice on ethical issues in relation to research conducted with Indigenous communities. The advisors provide support and guidance on draft ethics applications before they are submitted to REBs.

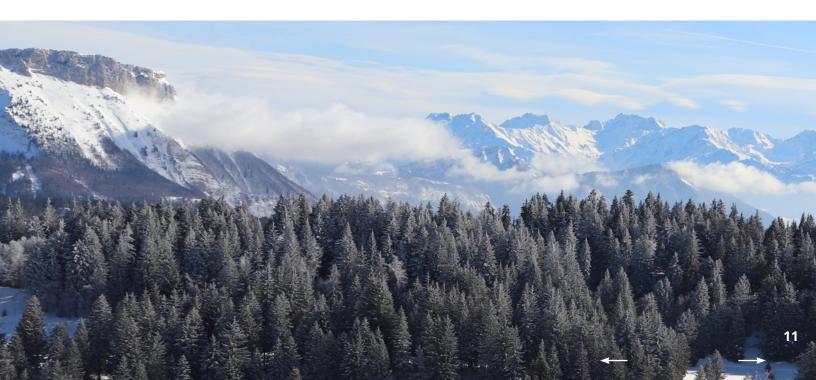
Furthermore, conversations are under way at the University of Calgary and York University about the potential development of independent Indigenous REBs with an authority to review Indigenous research proposals. The University of Calgary has also implemented a new oral process for discussing the ethics applications.

A recent cross-country survey (Langer, 2019) on the best practices in the ethical review of university-based research with Indigenous participants, conducted with participation of REB chairs and research ethics officers, indicates that while at some Canadian universities all ethics submissions with respect to research engaging Indigenous peoples are referred to full board review by default, others have established specific Indigenous ethics review sub-panels. Several institutions engage ad hoc reviewers to provide consultative input on applications that propose research with Indigenous communities, although the REBs make the final decision on the file. Nevertheless, the survey participants recognized that REBs should encourage a broad range of expertise, including experience with Indigenous-based proposals, in their regular membership (Langer, 2019). With respect to the composition of the REBs, some of the institutional policies require that, when possible, at least one member of an Indigenous community be appointed when REBs review research that recruits participants from that specific community. For example, the Université du Québec en Abitibi-Témiscamingue (UQAT) REB includes two members designated by Indigenous communities. Due to concerns about tokenization, these members don't just limit their participation to reviewing Indigenous research projects but evaluate all research projects submitted to the board (Crépeau & Grégoire, n.d.)

The university websites quote a variety of documents that summarize wise practices with respect to Indigenous research and guide researchers in the development of ethically sound applications. Many websites encourage applicants to familiarize themselves with TCPS 2, Chapter 9 (Government of Canada, 2018), several reference the principles of OCAP® and the CIHR Guidelines for Health Research Involving Aboriginal People (2007-2010) (Canadian Institutes of Health Research, 2013) in addition to internal guidelines, policies and protocols.

A few examples of institution-specific frameworks and policies include Memorial University's Policy on Research Impacting Indigenous Groups and Principles for Engagement (Memorial University, 2020), Framework for Research Engagement with First Nations, Metis and Inuit Peoples (University of Manitoba, n.d.), and Guidelines for Research Involving Indigenous Peoples in Canada (Ryerson University, 2017). Several of the reviewed websites feature links to external Indigenous research ethics committees that oversee research proposals engaging Indigenous communities in specific territories such as the Manitoulin Anishnaabek Research Review Committee (MARRC), Six Nations Council Research Ethics Committee and the Mi'kmaw Ethics Watch. An in-depth review of internal protocols was not always possible given that the users are often required to log in to an online system to access the ethics forms. This prerequisite points to the need of a more transparent research environment – one that allows members of the public, especially the Indigenous community members, to review important documents that reflect institutional accountability to Indigenous peoples (Bull, 2019).

In terms of building ethical research capacity, several websites reference Indigenous research centres or research support initiatives. Some of those units mention principles of engagement for Indigenous communitybased research, data governance and ethical best practices around the life cycle of Indigenous research as their areas of expertise. For example, the main purpose of the Carleton University's Institute on the Ethics of Research with Indigenous Peoples is to provide a week-long summer certificate programme where diverse audiences (Indigenous and non-Indigenous researchers, REB members, representatives of governmental and non-governmental organizations) have the opportunity to learn about wise practices in engagement and ethical conduct of research with Indigenous communities (Carleton University, n.d.). Indigenous Research Support Initiative (IRSI) at the University of British Columbia appears to be particularly well-positioned to accompany the academics and communities on their research journey, given that its primary focus is to provide supports during pre-engagement and engagement, and to gather best practices on Indigenous, community-based research. The Initiative supports specific research partnerships between UBC and Indigenous communities and serves as the first point of contact for the communities and researchers. Some of the resources offered by IRSI include cultural awareness training, co-development of research agreements, conflict resolution, and identification of funding opportunities. IRSI has established an Indigenous ethics steering committee comprised of Indigenous and non-Indigenous faculty and staff who have expertise in the UBC's Behavioural Research Ethics (BREB) process and in Indigenous research methodologies. IRSI is currently working to co-develop ethics guidelines and processes to support Indigenous, community-based research (University of British Columbia, n.d.).



# 4. SUMMARY OF FINDINGS FROM THE QUALITATIVE RESEARCH

# 4.1 Indigenous research ethics review model: general considerations

A vast majority of the participants agreed that the current model of Indigenous research ethics review needs to be changed. Several participants thought that the system currently in place is not designed for reviewing Indigenous research and fails to address the needs of Indigenous people.

Research ethics review is often perceived as a game that requires the "players" to use their "insider knowledge" to "write the right things" in order to secure ethics clearance. Some participants noted that reinforcing the existing practices causes harm to Indigenous people and stands in contradiction to Indigenous ethical guidelines that emphasize building strong, transparent relationships. The current procedures emerged from Western institutional standards and several participants advocated for a model that would provide a more balanced perspective, drawing from the strengths of both Indigenous and Western worldviews. REBs should share lessons learned through the review of Indigenous research in a transparent and accessible manner.

The new model cannot be too burdensome and too onerous so as not to discourage researchers and their Indigenous research partners from collaborative research. Researchers engaged in Indigenous research must have reliable supports and should benefit from the merit review metrics that recognize the complexities of work with Indigenous communities.

Finally, the new/modified model should be populated by a diverse representation of Indigenous people (e.g., First Nation, Métis, Inuit and urban Indigenous representatives). Having one Indigenous person on the REB is not enough to address diverse cultural realities because one individual cannot speak on behalf of multiple Indigenous communities. The participation of Elders is key to securing that the ethics review is done in a good way.

# 4.2 Overview of the proposed models

Roughly 42% of the participants agreed that there needs to be **a separate Indigenous REB** run by Indigenous people themselves with a decision-making power regarding ethical review of research that involves Indigenous communities. A separate REB would thus create an opportunity for Indigenous people to come together and create a self-determined research ethics review process that's more aligned with Indigenous ways of being and knowing. When asked about the mandate of the board, those participants asserted that the Indigenous REB should have complete authority over the review process rather than advising GREB and HSREB.

Establishing a separate Indigenous board is not an easy undertaking and may require a pilot, staged approach. This may entail the need to liaise with the existing boards for specific reviews and ask for recommendations if the Indigenous REB lacks the relevant expertise. The role of the Indigenous board may also involve consulting with ad hoc advisors who are holders of specific cultural knowledge or experts in a specialized area of research, as well as seeking insights from individuals representing Indigenous communities impacted by the proposed research. Furthermore, the applicants should have an option to suggest reviewers and reviewer exclusions.

Another important aspect of the REB's work would be mentoring early career board members on ethics review. In addition to following the general principles of Indigenous relational ethics, TCPS2 and institutional policies, the board would also pay close attention to local protocols and values specific to the context research is located within. The vision for the board is to create a transparent, culturally grounded review system that would eliminate the need to submit inaccurate or culturally inappropriate research plans or hide certain aspects of research out of fear that full transparency will raise flags with the board. At the same time, the creation of an independent Indigenous REB may address concerns about insufficient competency of reviewers who don't have the knowledge and cultural sensitivity to review Indigenous research proposals appropriately.

Almost one quarter of the participants (24%) supported a model involving **Indigenous research ethics advisors** while offering different perspectives on how it should be operationalized. Several participants proposed an approach that relies on the expertise of internal advisor(s) hired in paid roles to provide guidance on draft ethics applications before they are submitted to GREB/HSREB. These advisors were attributed certain characteristics by some participants, e.g., a skilled educator with a caring, listening heart and an Elder's mentality as well as flexibility, willingness to consider different perspectives, and the ability to talk things through in a thoughtful way to find solutions that will benefit everybody. Considering how overwhelming the ethics process can be for students and the impacts it may have on their confidence and sense of belonging, the advisors would need to be especially sensitive to the needs of Indigenous trainees. The participants also talked about the importance of a nested, collaborative approach. It would include continuous mentorship provided by the advisors who may host monthly drop-in sessions to discuss research proposals, help applicants identify ethical issues and work through them together, thus creating a supportive community of practice for students and researchers in training.

Other participants emphasized the need to engage external ad-hoc advisors when the REB members don't have the expertise that's relevant to a specific Indigenous context. Several participants, who located themselves within a particular First Nation, expressed that they wouldn't be comfortable evaluating an ethics application relevant to Inuit or Métis communities. Recruiting advisors representing different nations and diverse Indigenous communities who are available to participate in ethics reviews, although certainly challenging and taxing for community members, could potentially address this issue and facilitate the assessment of contextual complexities (e.g., the nature of the relationship with the community, the desirability of research and risks and benefits from the community perspective). The participation of Indigenous community members sought out for specific knowledge and expertise would facilitate a broader dialogue and an opportunity to test different scenarios so that the research impact can be evaluated more accurately.

Although not without merit, this approach requires a fair amount of caution and establishing clear policies about declaring conflicts of interest. In fact, the participants differed in their opinions about situations in which potential conflicts of interest may arise. Some stated that if the reviewed research involves the community of the committee member, they should be excluded from review and advising, while others emphasized that arms length requirement is a Western concept and that close relationships as well as the accountability to specific communities will ensure critical feedback and strengthen the review process.

Roughly 15% of the participants were in favour of creating a double review model with a separate **Indigenous** advisory ethics review committee, formed specifically to review Indigenous research proposals and make recommendations to the existing boards. The GREB and HSREB would use the committee's input in their review and retain their roles as ultimate decision makers in terms of ethics clearance. The pre-screening function would be similar to the role currently fulfilled by the Unit REBs, but with the focus on Indigenous research, combined with relevant domain knowledge and a capacity to advise researchers, mentor students and suggest proposal modifications. Some participants viewed this option as an initial step and a temporary model that would eventually evolve into a fully independent Indigenous REB, allowing the committee to develop a solid knowledge base and a strong membership over time. Others proposed a creation of an additional layer of review consisting of an Elders' Council available to advice both the Indigenous committee and the existing boards on proposals that address Indigenous knowledges, languages and ceremonies.

An integrated ethics review model with increased Indigenous participation was supported by 9% of the participants, on the condition that it can foster Indigenous research capacity building for all board members, especially those with no previous expertise in reviewing Indigenous research ethics applications. For example, one participant noted that there is no need to recruit a diverse group of Indigenous people representing different communities to sit on a separate Indigenous board. Such diversity may not be easily achieved, whereas a good quality review can be ensured by training the members of existing boards in general Indigenous research principles and frameworks such as Chapter 9 TCPS2.

The participants who shared a similar opinion felt that with separation and creation of a new body comes the risk of a lost opportunity for meaningful change and reconciliatory education. It is the responsibility of all to establish epistemological shifts in the academy and create a welcoming space for Indigenous people. The participants who supported the model that currently exists at Queen's expressed concerns about the potential marginalization and isolation of a new, independent Indigenous REB, which may be perceived as having a lower status in relation to GREB and HSREB. The integrated model based on the existing boards would encourage the board members to educate themselves and be accountable, whereas the model advancing separation carries the risk of putting an excessive burden on Indigenous people who may not consider university-based Indigenous research ethics review a high priority in relation to advancing the goals of their own communities. With increased Indigenous representation in the boards' regular membership, continuous, mandatory Indigenous research training and the ability to consult with Indigenous ad hoc advisors from diverse Indigenous communities, the integrated model could contribute to breaking silos, facilitating dialogue and a greater opportunity for non-Indigenous researchers to decolonize their ways of thinking and enact relational ethics.

Roughly 6% of the participants identified the need to channel supports, funding and other resources into creation of research ethics review authorities situated outside of the university setting. A creation of a **provincial Indigenous REB** was identified as one of the preferred approaches for oversight of Indigenous research taking place in Ontario. This was envisioned as a council with robust Indigenous membership representing diverse contexts, interests and sensitivities that ensures compliance with the TCPS2, consults with communities and provides a sign-off on ethics applications before they are evaluated by universities. Another option, similar to the creation of a provincial body, would be the establishment of several **Indigenous community-based research** hubs across the country. This model stems from the need to provide a structure that supports enhanced engagement and relationship building with funding flowing directly to communities, instead of fixing the existing university processes. These local organizations would be responsible for increasing the capacity for research in specific communities, bridging institutions and nurturing meaningful research partnerships wherein commitment to a relationship and a continuous reflection about community context takes precedence over project-driven research cycles. Within this approach, ethical conduct of research is not an add-on, but a natural consequence of deep relationships, built over a long period of time.

# Reflections about a separate Indigenous research ethics review body

# Composition

In terms of an ideal composition, most participants indicated that a separate Indigenous research ethics review body should be populated by Indigenous people and experts with hands-on knowledge of communitybased research and Indigenous methodologies. They would display qualities such as a listening heart, conflict resolution skills and openness to discuss diverse perspectives on Indigenous research in a thoughtful manner. The knowledge of university liability clauses, procedural ethics, Indigenous research contracts, data sovereignty and intellectual property was also considered important. The board should be led by an Indigenous chair and include a strong Indigenous representation from different faculties as well as Indigenous staff, graduate students, Elders and community members with experience navigating research partnerships and the ability to assess the impact of research. It was considered important that the members have expertise grounded in Indigenous knowledge, lived experience and cultural location in their own communities (e.g., the focus on the knowledge about Indigenous hereditary structures of stewardship and protocols that govern cultural legacies rather than Western copyright). It might also be appropriate to invite non-Indigenous researchers respected by Indigenous communities and knowledgeable about ethics to alleviate the disproportionate amount of service carried by their Indigenous peers. Some participants felt that the determination about extending membership to settler colleagues should be at the discretion of the Indigenous members and that the ally researchers should be selected among those recognized as appropriately informed, engaged and accountable by Indigenous rightsholders. There were also concerns about the fraudulent claims to Indigenous identity, followed by a recommendation to choose members among individuals with verified Indigenous identity and community ties. It was considered important that the board has a gender diverse and Indigenous diverse representation to minimize situations when a board member with a First Nations affiliation advises on Inuit or Métis cultural protocols. Ideally, the review should include representatives from a nation/community whose welfare is impacted by the research. Therefore, when justified by the circumstances, the REB may seek expertise outside of their regular membership to provide accurate assessment (e.g., members of communities impacted by the research, experts with relevant domain knowledge). This may prove to be less challenging in current circumstances, given the growing use of remote communication tools. As the board builds capacity, it may wish to invite paid visitors or guest members such as distinguished Indigenous scholars from other universities recruited for specific reviews or asked to contribute to the development of the board as part of the interinstitutional relationship building.

#### **Positive Shifts**

We heard strongly that the new board should generate several positive shifts at the university. HSREB and GREB do not always have Indigenous representation within their regular membership and the current system facilitates the review of Indigenous research proposals by members who may not have the necessary Indigenous research expertise. This sends an ambiguous message to Indigenous researchers and community members in terms of the boards' credibility and accountability. It also creates extra work for the applicants with lived experiences of conducting research with Indigenous communities. These applicants are often required to "spell things out" – a requirement that applies to all researchers who submit ethics applications since the reviewers do not possess specific expertise in all fields of study – which often results in an onerous back and forth with the reviewers. This challenge could be potentially addressed by forming an independent body composed by members who are Indigenous themselves and/or intimately connected to Indigenous communities, their priorities, worldviews and responsibilities. Such a board could lead by example and create a safe space for reviewing Indigenous research-related proposals combined with knowledge base that would potentially benefit other institutions.

The applicants would benefit from a deeper and more meaningful feedback and the new board could potentially become a recognizable and comfortable point of reference for the Indigenous communities, build trust in the university processes and create relationships with other Indigenous research ethics review boards. There were participants who felt that for Queen's to become an authentic driver and supporter of Indigenous research, it needs to shift the current dynamics that situates the power to grant ethics approval in Indigenous contexts within the non-Indigenous ethics review process. This process does not capture cultural protocols and other fundamental aspects of Indigenous research. A model ensuring that Indigenous knowledge, ceremonies and languages are protected to prevent appropriation and helicopter research, is therefore urgently needed. A separate Indigenous board would also fulfil an important role in educating researchers about the implications of their projects and create a safe space for conversations about relationality, reconciliation and research driven by benefits to Indigenous communities.

#### Challenges

The creation of an independent Indigenous REB may pose numerous challenges, but several participants were confident that these difficulties can be addressed by providing thoughtful institutional supports. The amount of service work invested in this undertaking would be significant. Depending on the volume of Indigenous researchrelated applications, the process may require additional Indigenous hires and capacity building. Indigenous faculty and staff at Queen's are highly sought after for their time and expertise and already heavily engaged in a variety of service and mentorship activities. Some Indigenous participants noted that asking Indigenous faculty to indigenize the university while requiring them to maintain the same workload as non-Indigenous peers is unfair. Indigenous faculty members often carry service responsibilities to both their communities and their institutions. Requesting that they cut service activities that are crucial to who they are as people and asking them to focus on teaching was considered harmful and inappropriate as it can negatively impact their relationships. Were these faculty members willing to sit on an Indigenous REB, their university-wide service should be recognized by providing them with teaching release, by reducing the service load in their respective units and by fully acknowledging their contributions through an inclusive merit review process. Other solutions included establishing a rotating leadership model to prevent burnout and increase productivity. Some Indigenous REB members could be recruited externally and receive compensation or be hired in paid roles. Furthermore, the board would require Indigenous ethics managers and coordinators to support the establishment of the board and facilitate review activities.

Other participants flagged several problematic issues in relation to recruitment of Indigenous community members outside of Queen's, such as asking them to invest their valuable time in a university-based process of evaluating research instead of focusing their energy on addressing the pressing needs of their own communities. Furthermore, this process may be viewed as a form of cooption of the community members' time and knowledge by an ethics review body situated at an academic institution when these resources could be invested in building capacity and strengthening research governance structures in their own communities.

Several participants expressed a concern that there may not be enough Indigenous faculty members with the expertise that's required to fulfill the membership requirements as outlined by Chapter 6 TCPS2 and other provincial/territorial or federal regulations (e.g., the membership requirements to review clinical trials or the knowledge of relevant law which is mandatory for biomedical research and advisable for other areas of research). Indigenous research applications may cover a wide scope of different research areas which would require not only a specialized knowledge of Indigenous research protocols, but also the expertise that's required to understand the content area and the methodology of the proposed research. Furthermore, if the mandate of the board expands to include research conducted with more than human kin on Indigenous territories, the members would need to have relevant expertise (e.g., local land-based cultural protocols, biohazard, chemistry, biology, etc.) To address this challenge Queen's could recruit external Indigenous experts to sit on the Indigenous REB. Reviewing applications from diverse areas of research was also seen as an opportunity to build and share a valuable knowledge base, drawing on the uniqueness of each research project and its impacts on Indigenous communities.

A small number of participants noted that one of the areas requiring capacity building in terms of reviewing Indigenous-related applications is international Indigenous research. They also recognized that it may be difficult to determine the kinds of research that would fall under the purview of an Indigenous REB versus GREB and HSREB. Some participants drew attention to the diversity of Indigenous research contexts and cautioned against attributing monolithic, overgeneralized qualities to Indigeneity and ways of conducting Indigenous research. Those participants pointed out that occupying the role of an Indigenous REB member is not synonymous with having a final say on how a particular Indigenous research project should unfold.

Other recurrent themes in our conversations about challenges included the risk of working in siloes, lack of transparency and lost educational opportunities for members of GREB and HSREB. This risk could be mitigated if all three boards engaged in dialogue with each other, documented their practices and shared the findings with the campus community. Furthermore, inviting academic leaders and administrators (e.g., Associate Deans Research) to sit on the Indigenous REB's meetings may also result in valuable learning opportunities.

# 4.3 Nation-to-nation relationship building

Our research provided an opportunity to discuss nation-to-nation relationship building and its implications in terms of providing a blueprint for Indigenous research ethics review. Based on what we heard, the University Research Ethics Boards are participants in the process of redressing past wrongs and advancing Indigenous people's self-determination over research. Furthermore, the conversations about Indigenous research ethics review need to be refocused. Recognizing Indigenous communities as rights holding partners instead of "inherently vulnerable subjects in need of care" is crucial, but so is the fact that there may be vulnerable segments within Indigenous populations. Their protection, based on contextual factors, merits special consideration in ethical assessment of risk, following the principle of concern for welfare.

Nation-to-nation relationships could be enacted both internally, through the ethics of mutual sovereignty and co-existence of Indigenous REB, GREB and HSREB, and externally – by forging high-level research agreements with specific First Nations, Métis, Inuit peoples and urban Indigenous communities. It is noteworthy that some institutions are already making efforts to implement this approach. For example, the Indigenous Research Support Team (University of Calgary) strives to forge long term research partnerships between the university and specific Indigenous nations that extend far beyond the duration of a particular research grant and an individual research collaboration between faculty members and community members.

Were this scenario to play out at Queen's, the participants suggested that the senior leadership could approach national or regional Indigenous organizations (e.g., Inuit Tapiriit Kanatami) to ask how our institution can help advance their strategic research priorities. Such conversations may result in agreements between the authorities at the highest level of institutional governance (e.g., between the Principal of the university and the Chief of the First Nation), providing general guidelines and blueprints for internal processes and protocols, including those relevant to Indigenous research ethics review. These relationships would have to be polished, honored, discussed and revisited periodically with an understanding that research partnerships are impacted by actions of entire organizations/institutions and not just individuals who collaborate on a specific project. However, some questioned the capacity of postsecondary institutions to nurture nation-to-nation relationships since most universities continue to sustain ongoing settler colonialism. Others cautioned against adopting a blanket approach because reconciliation efforts and the advancement of nation-to-nation relationships vary province by province. Furthermore, implementing this type of framework may be challenging for the nations and communities who don't have the capacity to assume certain regulatory and administrative responsibilities (e.g., the capacity to carry significant liability insurance). This prompts the urgency to establish a multi-pronged support system that channels the flow of funds towards building research capacity and administrative power in Indigenous communities, while simultaneously accommodating the need for flexibility to address unforeseen community circumstances that may deter or delay research. Following this line of thought, some participants noted that the post-secondary institutions should fulfill their reciprocal responsibilities within nation-to-nation framework by supporting Indigenous communities in developing their own research ethics review bodies and protocols and by advocating for the establishment of funding dedicated to creation of community-driven research administration processes. Since culture is what has kept Indigenous people alive, it is the obligation of the settler society to support research structures that sustain Indigenous governance and kinship.

The participants felt that our discussion about nation-to-nation relationships is meaningless without concrete practices that address lack of relationality and the dominance of litigious perspectives in the ethics review of Indigenous research. Academy indigenization requires a radical change in leadership practices of senior administrators so that they can honour nation-to-nation relationships and contribute to the "polishing of the chain" by learning about the ethics of research with Indigenous people.

Some participants thought that the only way to enact nation-to-nation relationships is to radically change the structure of existing boards either by increasing Indigenous participation to ensure that Indigenous individuals co-chair them or by creating a separate body specialized in reviewing Indigenous research proposals.

According to some participants, nation-to-nation framework recognizes that the review of Indigenous research requires specific expertise and that it should prioritize nation-specific research protocols as well as Indigenous-led, unique understanding of research partnerships. It respects the inherent power of a nation or a community to grant ethics approval and ensure the highest standards of research conducted with its people. It recognizes this approval as the primary ethics clearance, which in turn provides the basis for expediting the university ethics review process.

Ideally, enacting nation-to-nation framework in ethics review should foster transparency through easy access to the records of ethics clearance granted to Indigenous research projects conducted under the auspices of Queen's. Navigating the path of mutual sovereignties requires Queen's to respect self-determined Indigenous ethics processes while simultaneously upholding its own institutional responsibility to minimize the risk to research participants and assess the ethical behaviour of faculty and staff engaged in research with Indigenous communities.



### 4.4 Prescreening process prior to ethics review

Developing relationships with Indigenous peoples can take years whereas the funding competitions often have a short turnaround time and require researchers to quickly mobilize their relationships and resources to write a competitive proposal. While the funding agencies' timelines often do not leave enough room and flexibility for community-led research, strong engagement with First Nations, Inuit and Métis peoples prior to the development of any project that involves them remains an ethical imperative.

Unfortunately, the "nothing about us without us" principle is not always upheld, and some scholars continue to forgo the step of engaging in relationship building and collaborative research design with Indigenous communities prior to the submission of Indigenous research-related grants. In 2020, Memorial University approved the first of its kind Policy on Research Impacting Indigenous Groups that requires researchers to engage with Indigenous groups at the very start of research. We asked the members of our research community about their views in terms of formalizing a similar requirement at Queen's.

In general, the participants found some merit in the idea of establishing a pre-screening process at Queen's prior to the ethics review to ensure that community engagement is initiated at an early stage and before proceeding to the next steps of research such as submitting funding proposals. Several individuals thought that the pre-screening mechanism should be optional and apply primarily to researchers in training or those who are new to Indigenous research partnerships. However, many cautioned against paternalism and noted that adding another layer of bureaucracy to an already tedious process would be too burdensome, especially for Indigenous researchers who need to balance substantial workloads. The preliminary review was perceived as harmful by some participants who thought that the university administration should not be interfering with the research process by assessing and verifying the nature of relationships between researchers and Indigenous communities.

Some participants pointed to the existing gatekeeping mechanisms which could mitigate concerns about research co-creation such as the Tri-Agency peer review process. One of the participants, who has served as a member of the CIHR review panel, noted that the reviewers are usually very skilled at detecting and flagging lack of evidence of meaningful engagement in Indigenous-centred proposals.

Finally, the participants weren't sure if the university could dedicate resources to the process and what unit would be well positioned to navigate power differentials while implementing the pre-screening process in a way that doesn't create additional administrative obstacles.



# 4.5 Appropriate engagement strategies and evidence of engagement

The participants highlighted the importance of engaging in authentic, long-term relationship building before applying for funding. They were concerned that many researchers are not interested in that type of time and energy investment. Engagement was seen as a process that, in its initial stages, has little to do with research as it is designed to get to know each other and build trust.

Careful planning and long-term sustained commitment are crucial but may be especially challenging for students who struggle with rigid degree completion timelines. Engagement is not a box-ticking exercise and specific strategies will depend on several variables, including:

- The type of research and the associated risks and benefits (e.g., interventional health studies vs. arts-based research).
- The size of the grant.
- The community capacity and its desired level of research engagement.
- The track record and experience of the researchers in terms of partnership building.
- The existence of a predetermined consultation process. Some research governance authorities such as The Nunavut Research Institute share researcher proposals with key Indigenous stakeholders and request feedback as part of their scientific research licensing process.

Researchers will apply different approaches when engaging with a specific community vs. approaching Indigenous individuals from multiple communities or working in Indigenous contexts internationally. Culturally grounded forms of engagement should be encouraged if desired by the community (e.g., sending a runner to the community authority with a message and an invitation to meet). Some communities may wish to engage deeply throughout all stages of research, others may limit their involvement to the initial approval of research design and review of findings.

The participants highlighted the importance of context-specific, community benefit-driven, relational approaches when research includes primary and/or secondary data collection that covers a diverse range of Indigenous communities. Caution should be exercised in terms of the sources of secondary data, their use and interpretation even if the data are publicly available. As a wise practice, secondary research should be preceded by consultations with specific communities, experts in the field and Indigenous advisory bodies established by different institutions that hold Indigenous People's data (e.g., museums, archives, health institutions, universities). Secondary research should be conducted in collaboration with Indigenous partner(s) if the findings are anticipated to impact Indigenous communities. Sometimes the research license granting bodies (e.g., Nunavut Research Institute) can also provide guidance in terms of who should be consulted.

Another wise practice listed by the participants was "following the paper trail", e.g., reviewing the resolutions of the Assembly of First Nations or documents published by specific band councils and other Indigenous organizations to get a better understanding of the types of research that they currently support or advise against.

The participants proposed three main solutions regarding instances when research involves multiple Indigenous communities and/or organizations:

- 1. Establishing an advisory council consisting of the key community representatives to govern the research.
- 2. Consulting with and establishing accountability to the existing authority structures representing the collective interests of different communities. If the research has a large or national scope each community may wish to create their own local advisory council in addition to participating in the national governing body.
- 3. Engaging individually with each of the communities involved in the research project (e.g., through separate research agreements).

While seeking out diverse voices in the membership of advisory councils is certainly of value, one participant suggested that sometimes an open, relational membership approach works better than strict adherence to broad representativeness. For example, the council could build a relationship with a potential new member because they share similar values and understand the principles that guide the decision making.

Several participants emphasized that engaging individually and taking the time to build strong relationships with each of the communities participating in research is important as it leads to better research outcomes and strengthens Indigenous data sovereignty. Speaking to a specific community rather than defaulting to a provincial or a federal level Indigenous organization/advisory body was considered more meaningful since Indigenous research is often place-based and emerges from local knowledge, relationships, practices and needs. Furthermore, if the researcher doesn't have experience working with diverse groups of Indigenous people, then forming a large advisory body may pose a risk of damaging the relationships. If an independent REB is created it may consider helping researchers who are planning to take on large scale, complex studies involving multiple communities by assigning them an ethics mentor.

Accountability in fulfilling research obligations is of outmost importance and can be expressed through the implementation of a community-vetted plan for data management and through findings validation and sharing. Another important consideration is the need to secure funding for the communities to build local data storage infrastructure and management capacity rather than depending on the external entities. Establishing university-community partnerships to help build Indigenous data sovereignty while following culturally appropriate protocols is one way the academic institutions and individual researchers can give back to the communities they collaborate with. Researchers should be mindful of the fact that different nations and communities have varying degrees of research capacity and while some may have a robust research infrastructure, others have limited ability to engage in research. Finally, the key consideration in this process is respecting Indigenous peoples' refusals and their inherent right to say "no."

Meaningful engagement involves frequent check-ins and being mindful of changing circumstances, resources and timelines in the community. It extends beyond the duration of a particular research project. It also means that research fundings and benefits need to be readily and swiftly available to Indigenous communities and not just to universities so that they can develop their own research capacity and manage successful projects.

Research and knowledge mobilization should follow protocols that focus on reciprocity, celebration and gratitude (e.g., a feast, a ceremony, gift giving, paying for food baskets, hosting a lunch, offering tobacco). Research findings are meant to support Indigenous resurgence and should be shared using everyday plain language.

Offering one's skills and expertise, active listening, awareness of trauma associated with settler colonialism, and following research priorities that are self-voiced by Indigenous people rather than promoting research ideas that are shaped by non-community members are minimal requirements that support adequate research engagement. The necessary step for many non-Indigenous researchers involves taking cultural competency training and building awareness around Indigenous issues. The appropriate authority or a specific community segment that will guide and approve research is identified by the community and not chosen arbitrarily by the researcher or REBs. Space should be created throughout different stages of research to pause and check if the planned activities are still aligned with the goals and values that set the project in motion.

There needs to be a separate funding for relationship-building to ensure that diverse voices in the community (beyond the formal leadership) are represented and determine what kind of research is needed. Such funding would facilitate the space and resources needed to develop ethical processes and evaluation metrics that are meaningful to the community.

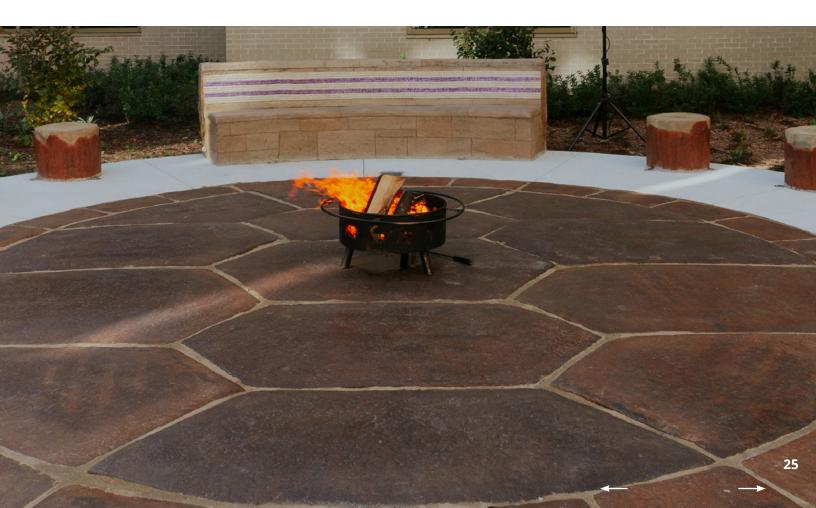
The participants listed a wide range of options that could be considered evidence of an appropriate engagement process with Indigenous research partners, depending on the preference of a community and a researcher:

- Description of the nature of a research collaboration and relationship with an Indigenous community (included in the ethics application form by the researcher). The summary clearly identifies what community the researcher has engaged with (e.g., a land claim organization, a land-based education community of interest, a Friendship Centre, a band council, a health authority in a specific First Nation, etc.) and how the consent protocols were followed (e.g., a smudge, a ceremony, a feast, tea and talk). Stories are considered a vital element of Indigenous research and a narrative of a research relationship should be considered appropriate by the REBs. The researcher may also wish to confirm that the letter of information was provided to the community members and describe how consent was obtained (without the requirement to sign the consent forms). If the narrative is not satisfactory, a letter of support or other documentation may be requested (e.g., previous work documentation and publications co-authored with the community if applicable).
- Inviting a community lead to a REB session to address the research proposal (if appropriate and does not put an unnecessary burden on community members involved in the research project).
- Resolutions from councils and Indigenous authorities.
- A letter of support.
- An email exchange.
- A text message.
- Community members being listed as PIs on the funding/research proposal.
- Providing contact information for a reference (e.g., a community lead on the project) followed by a phone call.
- A research or data sharing agreement.
- Ethics approval from an Indigenous REB.
- Records of engagement sessions, e.g., quotes from recorded conversations (shared with community members' permission).
- A form signed by a researcher, confirming that they have completed initial consultations, received the community's approval and will continue to engage at all stages of a research project.

Some researchers pointed out that the requirement to provide evidence of engagement automatically assumes "outsider positionality". Indigenous researchers who have long-standing research collaborations with their own communities are required to provide such evidence every time they embark on a new project. Providing the proof of engagement, as stipulated by Chapter 9, TCPS2, puts them in an awkward position because they are repeatedly asked to confirm that they belong – a prerequisite, which was described by some as paternalistic, insulting and condescending. The REBs should differentiate between the need to require a formal proof of engagement from researchers who are non-Indigenous or have recently initiated a relationship with a community and those individuals who have long-term continuous partnerships. This distinction could perhaps be addressed by including a relevant question in the ethics application.

The participants have also listed several accommodations and wise practices that should be followed to facilitate Elders' participation and to foster more accessible research:

- Examining university policies that may impact the ability of the Elders to be involved in the research project (e.g., payment policies).
- Offering the option to provide verbal consent or other, non-disruptive and culturally-appropriate forms of consent.
- Offering letters of information in accessible formats and using plain language summaries.
- Asking for support from the Elder's helper or a family member if available.
- Providing appropriate honoraria to Elders and their helpers and following reciprocity protocols.
- Providing translation services.
- If the Elder actively participates in the creation of research deliverables the researcher should offer to read the draft versions or share them in accessible formats.



# 4.6 Changes in the composition of GREB and HSREB

The participants differed in their opinions about the need to modify the current membership of the boards. Some thought that, since the GREB and HSREB review research from a perspective that generally privileges Western methodological, scientific, and ethical traditions, reserving one seat on each board for an Indigenous representative is clearly insufficient and will not effectively address the need to decolonize these structures. Thus, establishing a separate REB is key to sustainable change. Other participants pointed to the need of recruiting both Indigenous and non-Indigenous members and ad/hoc consultants (with accountability to Indigenous rightsholders) to serve on the existing boards. Such membership would represent different levels of seniority, diverse Indigenous communities, a proven track record in Indigenous research and a solid understanding of Indigenous worldviews. Another group of participants recommended training the current membership on Indigenous research methodologies and relational ethics review protocols instead of increasing Indigenous representation and putting unnecessary burdens on Indigenous people.

Overall, many participants recommended increasing the number of Indigenous people on the boards, although implementing this recommendation will likely be contingent upon the establishment of a new Indigenous Research Ethics Review Board. It is noteworthy that some participants considered it important to have Indigenous membership on the existing boards even if Indigenous research applications are channeled through an independent REB. Many projects that do not explicitly pursue Indigenous research could benefit from the expertise of an Indigenous researcher with an interdisciplinary outlook (e.g., land-based research). The boards' decision making should thus be informed by diverse perspectives and a dialogue of knowledges.

The obligatory requirement to recruit one Indigenous member and one alternate member on the REB has already been embedded in the policy of some institutions such as the Université du Québec en Abitibi-Témiscamingue (UQAT). However, one participant reported that HSREB has difficulties recruiting their general membership – a process which has proven even more challenging when attempting to recruit Indigenous faculty members, given the demands on their service. Furthermore, the time commitment required to be a member of HSREB is usually substantial, since the reviews involving clinical trials are very complex. Considering these difficulties, an obligatory requirement to incorporate Indigenous REB members may be problematic in terms of meeting the quorum rules.



# 4.7 Appropriate compensation and acknowledgment

In terms of culturally-appropriate, reciprocal strategies for recruitment of Indigenous community members to serve on institutional REBs, they should be asked about a preferred form of compensation. While making a request, the university administrators should bear in mind that not everyone wishes to receive honoraria, especially if they see specific types of service as tied to fulfilling their cultural responsibilities. However, one participant noted that there shouldn't be any exceptions or discrepancies when it comes to the payment of honoraria. Either all or none of the REB members should be compensated. Nonetheless, while reflecting on the importance of asking about people's preference first, most participants stated that some form of compensation should be offered and listed the following options:

- Teaching release and significant credit given to the Indigenous faculty in the merit review process and professional assessment.
- Honoraria should be offered to Elders and community members, external ad hoc advisors or visiting REB members. A community member's expertise is as valuable as that of an academic and they should be compensated accordingly.
- Honoraria for students. Research ethics review process can be complex and time consuming. The
  difference between the students' financial circumstances and the privileged position of other board
  members (e.g., tenured professors with service responsibilities) should be properly recognized. Other
  forms of reciprocity may include paying for the students' training, conference expenses or
  publishing fees.
- Building and maintaining meaningful relationships with Indigenous communities and following reciprocity protocols outlined by the community representatives (e.g., specific ways of giving back to their respective communities).
- Offering tobacco and/or other culturally appropriate forms of acknowledgment.
- Hiring board members in paid roles.



# 4.8 Navigating conflicts and ethics breaches

Several participants thought that Indigenous ways of doing and Indigenous community assessment of research risks and benefits should take precedence over university policies in instances where there are conflicting protocols, especially those relevant to Indigenous data sovereignty. Prioritizing university policies over Indigenous jurisdictions would further perpetuate paternalistic, colonial practices. REBs need to engage in a meaningful, continuous dialogue with Indigenous communities to address differences in policies and procedures. Indeed, as noted by some individuals, GREB and HSREB have demonstrated flexibility in the past and adjusted their policies and forms to align with the needs of Indigenous communities.

An example of tensions arising between the Indigenous and academic perspectives on research is the issue of anonymity. The reviewers need to be sensitized to the fact that protecting anonymity of research participants is not always a default practice in Indigenous, community-driven research. The participants brought up the importance of honouring relationships with the Elders and bringing validity to the teachings by quoting the Knowledge Keepers by name (with permission) and clearly identifying the knowledge sources.

When discussing ethics breaches and violations of ethical standards of research involving Indigenous communities, several participants viewed the current adverse event investigation format as problematic and confrontational. The process centres the role of the REB Chair or the ethics compliance advisor who reviews the study file, investigates the nature of the complaint, communicates with the PI and seeks advice of the REB to determine if there is merit to the concerns. The anonymity of the complainant is protected throughout the process. The need to protect the complainant is valid and understandable, however anonymity makes it challenging to fully understand the context of the complaint. One of the participants, who was involved in an adverse event investigation, noted that not knowing the source of the complaint and not having an opportunity to discuss the issue openly and directly with the impacted party hindered their ability to meaningfully address the concerns about the research process. The process can be particularly impactful for graduate students and leave them in a vulnerable position especially if they lack supports throughout the investigation.

Our discussions pointed to the need of approaching problems affecting the welfare of research participants with the intention to heal, remedy and support the impacted community/research participants rather than penalize or do damage control. Specific strategies would of course depend on the context and severity of a conflict or an ethical violation. In case of serious breaches, the university should take decisive measures to ensure that those responsible bear the consequences of their actions. Some participants also flagged the lack of continuous engagement on the part of the researcher as the root cause of many conflicts.

One of the recommendations that emerged during our interviews was to tackle adverse events/conflicts from an Indigenous community-based justice perspective as an alternative to mainstream, punitive approaches to addressing alleged breaches of responsible conduct of research. The participants listed several possible conflict resolution mechanisms such as following the community protocols for rectifying harm, engaging Indigenous experts in a consensus-based decision-making process or adopting a restorative circle approach. Restorative circles would create space for the responsible and impacted parties to come together in an open dialogue and address harm with support from Elders, friends, community members, senior university administrators and facilitators. Some participants noted that an ethics breach impacts not only the relationship between an individual researcher/team of researchers and a community, but also the relationship between the university and community. The actions of an individual impact the entire institution. The circle should thus ensure that the responsible party can rectify the damage or make amends in a way that's contextual and responsive to local community protocols.

The restorative process could be documented for the sake of transparency and a summary of lessons learned posted to encourage wise practices and demonstrate the steps taken by the university to stay accountable. Determining specific guidance for addressing ethics breaches would be at the discretion of an independent Indigenous REB if such body is created at Queen's.

Stiegman & Castleden (2015) noted that the rigidity of university policies and procedures may lead the applicants who wish to meaningfully address the community priorities and ethical directives to lie in their ethics submissions. The participants in this research recognized the transformative, dynamic nature of community-driven research and called for greater flexibility combined with speedier review times. For example, some participants noted that research design may need to be adjusted and changed in response to shifting community priorities and that the changes emerging from the new research circumstances should be reviewed quickly by the REBs. Rather than submitting a detailed work plan with pre-determined schedules and locations, researchers who take an emergent approach to qualitative research may wish to provide a more general outline describing a way of conducting research and a set of principles they plan to adhere to as per community guidance. The outline could be followed by more detailed summaries developed as the research progresses.

Several participants mentioned the importance of factors such as internal diversity, competing agendas, and lateral violence in Indigenous communities and how they may impact the ethics review process. Indigenous communities are not monolithic entities, and their members may differ in their opinions about a specific research project. Creating space for disclosure of conflicts and disagreements would enhance transparency in the ethics review process.



# 4.9 Community-based research vs. research with Indigenous individuals

The participants discussed the distinction between community-based Indigenous research and research conducted with Indigenous individuals. They flagged the importance of balancing individual autonomy and agency over research against the need to ensure community accountability and collective consent. They were also cognizant of conflicts that may arise when community authorities contradict the consent given by individual participants. Avoiding vague language and clarifying the definition of a "community" in a particular context is a vital first step in a research journey. REBs are encouraged to build a knowledge base and share, in the spirit of transparency, how the balance between individual and collective rights is addressed in different research scenarios and ethics reviews.

We heard clearly that community-based research centering Indigenous ways of knowing should be conducted with community oversight. However, the participants recognized that each ethics application is different. Gatekeeping is context-dependent and not all Indigenous-related research proposals are channeled through or require consent from an Indigenous governance authority. For example, some participants indicated that research with Indigenous students representing diverse communities or research with an urban Indigenous group that includes status and non-status people and those who are Indigenous to lands outside of Canada doesn't necessarily require permission from each of their respective governance authorities.

In some cases, the requirement to seek consent from a specific authority is considered paternalistic as certain types of research may centre individual rather than community perspectives. Some participants thought that these projects do not require the approval of an Indigenous organization any more than research involving several members of a specific Canadian municipality requires permission of a municipal government. Depending on the context and scope of research, examples may include autoethnography, oral history studies and - as noted in the example above - research with individuals from multiple communities. For example, one participant was concerned about a requirement to seek permission from community authorities to be able to record family stories shared by their own mother – a demand which they thought infantilized Indigenous people. This person felt that the consent of a family member should suffice and the requirement to obtain higher level permissions restricts research and impacts individuals (and especially students) who intend to work with their own families. Other participants indicated that they don't feel the need to consult with a particular First Nation, Inuit or Métis authority each time they give feedback about issues that are relevant to their communities. The autonomy of individual participants should be respected, and researchers should clarify with them whether collective consent should be sought, depending on the nature of the proposed project. However, caution is advisable, and one participant shared an example of genetic research which may generate serious ethical issues if consent is not sought at all appropriate levels. Similarly, other participants observed that permission from the governance authorities may be necessary when there is a chance that research with individuals could impact the whole community and when the recruitment strategy is supported by the community resources. Queen's REBs may need to address this complexity on a case-by-case basis.

# 4.10 Research conducted by applicants with their own community vs. research conducted by applicants who are external to the community

Research ethics review system often assumes that the applicants are external to Indigenous communities. That's certainly not always the case and many Indigenous scholars conduct research in partnership with communities they are members of. Some participants thought that it would be beneficial for the ethics review process to take into consideration the positionality of the researchers and that the review should be streamlined or modified depending on different scenarios. Other individuals felt that researchers who work with their own communities or families should follow the same set of standards as their non-Indigenous colleagues since Indigenous identity does not guarantee attunement to cultural protocols and the ethical conduct of research. One participant noted that whether or not any distinctions are made should depend on the determination of a specific community and that the insider/outsider status is irrelevant if the community truly drives the research project.

Both Indigenous and non-Indigenous academics may face distrust and fear from community members who perceive universities as sites of colonialism and epistemic violence. However, Indigenous scholars who conduct research with their own communities may have to assume an additional level of accountability. Those individuals sometimes suffer disproportionate consequences in terms of disruption of their kinship networks as they navigate their responsibilities to both the Indigenous community and the university. Insiders working at mainstream institutions can sometimes be perceived as outsiders due to inherent power imbalances and structural issues rooted in funding distribution inequities and the extractive nature of academic research.

As we mentioned in the previous section of this report, some Indigenous researchers who have longstanding research partnerships with their communities are required to provide letters of support or research agreements every time they collaboratively initiate a new research project. Those individuals may feel that they are put in an awkward position of having to repeatedly reassert their identity, cultural location, and relational responsibilities. These challenges could be addressed by increasing transparency and including culturally-sensitive questions about positionality and nature of the collaboration/relationship in the ethics application form to clarify who is doing the research and who it is conducted with. While it is important to follow ethical protocols and ensure that Chapter 9 TCPS2 is adhered to, some participants suggested that the level of scrutiny regarding the evidence of engagement should be contextualized depending on the answers provided, with a possibility of expediting the process. One of the wise practices offered was to foster reflective practices about one's insider/outsider status. The applicants should be encouraged to think through the tensions associated with navigating different roles and their impact on research. Finally, some participants noted that if an accepted and recognized community member conducts community-based research, the community always has a responsibility to monitor and sustain the good behaviour of that individual.

# 4.11 Measures to protect Indigenous knowledge

In terms of appropriate mechanisms for safeguarding Indigenous knowledge over the course of research, the participants emphasized the need to check in with the Knowledge Keepers to ask for consent and learn about the protocols accompanying knowledge transfer. It is the responsibility of community members and researchers to ensure that any restrictions and stewardship responsibilities associated with sharing specific knowledge are respected. These restrictions may include strict adherence to protocols surrounding knowledge that is place-based, sacred, not to be disseminated widely, not to be disseminated by non-community members, restricted to clan or family members, restricted to men/women or to be shared during specific seasons. The researchers should also recognize that there may be a difference of opinions among community members about if and how specific knowledge should be shared. The processes for knowledge sharing will also depend on the nature, length, and strength of relationships between the researchers and the community.

One participant noted the importance of storing Indigenous knowledge-related deliverables in the community. Sharing information outside of the parameters outlined by the research project and storing data beyond the project duration was considered harmful since Indigenous data is dynamic, relational and context dependent. Any materials should be vetted by the community prior to publishing. Another participant thought that research projects involving collection of oral histories, documenting Indigenous ceremonies, stories and practices should be automatically flagged and the researcher(s) should be advised to consider a data sharing agreement. Indigenous knowledge ownership and stewardship concepts associated with specific research areas need to be addressed in the ethics application.

The participants listed several reflection questions to consider before initiating research that involves mobilizing Indigenous knowledge:

- Have you considered how the history and continued practices of knowledge extraction from Indigenous communities may impact your work?
- How will you address cultural protocols accompanying the transfer of knowledge?
- Who stewards specific knowledge, art, stories or songs?
- In what ways will the knowledge be shared and used, and for whose benefit?
- How will you ensure that you are speaking "with" and not "for" or "about" the community?
- Have you considered community perspectives on kinship, relationality and what the community members consider animate/inanimate? Are you sharing knowledge about an ancestor, a sacred entity, an animal nation?
- How will you incorporate opportunities for check-ins and co-creation of your analysis with the community?
- How will you and your research partners operationalize the principles of OCAP®/ Principles of Ethical Métis Research/ the National Inuit Strategy on Research/ other Indigenous research and data governance frameworks?
- How will you cultivate accountability and humility?

#### 4.12 Ethics review of research with more-than-human kin

Although TCPS2 in its current form does not capture in-depth ethical considerations pertinent to kinship with the more-than-human world, most participants enthusiastically supported the idea of including more-than-human kin in the ethical review of Indigenous research. Indigenous view of relationality extends beyond humans to the land, plants, animals, archival files, art, sacred bundles and other entities which are often considered to be living beings. Research with more-than-human kin may span different disciplines, e.g., geoscience, oral history research and art forms that incorporate working with the natural world (e.g., Indigenous weaving practices). Thus, researchers working in diverse research areas should adhere to cultural protocols that strengthen Indigenous stewardship and self-determination while critically assessing the risks and benefits of research that takes place on Indigenous lands and in connection to Indigenous cultures.

One of the examples discussed with the participants was research involving Indigenous art, archives and material culture. Accessing information in archives and museums requires permission because some of the information and items stored in those repositories are sacred. Dissemination of knowledge about Indigenous art and culturally-significant items without the input and consent of Indigenous people runs the risk of disclosing sensitive information (e.g., family history) in addition to misrepresenting historical narratives and distorting the complexity of Indigenous cultures. Similarly, although examining old, archived recordings and collections of stories in Indigenous languages seemingly does not involve human research, such work may have impact on contemporary communities and remains relationally accountable (e.g., risks associated with epistemic violence, benefits in terms of Indigenous language revitalization, etc.).

The advancement of a more comprehensive ethical framework raises questions about determining consent from non-human relations and respecting the agency of animals, land, water and other entities. Entering Indigenous territories to collect samples of soil, plants, minerals and wildlife specimen without consent and consideration of culturally-appropriate, reciprocal harvesting protocols disrupts Indigenous stewardship responsibilities and perpetuates harmful and extractive research practices. Some participants shared examples of specific wildlife manipulation techniques such as GPS animal tracking and tranquilizing which may be considered highly inappropriate by Indigenous communities. Permission is also required when natural scientists cocreate knowledge with Indigenous communities and include it in their data sets. The knowledge produced collaboratively on the land needs to be centred in ceremony and reciprocity.

The health of human beings relies on the health of the environment. It was clearly stated that following the reciprocal protocols of engagement with the land, the plant and animal nations, learning about traditional teachings relevant to specific research areas and relationship building with the keepers of those knowledges are fundamental components of an ethical conduct of research. This may include collaboration between the researcher and Indigenous Knowledge Keepers to jointly develop research protocols and decision-making frameworks for natural scientists engaging with the land and water, especially considering that the data resulting from the assessment of those larger environments is often crucial to the wholistic health of Indigenous individuals and communities.

We heard clearly that research with non-human participants requires human collaboration and meaningful relationship building with Indigenous communities. Future versions of TCPS2 need to consider the impacts of non-human research on the human population that has stewardship responsibilities over a specific research site, e.g., in situations when research is paid by the industry with a monetary goal in mind. However, some participants thought that including non-human kin in research ethics review will provoke pushback and create the need for additional layers of expertise required to review applications (e.g., knowledge of biohazard, animal science, chemistry, etc.). It may become an additional administrative, box-ticking exercise for researchers rather than a meaningful reflective practice that fosters greater relational awareness. Those participants flagged that the process of obtaining consent for non-human research and following community research protocols is context dependent and should be separate from Queen's application for ethics clearance. The responsibility of researchers should be limited to securing letters of support and clear research directions from the community. Further dialogue is needed to consider these challenges and differences of opinion.

In summary, when we discussed research with more-than-human kin, the participants were concerned about several risks, including extraction, theft of culturally significant items, misrepresentation, violation of permission and access protocols, impact of helicopter research on Indigenous lands and communities, and culturally inappropriate practices. These problematic issues provide a strong rationale for the REBs to expand the scope of their review in alignment with Indigenous worldviews to include more than human relations. The review of research with more-than-human kin can be particularly useful in circumstances where communities don't have the protective mechanisms, laws, policies, procedures and ethical safeguards in place. Precedents such as creating legal personhood for lakes and rivers were considered an important component of this discussion.





#### 4.13 Alternative ethics review formats

Several participants recognized the need for creating optional Indigenous ethics research review formats that could provide a culturally-appropriate, relational alternative to the current TRAQ e-submission system. Some suggested that the reviews should take place with the applicant in the room/virtual space to establish an open dialogue. The conversation would be recorded, and the process documented to ensure transparency. Those participants felt that a conversational ethics review is better aligned with Indigenous oral traditions, ways of being and knowing and may result in clearer guidelines and recommendations. It can help prevent misunderstandings and increase accessibility for those applicants who prefer to give presentations instead of filling out application forms. It can also support REB members who may not have the capacity to review extensive documentation (e.g., Elders). One participant noted that the existing process is alienating because it only allows for face-to-face meeting between researchers and members of institutional REBs when the researcher is in trouble, e.g., when an ethics complaint has been filed. In fact, the REB members can meet with the researchers for a variety of reasons and the applicants have the option to attend the full board meetings which happens occasionally. However, a significant portion of communication is channelled through TRAQ. The interaction between the applicants and reviewers could benefit from more frequent conversations with questions and concerns addressed on the spot instead of relying on webform exchanges that are not always conducive to open communication and may turn out to be more time consuming. A conversational, phased ethics review might prove especially beneficial for students and researchers in training who find the process of applying for ethics approval overwhelming and would appreciate opportunities to talk through their draft applications in a safe and welcoming environment before presenting it for a final review. Some participants suggested a mixed, flexible approach, depending on the needs of the researchers and their partners, with an option to submit material in advance in different formats (e.g., a standard, but simplified ethics application form, a video presentation) followed by a conversation with reviewers with an option to invite community representatives who will be impacted by the proposed research. One participant recommended the option to open the process to the public through a digital database listing approved research. The database would feature summaries of different research partnerships to facilitate greater transparency and accountability to Indigenous communities.

While several participants were supportive of a conversational method of research ethics review, some thought that it would violate confidentiality by revealing the identity of the reviewers. Currently, the applicants don't know who reviews their applications, but they may seek support from the ethics compliance advisors who can address their questions or concerns. However, the option to speak with the researchers is left at the discretion of the HSREB/GREB members. The participants confirmed that such conversations tend to take place when an ethics file is complex and the application requires substantial changes. Another concern was that the conversational review may result in some applicants "taking shortcuts" and not providing all required information.





# 4.14 Changes in the application forms and the need to reduce burdensome protocols

Most changes suggested by the participants are consistent with modifications already made to the GREB application form which was updated in 2021. It features a new, comprehensive Indigenous and community-based research section with questions relevant to reciprocal engagement at all stages of research, addressing community research priorities, data governance, knowledge mobilization and plans to continue the research relationship after the completion of the project. The updated form is currently being piloted with a hope of providing greater clarity to researchers and reducing the back and forth between the applicants and the boards. Similar modifications will be included in the next revision of the HSREB application form.

In terms of further changes, some participants suggested adding questions about the researcher's relationship with the community, their positionality (if comfortable disclosing) and motivation to pursue a particular research project. These additional questions may help the reviewers flag biased research narratives that reinforce the image of Indigenous peoples as inherently high-risk or vulnerable. Furthermore, the GREB and HSREB need to ask whether the project was approved by an Indigenous REB and request that the feedback be attached.

Several participants flagged the need to refine and clarify the definition of a community. The applicants should be able to provide clear and detailed information about the community or a segment of community they have engaged and developed a research partnership with (e.g., a friendship centre, a band council, clan mothers, a language revitalization community of interest). This is especially relevant to instances where research is conducted without direct mediation and oversight of formal authority structures and where it involves traditional leaders or a specific subset of a larger community.

A suggestion was made to add a question relevant to the assessment of risk to researchers to tease out information about strategies put in place by the applicants to protect their wellbeing throughout the research lifecycle. An option to add a question about feedback related to the ethics review process was also considered helpful.

Some participants viewed the content of the application form as heavily influenced by biomedical studies and individualistic perspectives which tend to overlook Indigenous wholistic worldviews and collective rights concerns. One participant recommended reframing the language of direct benefits to make it more inclusive and address the conceptual differences between the Western, materialistically oriented understanding of direct benefits and Indigenous ways of being and knowing. In its current form, the letter of information and the ethics application form require the applicant to state whether there are any direct benefits to individual research participants. The applicants often indicate that there are no direct benefits to the participants unless the research includes a new treatment, a medical intervention or physical benefits and learning advantages. Indigenous people participate in research for reasons that extend beyond the common benefits of Western research. They may value the relationship with the researcher and the reciprocal research process (e.g., a conversation, arts-based research, storytelling, a walk on the land). They may also appreciate an opportunity to extend kindness and benefit others in addition to the potential positive outcomes of a particular research project. Furthermore, the part of the LOI script indicating that Queen's REBs may request access to study data to ensure that the researcher(s) have or are meeting their ethical obligations in conducting research has generated concerns about confidentiality among some participants who emphasized the right of Indigenous communities to make decisions about access to their data.

The new model of Indigenous ethics review at Queen's should honour community research protocols and address the tension between the current requirements in terms of using rigid templates (LOIs, consent forms, detailed questionnaires) and the community processes and protocols. One of the participants critiqued the need to submit detailed questionnaires. This individual noted that using a specific, predetermined set of questions should be optional as it may limit research that requires a flexible approach such as oral history or grounded theory studies. Some participants highlighted the importance of alternative, relational forms of consent giving such as a conversation, a ceremony, a smudge, a tobacco offering as opposed to LOIs and signed consent forms. These relational protocols could be documented by the researcher using flexible formats. Although oral consent was generally considered more beneficial than signed forms, one individual noted that research participants may still feel triggered or victimized when the researcher reads a list of potential risks and discomforts. This, in turn, can negatively impact the interview process. In summary, the consent process is going to look different in different communities. Asking community members to sign LOIs and consent forms may negatively impact research and disrupt the relationship. Some research participants may have low literacy skills or simply refuse to follow the technical language of consent forms. Signing documents may also be triggering given the extractive history of colonial research, thus REBs should embrace culturally-grounded forms of consent. Queen's does allow alternative forms of consent, as per the TCPS2, including verbal consent.

Some applicants received criticism about consulting with communities prior to submitting an ethics application. The community participation in research design was mistakenly interpreted by the reviewers as data collection. The participants emphasized the need to educate the REBs about differences between community engagement and research. At the same time, it's important for the researchers to clarify that the consultation was part of the engagement and not data collection activities.

Another issue raised by the participants was the need to decolonize financial protocols in terms of payment of honoraria, and research expenses around ceremony and gift giving. The protocols, forms and guidelines should be reconciled with Indigenous ways of being and allow for a barrier-free disbursement of funds.

In summary, the participants agreed that the contents of the application form should strike the right balance between ensuring the accurate assessment of the risks and benefits of research and reducing the burden of providing the lengthy explanations. Again, several individuals requested the implementation of an oral, conversational review and an option to use different submission formats that would centre Indigenous knowledge, relationship building and care in research administration processes. Some participants would find it helpful if Queen's REBs published sample interpretation logs to demonstrate the reviewer's thinking process and flag common issues. The GREB and HSREB have already published some checklists that explain what the reviewers are looking for as well as several guidelines documents that are available on the institutional websites. Others critiqued the need to interact with the TRAQ system, the length of the current form and the fact that the system discourages Indigenous students (and students coming from other cultural contexts such as Africa or South-Asia which place greater emphasis on relationality) from pursuing research. Students are especially triggered by comments received from reviewers who critique different ways of knowing and doing research without consideration for cultural protocols and epistemic locations that don't fit within Western research methodologies. On the other hand, more faculty mentorship is needed in addition to existing supports offered by the Ethics Unit, so that students, ECRs and new research personnel can learn to effectively navigate the ethics system.

# 4.15 Prioritizing ethics review conducted by an Indigenous research governance body

When we asked the participants whether the ethics review at our institution should be secondary and complementary in relation to an ethics review conducted by a relevant Indigenous research governance body external to Queen's, the majority were supportive of this idea. They highlighted the importance of prioritizing community-driven research protocols and viewed honoring the ethics approval of an external Indigenous REB as a clear recognition of Indigenous sovereignty and self-determination over research. Within this context, the primary function of the university ethics review would be to complement the in-depth, contextual Indigenous review and ensure compliance with applicable policies, laws and regulations the university abides by without contradicting the decision of a nation or a community to approve a specific research project. This process should prioritize relationship building and the need to meaningfully balance the university policies with the needs and protocols of the community. Several participants appreciated that prioritizing Indigenous research ethics review would likely make Queen's process less onerous, provided that both types of reviews consider similar issues. A useful precedent is the expedited review of multijurisdictional research (research conducted under the auspices of multiple institutions) which has been adopted by Queen's.

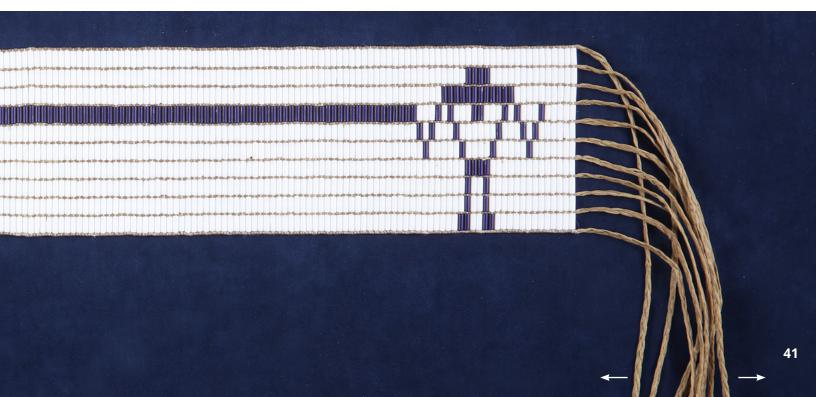
As suggested by some participants, the work of a separate Indigenous REB, should it be established, may include assessing the applications that have already received approval from Indigenous authorities to determine if the expedited review should occur. The Indigenous REB at Queen's may also wish to establish a communication protocol between the university and external Indigenous REBs/organizations to enhance clarity and reduce the burden placed on researchers who often play the role of intermediaries responsible for facilitating the back and forth. The participants recognized that the option to proceed to an expedited review would likely be impacted by several factors such as the capacity of a community to review research, the number of Indigenous research partners, issues of representation, community politics, conflicting interests, etc.



Several Indigenous organizations have created detailed and robust ethical processes aimed at protecting their research agenda and ensuring that the proposed research is beneficial to community members. However, many Indigenous communities don't have the capacity to review research and they are likely to focus on addressing priorities that are much more urgent (e.g., Federal recognition, health crisis, food insecurity). The research community should strive to seek out and honour the ethical recommendations of those smaller communities and organizations which may not have the same research capacity as large national Indigenous leadership organizations.

One of the participants suggested that if a community involved in a research project does not have an ethics review process, an ethics application designed by another organization working in a similar context could be used instead, provided that the necessary permissions are secured. Another participant noted that the policies of some communities and universities which operate outside of the TCPS2 (e.g., in international contexts) may be perceived as inferior and not up to institutional standards and this harmful pre-conception may limit research partnership options.

Although it was stated clearly that the university ethics clearance should be conditional on community consent, some participants thought that Queen's REB review must retain the primary review and oversight responsibilities due to practical considerations. Providing the community with an ethics application that was reviewed by the university may save them the time and effort needed to conduct their own review, seeing as certain questions have already been addressed and one level of assessment has been completed. Furthermore, some Indigenous jurisdictions require the university stamp of ethics approval prior to conducting their own review. The participants were also concerned that differences between the university and the community reviews (e.g., in relation to compliance with different legislative and regulatory instruments) may be difficult to reconcile. Designating Indigenous authorities as primary reviewers would therefore require careful consideration and dialogue. An environmental scan would likely be necessary to provide an overview of research ethics review applications and governance structures in different Indigenous communities.



### 4.16 Feedback about Chapter 9 TCPS2

The current version of TCPS2 includes a chapter dedicated to research with Indigenous peoples in Canada. Chapter 9 provides guidance to researchers and REBs on the ethical conduct of research involving Indigenous peoples, however it is not intended to override or replace ethical guidance offered by Indigenous peoples themselves. In seeking feedback about Chapter 9 from external experts we wanted to establish whether there are any areas of disconnect between the goals of the Chapter and the ethical challenges emerging in the actual research practice of those who follow its guidance.

The general feedback offered by the participants was positive. They appreciated the comprehensive scope of the Chapter, the values embedded in the guidelines, the acknowledgment of OCAP® principles, the focus on relationship building and the importance of acknowledging complex authority structures in Indigenous communities.

In terms of areas of improvement or possible new content that could be added to the future editions of Chapter 9, the participants identified the following:

- The acknowledgment of the emergent, dynamic and transformative nature of Indigenous research.
   Research partners should be encouraged to build reflective practices into the research to revisit the initial goals at regular intervals and adjust their plans moving forward based on changing research capacity in the community, shifting priorities, risks and incentives as well as conflicts.
- Researchers would benefit from companion documents including references to actual research projects
  that exemplify how the guidance has been operationalized, case studies, examples of approaches that
  increase the validity and reliability of research findings and wise practices learned from positive and
  negative scenarios.
- Chapter 9 should examine the notion of community and its meaning in highly heterogenous Indigenous contexts more thoroughly. Researchers tend to use the word "community" quite freely and without specifying exactly what type of community they refer to. The policy should dive deeper into the issues of representation (e.g., in relation to Indigenous people living off-reserve or non-status). It should also provide adequate guidance on determining the right scope of consultations and an appropriate level of engagement for the project to be considered community-based or led, drawing upon scenarios involving different types of communities and their subsets.
- Instead of using the phrase "building reciprocal, trusting relationships", Chapter 9 should refer to "reestablishing trust" to further emphasize and explain how the trust was broken throughout the history of extractive research conducted "on" instead of "by" and "with" Indigenous peoples.
- The Chapter should place greater focus on Indigenous languages and their significance in Indigenous research contexts.
- The Chapter should consider the impacts of research with more-than-human kin on Indigenous communities who steward the lands and waters where research occurs.
- The Chapter should identify meaningful ways of evidencing research engagement with Indigenous communities.
- More in-depth information should be provided about Indigenous research and data governance frameworks such as OCAP®, the Principles of Ethical Métis Research and the National Inuit Strategy on Research.
- The term Traditional/Indigenous Knowledge should be revised in the French version of the Chapter. The term "connaissances" should be replaced by "savoirs" to reflect a more accurate meaning and scope of the concept of Traditional Knowledge in Indigenous communities.

### 4.17 Capacity building

The participants listed several types of training that should be taken by the research community involved in the conduct and review of Indigenous research, depending on their positionality, role and experience conducting research with Indigenous communities. There is no "one size fits all" solution and capacity-building strategies should be tailored individually. In addition, we heard that training resources, mentorship and opportunities for capacity building should also flow to Indigenous communities as many have yet to establish their own research ethics boards and committees. Academics and universities have an important role to play in supporting the communities who wish to develop these processes e.g., by helping to secure funding and volunteering their time and expertise.

Researchers and students who are new to Indigenous research partnerships and have recently begun their learning journey are encouraged to take the Indigenous Canada – a 12-lesson Massive Open Online Course (MOOC) at the University of Alberta. Non-Indigenous researchers should consider taking a cultural competency training such as San'yas Indigenous Cultural Safety Online Training and Kairos Blanket Exercise workshops in addition to learning about the history of Residential Schools in Canada and the TRC Calls to Action.

Other suggested learning opportunities included the OCAP training, Indigenous Community Research Partnerships (ICRP) open education training resource hosted on the website of the Office of Indigenous Initiatives at Queen's, Indigenous Relationship and Cultural Awareness Courses (Cancer Care Ontario), Indigenous Research Collaboration Day organized annually at Queen's, training on trauma-informed approaches in Indigenous contexts and training focusing on different Indigenous research principles, frameworks and strategies such as the USAI Research Framework, National Inuit Strategy on Research and Principles of Ethical Métis Research.

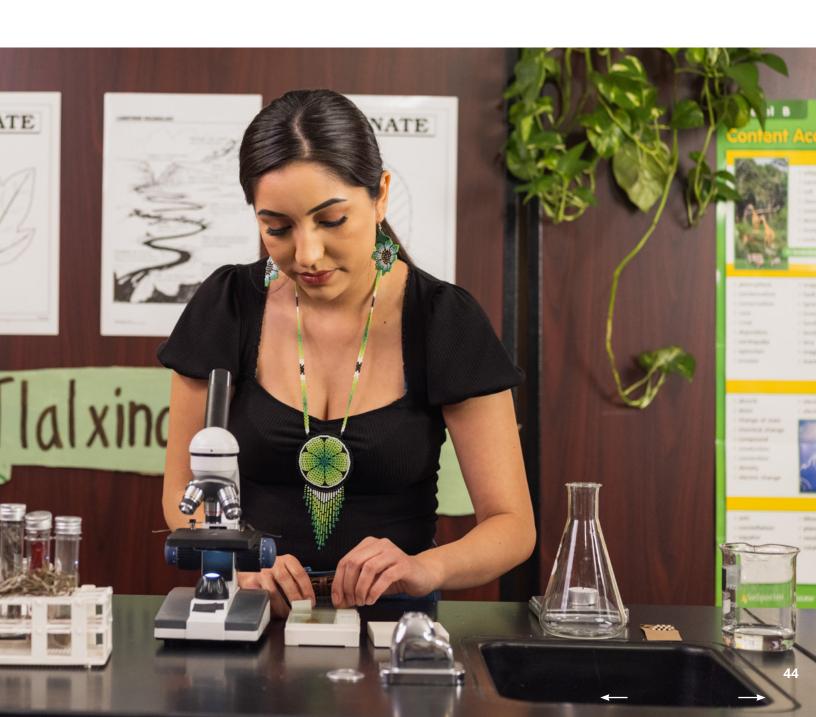
In addition to taking courses which focus on Indigenous ways of being and knowing, respectful relationships with the land, Indigenous research ethics, methodologies and priorities, the researchers should also consider engaging in experiential learning to build authentic relationships with Indigenous community members. Individuals who plan to conduct Indigenous research in international contexts are encouraged to seek training resources that are place-specific instead of relying on training available in Canada.

Queen's should offer resources and supports for students and ECRs to help them develop their ethics applications (e.g., one on ones with ethics advisors who have expertise in Indigenous research, monthly drop in sessions and opportunities to discuss draft applications with REB reviewers and seek guidance on how to complete application forms). In addition to supports offered by the ethics compliance advisors, Queen's faculty members can also connect with the Office of Indigenous Initiatives and with the Research Advisor, Equity, Diversity, Inclusion and Indigenization (EDII) who works collaboratively across campus, providing advice on embedding EDII principles, theories and wise practices in research design and practice.

If the creation of an Indigenous Research Ethics Board comes to fruition, the board could hold open review sessions and invite the members of HSREB and GREB to observe the meetings and learn about wise practices through modelling and mentoring. It would be beneficial if an independent Indigenous REB liaised with other Indigenous REBs to build collective capacity.

Several participants encouraged members of the existing boards to deconstruct the understanding of ethics and the positivist model of research rigor that emerged from a colonial way of thinking and bureaucratic, litigious approaches. All REB members should be familiar with Chapter 9, TCPS2 and seminal books on decolonizing methodologies to understand ethical implications that are specific to Indigenous research. One participant suggested organizing an annual retreat for REB members with a focus on relational approaches to ethics and Indigenous research.

Some participants thought that completing Indigenous research training certificate, including an especially curated reading package, should be mandatory for REB members, faculty, research coordinators/associates and students who intend to conduct research that centres Indigenous peoples and/or the lands they steward. Others suggested making it optional. Should a certificate be introduced as a mandatory requirement, the Indigenous Research Community Partnerships modules could be incorporated as its core component.



## 5. CONCLUSIONS

The university ethics landscape described by the members of our research community has been dominated by the formalistic, pragmatic, and hierarchical notions of research evaluation. The perception of several participants was that the primary goal of the university-based ethics review process is to minimize institutional risks and provide a bureaucratic shield from liability to ensure continued funding.

Ethics review may take a long time, depending on the complexity of the file and the number of revisions required. Researchers spend a fair amount of energy interfacing with the REBs and seeking support from the ethics compliance advisors who are asked to clarify the reviewers' comments. Meanwhile, Indigenous communities are concerned with their own research timelines which often depend on the community capacity, seasonality, and availability of resources to support the research. Poor communication and delays in REB reviews may result in damaged relationships and lost opportunities to address urgent research priorities, including Indigenous food sovereignty, health inequities and lack of access to clean water.

As revealed by this study, the protection mechanisms at our institution, although applied with the intention to facilitate research and safeguard the welfare of the research participants, can sometimes hinder Indigenous research and community-based research more broadly. Our findings point to the need for the institutional shift from bureaucratic ethics to ethics of connectivity. Installing flexible review formats that flatten hierarchies and provide a relational alternative to filling out dense forms may help to de-intensify the regulatory practices, foster a more productive dialogue between the applicants and the REBs and create a safer, more transparent space for deeper reflexivity about ethical merits of the proposed research.

Furthermore, our findings raise important questions about the ultimate accountability for research outcomes. Queen's should be transparent about the research that has been conducted under its auspices, e.g., by seeking appropriate consent channels to publish a database of all projects that involve First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals. Several participants agreed that the University is situated in a network of research relationships and carries a responsibility to ensure that Indigenous research partnerships are in good standing, and that research centering Indigenous communities has long-term, positive impacts. However, no formal mechanism for verifying whether the research plans and promises have been fulfilled currently exists.

The creation of an independent Indigenous research ethics review board may provide much needed solutions to the challenges articulated in this report, however its implementation requires careful consideration. Thus, we recommend striking a working group formed by change champions including Indigenous faculty, staff, students, community research partners and representatives from the Office of Indigenous Initiatives and the Vice-Principal Research Portfolio.

The working group would be tasked with actioning the following key recommendations stemming from our study:

- Conduct an analysis of the institutional capacity to form a separate Indigenous REB, followed by an implementation strategy.
- Establish a pathway for a conversational Indigenous research ethics review and for alternative submission formats.
- Foster mentorship supports and a community of practice for students and ECRs around Indigenous research ethics review.
- Explore options for prioritizing ethics review conducted by external Indigenous research governance bodies and for including more-than-human kin in the ethical review of Indigenous research.
- Advocate for culturally-grounded ethics protocols.
- Facilitate dialogues and consultations with Queen's research community, including Indigenous faculty, staff and students, Queen's REBs, Indigenous Council, the members of EDII-focused working groups and the campus community more broadly to validate the findings and seek advice on how to implement a new model of Indigenous research ethics review at Queen's.



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## 7. APPENDIX 1: QUESTIONNAIRES

### 7.1 Survey questionnaire (Queen's)

#### Introduction

Welcome and thank you for taking the time to fill out the questionnaire. Please feel free to provide brief answers and use bullet points if that's helpful to you. This questionnaire adopts SSHRC's definition of Indigenous Research: "Research in any field or discipline that is conducted by, grounded in or engaged with First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals, and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present. Indigenous research can embrace the intellectual, physical, emotional and/or spiritual dimensions of knowledge in creative and interconnected relationships with people, places and the natural environment." We appreciate your valuable feedback.

#### Ethics review process at Queen's

- 1. In your opinion, what model of Indigenous research ethics review would be the most appropriate for Queen's University?
  - a. Standard model involving the delegated or full board review by GREB/HSREB depending on the level of risk (this model is currently in place at Queen's).
  - b. Double review model with a separate ethics committee formed specifically to review Indigenous-related research and advise the GREB/HSREB. The review by the committee is followed by GREB/HSREB review using the committee's input. The GREB/HSREB makes the ultimate decision about the ethics clearance.
  - c. A model involving a separate Indigenous research ethics review process, with an independent REB that is given the mandate to grant or refuse ethics clearance, renew, propose modifications to, or terminate any proposed or ongoing research involving Indigenous peoples.
  - d. A model relying on the expertise of Indigenous research ethics advisors who may be asked by the researcher and by GREB/HSREB to provide advice on ethical issues in relation to research conducted with Indigenous communities. The advisors provide support and guidance on draft ethics applications before they are submitted to GREB/HSREB.
  - e. Other: please describe.
- 2. If a separate, Indigenous research-related ethics review body is created, what would be its ideal composition? Please provide details.
- 3. GREB's Standard Operating Procedure 201 Composition of GREB indicates that the Board will include "at least one member who is either a researcher who is knowledgeable of First Nations, Métis, Inuit (FNMI) issues or an FNMI member of an identifiable Indigenous community/Centre, or non-Indigenous member closely associated with FNMI community." Similarly, HSREB will include "at least one member, when possible, from an identifiable Indigenous community, when the HSREB reviews research that recruits participants from that community" (HSREB SOP 201.001). Are any changes required in the composition of GREB/HSREB that could enhance the quality of the review of Indigenous research?
  - a. Yes / b. No / c. No opinion / d. Other: please describe

- 4. What changes are required in the composition of GREB/HSREB to enhance the quality of the review of Indigenous research? Please provide details (this question is displayed if a participant answers "yes" when answering question 3).
- 5. What should a culturally-appropriate, reciprocal process of recruiting Indigenous community members to serve on GREB/HSREB look like? Please provide details.
- 6. Should the ethics review at our institution be secondary and complementary in relation to an ethics review conducted by a relevant Indigenous research governance body external to Queen's?
  - a. Yes / b. No / c. No opinion / d. Other: please describe
- 7. Should Queen's have a preliminary review process prior to research ethics review to ensure that the researchers initiate community engagement at an early stage before proceeding to the next steps such as co-designing the research project or submitting funding proposals?
  - a. Yes / b. No / c. No opinion / d. Other: please describe
- 8. What types of research engagement strategies with Indigenous communities should be considered adequate in the ethics review of the proposed research by the GREB/HSREB? Please provide details.
- 9. How can research engagement strategies be evidenced in the ethics review process (i.e., submission of data sharing agreement, letters of support)?
- 10. The TCPS 2 Chapter 9 suggests that community engagement is required when interpretation of research results will refer to Indigenous communities, peoples, language, history or culture. What would be sufficient for engagement purposes when research includes primary and/or secondary data collection that covers a diverse range of Indigenous communities (i.e., national health data)? Please provide details.
- 11. Should the ethics review process address the distinction between research conducted by applicants with their own community and research conducted by applicants who are external to the community?

  a. Yes / b. No / c. No opinion / d. Other: please describe
- 12. How can GREB/HSREB collaborate and dialogue with Indigenous peoples (and specifically with local Indigenous communities) to build a shared understanding of ethical wise practices and ensure effective evaluation of research with Indigenous communities? Please provide details.
- 13. What measures should be considered adequate by the GREB and HSREB in terms of protecting Indigenous knowledge and respecting ceremony and spirituality during the conduct of research (i.e., data sharing agreements, familiarity of the researcher with the community's cultural protocols)? Please provide details.
- 14. Should research pertaining to non-human entities (e.g., land, animals, plants, archives, culturally-significant items) and impacting Indigenous communities be included in Queen's ethics review of Indigenous-related research?
  - a. Yes / b. No / c. No opinion / d. Other: please describe

#### Application form: are we asking the right questions?

- 1. Are there any ethical challenges encountered in the actual research practice with Indigenous communities that are overlooked in a typical research description and should be addressed in the ethics application forms? Please provide details.
- 2. Should any changes be made in the content of the current GREB standard application form and HSREB standard application form? Please provide details.
- 3. Are there any ethics review protocols that are burdensome and could be simplified without compromising ethical practice? Please provide details.

#### Training and capacity building

- 1. What practical things could be done to assist researchers who collaborate or intend to collaborate with Indigenous communities? Please provide details.
- 2. What types of training should be taken by the research community involved in the conduct and review of Indigenous research? You may choose multiple options.
  - a. Cultural safety/competency training.
  - b. Indigenous Community Research Partnerships an online training resource currently hosted on Queen's websites.
  - c. Training on Indigenous research principles, frameworks and strategies such as OCAP, USAI, National Inuit Strategy on Research.
  - d. Training on trauma-informed approaches.
  - e. Training on TCPS2, Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada.
  - f. Other: please describe
- 3. Are there any other topics in relation to Indigenous research ethics review that should be addressed in this survey? Please provide details.

We thank you for your time spent taking this survey.

Your response has been recorded.



### 7.2 Interview questionnaire: key knowledge holders (Queen's)

#### Ethics review process at Queen's

Please note that this questionnaire adopts SSHRC's definition of Indigenous Research: "Research in any field or discipline that is conducted by, grounded in or engaged with First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals, and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present. Indigenous research can embrace the intellectual, physical, emotional and/or spiritual dimensions of knowledge in creative and interconnected relationships with people, places and the natural environment."

- 1. In your opinion, what model of Indigenous research ethics review would be the most appropriate for Queen's University?
- 2. Can nation-to-nation relationships between Indigenous peoples and settler society provide a blueprint for a university-based ethics review process? E.g., relationships that recognize Indigenous peoples as rights-holding partners rather than "vulnerable subjects in need of protection" in the process of research ethics review.
- 3. Should Queen's have a preliminary review process prior to ethics review to ensure that the researchers initiate community engagement at an early stage before proceeding to the next steps such as codesigning the research project or submitting funding proposals?
- 4. What types of engagement strategies for research purposes should be considered adequate and how can they be evidenced in the ethics review process (i.e., submission of data sharing agreement, letters of support)?
- 5. The TCPS 2 Chapter 9 suggests that community engagement is required when interpretation of research results will refer to Indigenous communities, peoples, language, history or culture. What would be sufficient for engagement purposes when research includes primary and/or secondary data collection that covers a diverse range of Indigenous communities and/or National Health data?
- 6. Are any changes required in the composition of GREB/HSREB that could enhance the quality of the review of Indigenous community-based research?
- 7. What should a culturally-sensitive, reciprocal process of recruiting Indigenous community members to serve on GREB/HSREB look like?
- 8. What are your thoughts regarding providing an honorarium for Indigenous community members to serve on GREB/HSREB?
- 9. How can GREB/HSREB collaborate and dialogue with Indigenous peoples (and specifically with local Indigenous communities) to build a shared understanding of ethical wise practices and ensure effective evaluation of research with Indigenous communities?
- 10. How can GREB/ HSREB navigate the possible conflicts arising between Indigenous jurisdiction and/or cultural protocols and university policies in a good way? E.g., privileging detailed academic protocols committing to specific research activities over the autonomy of Indigenous community to change the research design over time?

- 11. How can the ethics review process address the distinction between community-based research and research that is done with individuals who are Indigenous?
- 12. What measures should be considered adequate by the GREB/HSREB in terms of protecting Indigenous knowledge, ceremony and spirituality during the conduct of research?
- 13. What measures should be considered adequate by the GREB/HSREB in terms of ensuring accommodations are made for the participation of Elders (e.g., there may be issues with respect to literacy and disability that may prevent Elders from full participation in research)?
- 14. Should the ethics review process address the distinction between research conducted by applicants with their own community and research conducted by applicants who are external to the community?
- 15. Should research pertaining to non-human entities (e.g., land, animals, plants, archives, culturally-significant items) and impacting Indigenous communities be included in the Queen's ethics review of Indigenous-related research?

#### Application form: are we asking the right questions?

- 1. Are there any ethical challenges encountered in the actual research practice with Indigenous communities that are overlooked in a typical research description and should be addressed in the ethics application forms? Please describe.
- 2. Should any changes be made in the content of the current application forms?
- 3. Are there any ethics review protocols that are burdensome and could be simplified without compromising ethical practice?

#### Institutional concerns

- 1. Should Queen's have a separate ethics review body intended specifically for the review of Indigenous-related research?
- 2. If a separate, Indigenous research-related ethics review body is created, what would be its ideal composition?
- 3. If created, what mandate should such Indigenous research-related ethics review body have?
- 4. Should the ethics review at our institution be secondary and complementary in relation to an ethics review conducted by a relevant Indigenous research governance body external to Queen's?

#### Training and capacity building

- 1. What capacity building strategies should be implemented to assist researchers who collaborate or intend to collaborate with Indigenous communities?
- 2. What specific types of training should be taken by the research community involved in the conduct and review of Indigenous research?

### 7.3 Interview questionnaire: key knowledge holders (Tri-Agency)

Please note that this questionnaire adopts SSHRC's definition of Indigenous Research: "Research in any field or discipline that is conducted by, grounded in or engaged with First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals, and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present. Indigenous research can embrace the intellectual, physical, emotional and/or spiritual dimensions of knowledge in creative and interconnected relationships with people, places and the natural environment."

- 1. Are there any gaps in the content of TCPS2 Chapter 9 that should be addressed to provide more guidance with respect to ethical conduct of research involving Indigenous communities?
- 2. In your opinion, what model of Indigenous research ethics review would be the most appropriate for universities?
- 3. Are there any ethical challenges encountered in the actual research practice with Indigenous communities that are overlooked in a typical research description and should be addressed in the ethics application forms? Please describe.
- 4. Should research pertaining to non-human entities (e.g., land, animals, plants, archives, culturally-significant items) and impacting Indigenous communities be included in the ethics review of Indigenous-related research?
- 5. Can nation-to-nation relationships between Indigenous peoples and settler society provide a blueprint for a university-based ethics review process? E.g., recognizing Indigenous peoples as rights-holding partners rather than "vulnerable subjects in need of protection" in the process of research ethics review.
- 6. Should the university-based ethics review be secondary and complementary in relation to an ethics review conducted by a relevant Indigenous research governance body external to the university?
- 7. What types of engagement strategies for research purposes should be considered adequate and how can they be evidenced in the ethics review process (i.e., submission of data sharing agreement, letters of support)?
- 8. The TCPS 2 Chapter 9 suggests that community engagement is required when interpretation of research results will refer to Indigenous communities, peoples, language, history or culture. What would be sufficient for engagement purposes when research includes primary and/or secondary data collection that covers a diverse range of Indigenous communities and/or National Health data?
- 9. How can REBs navigate possible conflicts arising between Indigenous jurisdiction and/or cultural protocols and university policies in a good way? E.g., privileging detailed academic protocols committing to specific research activities over the autonomy of Indigenous community to change the research design over time?
- 10. How can the ethics review process address the distinction between community-based research and research that is done with individuals who are Indigenous?
- 11. What should be the consequences of ethics breaches for individuals responsible for violations of ethical standards of research involving Indigenous communities? How can such breaches be rectified?
- 12. Should the ethics review process address the distinction between research conducted by applicants with their own community and research conducted by applicants who are external to the community?





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