



BC NEIHR, MSHRBC, FNHA & UBC
PARTNERSHIP

Internal Summary Report:
**BC Research
Ethics Board
Environmental
Scan & Ethics
Sharing Circles**

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Introduction

First Nations, Métis and Inuit Research Ethics in BC, a Collaborative Project

A crucial component of research with First Nations, Métis and Inuit peoples is competent research ethics review to ensure safe, collaborative, and productive research. Research involving Indigenous peoples in Canada has predominantly been led and carried out by non-Indigenous researchers (Government of Canada Panel of Research Ethics, 2018), and has been characterized by extractive research methodologies that may not adequately reflect the values and priorities of those involved as participants in the research. Research involving Indigenous nations and communities should, first and foremost, be led by communities themselves, ensuring and enforcing the self-governing abilities and priorities of Indigenous nations. Indigenous-led research should be supported through a strong lens of collaboration and respect on the part of non-Indigenous researchers working for and alongside communities. With the research grounded in relationship, involved parties should be knowledgeable and open to learning from the nations and individual communities they seek to work with. Recent changes to CIHR funding guidelines support more community-based and Indigenous governed research being funded in Canada and this creates a need to ensure ethics review reflects this reality.

Researchers, research ethics boards (REBs), and institutions collectively hold responsibility to ensure that research involving Indigenous communities is proposed and carried out in a culturally safe research environment, does no harm, and is carried out through a lens of meaningful collaboration. This includes ensuring that community and nation jurisdiction, protocols, and priorities are guiding the ethics review process, and research projects. The research ethics review process must go beyond ensuring a culturally safe review. REBs and their institutions must ensure that those protocols and principles are being respected and applied throughout the activities of the research project and that the partnership is meaningful and is integral to the entire research process.

Currently, there are a number of initiatives, strategic plans, and organizational priorities from across different institutions and networks working in the realm of Indigenous research ethics. These initiatives are working towards supporting a culturally safe and meaningful ethics review process grounded in Indigenous self-determination, and supporting REBs and researchers to apply these principles through their work.

Our Collaboration

A collaborative team including **Research Ethics BC** (Terri Fleming, Director; Gillian Corless, Senior Advisor Research and Ethics), **BC NEIHR** (Dr. Charlotte Loppie, Professor of Public Health and Social Policy, University of Victoria and Principal Investigator of the BC Network Environment for Indigenous Health Research; Tara Erb, Network Coordinator, BC Network Environment for Indigenous Health Research), **UBC Research Ethics** (Laurel Evans, Director, Research Ethics), **FNHA** (Gillian Corless, Senior Advisor Research and Ethics) and **UBC IRSI** (Lerato Chondoma, Associate Director, Indigenous Research Support Initiative) came together to develop this project in British Columbia.

Project Considerations

Two streams of Indigenous research and ethics priorities were considered by this project group:

- Indigenous-specific questions (current) in BC harmonized ethics review processes and signal jurisdiction ethics review processes; and,
- Transformative learning and education.

These streams can be understood as interdependent and intersecting priorities, with the opportunity to reinforce one another through coordinated efforts.

Project Objectives

Given the current context of lateral initiatives in the realm of Indigenous research ethics, there is opportunity to create a strong network of scholars, institutional leaders, and professionals to work together towards a common goal.

We proposed that a precursor to any larger collaborative projects be an environmental scan of current ethics processes/questions as they pertain to First Nations, Indigenous research within the province, with potential for this scan to be expanded outside of BC in time. In addition to doing a scan of the current research ethics processes/questions across the province as they pertain to Indigenous research, the scan would also provide an opportunity to identify the key people at the various research institutions with innovative approaches to ensuring the Indigenous voice is in the research ethics process.

Funding for the environmental scan was made available through BC NEIHR to fund an Indigenous student and supervisor, and supported by Research Ethics BC for technical support and guidance in harmonized ethics review.

To further inform this work, the BC NEIHR also conducted a series of Ethics Sharing Circles that gathered experiences from Indigenous faculty, researchers, students and some members from ICCOs (Indigenous communities, collectives and organizations).

We invite others to share in this work and envision the ways in which their areas of expertise and activities may strengthen and intersect with shared priorities among institutions and organizations. We welcome any feedback, guidance, or thoughts on this shared initiative in order to move forward together.

Summary of Environmental Scan

Introduction

The BC NEIHR's (British Columbia Network Environment for Indigenous Health Research) purpose for completing this environmental scan is to document the application, review, and approval processes for each of the 27 BC Research Ethics Boards (REBs), including any strengths, gaps, and level of involvement of Indigenous communities, collectives, and/or organizations (ICCOs). In particular, we wanted to learn about Indigenous culturally safety (ICS) and anti-racist awareness and practices within the REBs ethical review processes. In January 2022, Indigenous graduate student Sarah Littlechild (University of Victoria) was hired to gather information from each of the REBs in BC. This report provides a summary but not an analysis or interpretation of that information.

Indigenous Cultural Safety (ICS) and anti-racism are important considerations in research ethics and ethical review processes, in order to prevent harm to Indigenous researchers, to ensure there is protection for ICCOs and Indigenous knowledges, to support the strengthening of relationships between ICCOs and institutions, and to ensure that REBs have the resources they need to review Indigenous-focused research ethics applications. Importantly, this work will also inform the BC NEIHR and Research Ethics BC (REBC) on how to best support REBs in BC as well as support ICCOs to be self-determining in research that involves their peoples, lands, and knowledges.

Methods

Over a period of four months, our assistant, graduate student Sarah Littlechild, gathered information via publicly available research ethics application material as well as discussions (Zoom, phone, and email) with REB administrators, including both academic institutions and health authorities. **Out of the 27 REBs in the province, 21 responded to our request to share their ethical review processes involving Indigenous-focused research.**

Each REB meeting involved 1-3 REB members, including the chairs and often Indigenous REB members who also fill other Indigenous-specific roles within their respective institutions. The discussions were guided by the following questions developed by Dr. Charlotte Loppie and Tara Erb from the BC NEIHR:

- What, if any, Indigenous-focused learnings are REB members required to receive?
- What, if any, involvement do ICCOs have in the REB process (e.g., developing protocols, materials, reviewing applications)?
- How many, if any, Indigenous peoples are on the REB? Are they allocated all the Indigenous-focused applications?
- Is ICCO ethical approval required? If so, what process is undertaken to confirm it?
- Are there any "wise practices"/strengths, as well as any gaps or missteps, that REB members saw within their board processes?

In addition to speaking directly with REB members, each institution's single jurisdictional application forms were closely reviewed, including both behavioural and clinical forms, depending on the institution (for example, some institutions only engage in behavioural research). Our Assistant also reviewed clinical and behavioural Harmonized Research Ethics Review application forms that 22 of the 27 REBs use for multi-jurisdictional research. Five of the REBs are not part of the harmonized research ethics process.

These five REBs each have their own ethical review applications, but only two were accessible for review. Nine of the 22 REBs who are part of the harmonized research ethics review process utilize the same questions in their single-jurisdiction ethics application forms as the harmonized applications. For all of the available ethical review application forms, we documented whether or not they had questions that pertained to the following:

- Existing relationships with ICCOs
- Level of leadership and/or involvement by ICCOs
- OCAP® or TCPS2 Chapter 9
- Protecting Indigenous knowledge(s) shared through research

It should be noted that these four key areas are not mutually exclusive but are interconnected and most often have a positive relationship (i.e., when one increases, then others increase). For example, increased levels of ICCO leadership and/or involvement in REBs and ethical review processes, can lead to increased protection of Indigenous knowledge(s) shared through research.

Overview of Key Points

- The majority of research ethics applications are harmonized.
- The REB application is not the start of the research process (i.e., engagement with ICCOs should happen before ethics).
- First Nations Health Authority (FNHA) is often the only ICCO involved in applications. Note, FNHA is only involved in reviews for projects that they are leading or partnered on.
- Issues of compensation for ICCO involvement within REBs and ethical processes needs to be addressed (i.e., REB members who are faculty receive compensation via time buyouts, but community members need to be honoured for their time and guidance in other ways). Lack of ICCO and Indigenous representation on REBs is largely capacity/budget/ability to compensate.
- Awareness of the need for improvement and actively trying to make changes.
- Many REBs do not receive, or rarely receive, ethics applications for research that is Indigenous-focused. For example, “Don’t receive many Indigenous focused applications- this may be because of the nature of the REB and that they may not be very supportive to Indigenous researchers. They need to change things, so they [the REB] are not seen as a barrier to Indigenous research”.
- REBs rely on researcher honesty, volunteerism, and compliance to ensure ethical research.
- Trying to be flexible when the researcher is Indigenous and working with their own community. i.e., researchers are given the authority through the REB to lead and control their own community’s knowledge and study alongside community’s consent/partnership.
- Concern of potential taxing and overburdening of ICCOs and Indigenous faculty.
- Voluntary nature of REBs members make it a challenge to require training. Cannot enforce other training. Instead, when referring to training such as OCAP®, REBs use language such as “try to follow”, “encourage others to”, “ask politely” and “suggest”.
- Varying ways to demonstrate ICCO research relationships and consent (e.g., formal research agreement, letters of support, etc.). Acknowledgement that it should be done according to community need and want.
- Importance of REB leadership and organizational readiness for change. E.g., a very supportive VP Research who is onboard with changes helps to make them happen.
- Gap between support for Indigenous graduate students seeking to do research versus other researchers. However, some REBs actively recruit Indigenous graduate students to be REB members.
- Additional questions may be asked of Indigenous applicants because they may not self-identify within the ethics application, which can cause unintentional harm to the Indigenous researcher.

Primary Findings

What, if any, Indigenous-focused learnings are REB members required to receive?

Among the 21 responding REBs, 7 of them require some Indigenous-related training, while 5 are in the process of developing and/or mandating training, or want to incorporate it into their boards. These trainings most often include the updated TCPS2 with Ch. 9, but also involve OCAP® and informal discussions on Indigenous research. Most often in those who require training, it is only mandatory for new board members.

What, if any, involvement do ICCOs have in the REB process (e.g., developing protocols, materials, reviewing applications)?

Among the 21 responding REBs, 7 have direct involvement with ICCOs in some part of the REB process. These relationships largely involve FNHA, who are consulted only when needed. However, the University of Fraser Valley has a research relationship with the Sto:lo Nation for projects involving that community, and Island Health holds a research relationship with Cowichan Tribes. While many REBs do not involve ICCOs directly, they may support them to develop their own ethical review processes for research that involves them as well as respect the authority of ICCO-based ethics/research processes. For example, one REB's Indigenous member has partnered with another Indigenous researcher to discuss Indigenous research ethics with local First Nations, with the goal of supporting these communities to (re)develop their own ethical review processes for research within their jurisdictions. Another REB commented, "they want to support communities and nations to have their own REBs and ethics processes but need guidance on how to do so".

How many, if any, Indigenous peoples are on the REB? Are they allocated all the Indigenous-focused applications?

Among the 21 responding REBs, 9 have 1-3 Indigenous members. As most REBs are cognizant of overburdening Indigenous board members, they will often ask them beforehand if they have the personal resources to review Indigenous-focused applications.

Is ICCO ethical approval required? If so, what process is undertaken to confirm it?

Among the 21 responding REBs, the majority were unaware of any formal ICCO ethical approval processes, though all REBs recognized that community consent is unique to each community and must occur before the REB's approval. One REB commented, "they are striving to acknowledge that there are multiple ways of seeking consent and so they are trying to build this into the application". However, few REBs take any action to confirm this consent/relationship and instead rely solely on the researcher to demonstrate this.

In the ethics application(s), what questions (if any) are asked about existing relationships with ICCOs?

Used by 22 of the 27 BC REBs, the Harmonized Behavioural and Clinical Ethics applications have one question pertaining to existing relationships with ICCOs, which is written in the context of “community engagement”. In REB’s single-jurisdiction application, 13 ask any questions relating to existing relationships with ICCOs, which is largely in the context of asking about prior engagement/consultation before initiating research.

In the ethics application(s), what questions (if any) are asked about level of leadership and/or involvement by ICCOs?

Used by 22 of the 27 BC REBs, the Harmonized Behavioural and Clinical Ethics applications have no direct questions pertaining to level of leadership/involvement with ICCOs, though they do ask if the research seeks “input” of Indigenous knowledges and peoples. In REB’s single-jurisdiction application, seven ask questions relating to leadership/involvement with ICCOs, and these tend to involve questions about how community members will be meaningfully involved throughout the research.

When the researcher is Indigenous and/or working with their own community, many REBs try to be flexible and support them in leading the ethical review process. As well, REBs noted that they support ICCOs to review any applications themselves when the research is happening within their own ICCO; however, they also support the process if the ICCO requests or does not have the resources.

In the ethics application(s), what questions (if any) are asked about OCAP® or TCPS2 Chapter 9?

Used by 22 of the 27 BC REBs, the Harmonized Behavioural and Clinical Ethics applications have no questions about OCAP® or TCPS2 Chapter 9. In REB’s single-jurisdiction application, eight ask questions specifically about OCAP® or TCPS2 Chapter 9.

There was more than one REB that did not have an awareness of OCAP® principles and lacked an awareness that some ICCOs have their own ethical review processes. “I am not sure we’re consistent about OCAP® or protecting Indigenous knowledge”.

One REB commented on slowly changing the language to be centred on the needs and wants of the ICCO rather than using the language of the TCPS2 Chapter 9 because of its academic-based language.

In the ethics application(s), what questions (if any) are asked about protecting Indigenous knowledge(s) shared through research?

Used by 22 of the 27 BC REBs, the Harmonized Behavioural and Clinical Ethics applications have no questions about ways to protect Indigenous knowledge(s) shared through research. In REB’s single-jurisdiction application forms, a few (e.g., Royal Roads University and Camosun College) ask questions pertaining to the protection of Indigenous knowledge(s) shared through research.

Main Topics of Discussion

Restricted Power

For many REBs, power is not held with the board to make meaningful changes within their institution.

Further, it can be a challenge to get everyone on board with the meaningful changes needed to support and understand Indigenous research ethics, including individual board members, faculty, and the larger institution (e.g., they cannot require additional trainings such as OCAP®). For some REBs, “a cultural shift” is needed to change structural practices and ethical review processes. For instance, one REB is under pressure to “move things along” in their reviews so as to not hold research up because of “cultural issues.”

Capacity and Resources/Supports

There is often a lack of resources (including time or financial and institutional support) to make many of the changes REBs believe are necessary to provide awareness and support around Indigenous-focused research ethics. Board members are often overworked and under supported in their roles, particularly if they are Indigenous, and REBs are generally made up of volunteers. Moreover, training, like OCAP®, requires funding, for which REBs do not always have access. For one REB, the biggest struggle is bridging the gap between intentions and practice as a small, severely under resourced board in a health authority. Among larger institutions, there is not always a recognition of the value in providing structural and systemic support to REBs, so that they have the resources required to do this work. One REB shared that funding for capacity building is sought from external sources, as there is not enough in their budget.

On some level, lack of capacity and resources/supports can be an issue for all REBs. For example, REBs face “overburdened faculty and lack of resources– hard to fully show up for training”, as well as “high turnover rate”, or

“We constantly lack the resources to be able to do the good things we want to do... Because TCPS2 isn’t prescriptive, there’s no real ‘right’ way to do REBs reviews on any subject matter or with any populations. As a result, our REB staff are constantly stretched thin trying to develop expertise & appropriate practices to support our board members to do their due diligence with every new study that comes through.”

The benefit of a large and strong network of REBs is it helps to cover gaps in knowledge and expertise. For example, one resource/support for an REB is having strong working relationships with those who have awareness of power dynamics, consent issues, Indigenous cultural safety, etc. (e.g., clinicians, community members, etc.). Furthermore, a connection to FNHA and other Indigenous centres (e.g., UBC Indigenous Research Support Initiative–IRSI) and communities are significant resources for REBs. For example, one REB does not have the cultural safety and knowledge on their board to work with Indigenous-focused applications and, in those cases, they consult with FNHA for direction.

Clearly, Indigenous representation on REBs increases capacity and confidence to review Indigenous-focused applications.

“Even if she [Indigenous member] is not directly assigned to a particular study, she always contributes to the discussion of each and has been an amazing resource for our board and increased the board’s knowledge and again their confidence in reviewing applications involving Indigenous participants.”

Education/Training

Key for REBs is the opportunity for formal education, training, and engagement in the context of Indigenous research and ethics. Some REBs are initiating a different training process for new REB members, including Len Pierre from FNHA involvement (for relationship building and addressing key gaps), OCAP® training, ICS workshops, etc. Yet, “more funding/resources are needed to provide Indigenous-focused learnings for members”. Also,

"A big gap is how to adapt and how to change – without guidance and suggestions to Indigenize, the board is hard. How to do it in anti-racist way... biggest gaps are not having guidance/information from their own institution or even Research Ethics BC...feel like they're floundering in the dark [and] been working through the old model of doing research and it's not viable anymore... A lot of people recognize cultural safety and being focused on what they're asking of people, but a lot of people are frightened to bring these issues up because they don't know what language to use/ensure the language they use is "correct" and isn't causing harm inadvertently... They need to be told about/shown the steps required to go about having a formalized research relationship [with ICCOs]."

Many REBs lack confidence in reviewing Indigenous-focused applications because of a lack of knowledge and expertise. Notably, taking the OCAP® training and TCPS2 CORE-2022 tutorial increased the confidence of some REBs.

"Our REB regular members (16) have all recently completed OCAP® training within the last 12 months and it has increased the board's confidence in asking questions around data governance and meaningful community engagement for studies that take place in an urban setting."

"The inclusion of Chapter 9 as an integral part of the TCPS2 CORE-2022 tutorial was a wise decision since all of our researchers are required to complete the tutorial and they will now become familiar with the issues and requirements of research with Indigenous individuals and communities as part of the tutorial."

Also, it is important that REBs can learn from one another and have structured opportunities to network and share.

"Having REBC increase its educational offerings on Cultural Safety & Humility and guidance for working with Indigenous communities has been extremely valuable for us. The more we can learn from others doing this work well, the better all REBs will be than if we were trying to figure it out on our own."

Ethical considerations for Indigenous participants versus ICCO partnership

There is a concern among REBs about the lack of ethical consideration for research samples that are very likely to have Indigenous participants. As far as ethics application questions, there seems to only be consideration for research working directly with an ICCO.

"During Covid so many clients/patients were Indigenous, but no questions were asked re. Indigenous cultural and ethical safety; they are doing a lot of education and changing this now because they see where they failed – the effort is now there, but it was a huge issue at the time... Also, there can be a disconnect with urban Indigenous communities where the REB may not necessarily have a centralized person in this community to connect with."

"Most of the research projects involving Indigenous people are community-based projects in the urban setting in the DTES. Unfortunately, the questions in the RISE application currently are taken from TCPS2 Chapter 9 but do not address projects where it is anticipated that Indigenous participants will be overrepresented. I would like current questions in the application like 5.5 to be changed to something like "Does this research focus on Indigenous peoples, communities, or organizations OR are Indigenous participants anticipated to be overrepresented in the sample population" Or something like this? The problem with the current language below is that for studies in the DTES, researchers can arguably check "No" to 5.5 and then all the other questions that follow disappear which is a huge problem... My biggest concern with regards to gaps are with the longitudinal studies that were approved in some cases 15 years ago when the REB application did not even include the questions above or 5.5. was answered No and these questions have not been appropriately addressed."

"In a couple of cases, the researchers had not adequately addressed the fact that while they were not specifically addressing Indigenous issues in their research design, they were very likely to recruit Indigenous people among their participants. We required these researchers to familiarize themselves with the requirements of Chapter 9 and to be clear about how they would respectfully and appropriately include Indigenous participants. We are also clear that deciding to exclude Indigenous participants in a study because of the increased complexity involved is not acceptable and a violation of the TCPS2 principles of Respect for Persons and Justice.... For our REB, we now do our own research when presented with an application in which the researcher proposes to conduct a study in a community that we suspect would have a substantial Indigenous population. An example is a recent application in which the researcher proposed to look at mental health services access in a northern BC community but hadn't addressed the inclusion of Indigenous people. After looking at the demographics for the community, it was clear that at least one quarter of the population identified as Indigenous. We returned the application with a requirement to develop strategies that would effectively and appropriately include Indigenous participants, including consultations with mental health practitioners who work specifically with the Indigenous community. We also made it clear that it was not an option to exclude Indigenous participants for any reason."

Key ethical issues for institutions and non-Indigenous researchers

- Research protocols that have not fully thought about cultural safety in their Indigenous participant / community engagement.
- Principles of OCAP® are not fully developed across the lifecycle of the project (from design to dissemination and beyond).
- Study risks are overstated and lack a strengths-based representation or other times, are understated and need careful reconsideration/education within the study team.
- Benefits to participants/communities could be greater across the applications.
- At times, researchers (especially students) may be reluctant to address issues or to conduct research in communities in which Indigenous people could be included as participants primarily out of perceived extra work or feel they do not have enough knowledge about cultural safety, appropriate research protocols, the obligation to consult, Indigenous control of data, and other requirements and considerations.
- Faculty often do not understand Indigenous research ethics and how to follow proper protocols and they often think doing Indigenous research involves doing more/added work in the research, so they may even go as far as to recommend against doing Indigenous-focused research to a student. More than one REB commented that some researchers and faculty are not always on board with Indigenous ethical processes.
- Institutions may sometimes be only interpreting the minimum standard of ethical policies for Indigenous research through their own lens. While a local lens is needed, the support between REBs and the institutions is not consistent (harmonization process helps with this as it provides a baseline and is standardized).

Examples of REBs with Wise Practices

Overview of wise practices

Each REB member was asked if they could identify any strengths and/or wise practices within their work.

Key characteristics of wise practices:

- Attempts to support ICCO research infrastructure;
- Attempts to support researchers;
- Mindful of overburdening Indigenous board members and ICCOs; and
- Desire for change.

Camosun College

- REB application requires that those applying to do research directly consult with Eyē? Sqā'lewen to ensure they have community connections prior to submitting REB application, read the Guide to Research with Indigenous Communities, review Ch. 9 of the TCPS2, familiarize themselves with Indigenous research ethics, and consider reviewing UNDRIP, TRC Calls to Action, AFN, and OCAP®.
- If the project will recruit Indigenous people or could inadvertently recruit them, or has to do with Indigenous knowledge, then it is sent to the Indigenous subcommittee (comprised of two Indigenous people, including the head of Indigenous studies at Camosun and another Indigenous person).
- Questions or comments that directly ask about the protection of Indigenous knowledge(s) shared through research. E.g., "...ensure that the participants have the authority to answer", "...questions they may find private, stressful or sacred" and "research results do not belong to the researcher or a sponsoring institution".

Douglas College

Note, they modelled their section on Indigenous research after UVic's application process.

- They are actively connecting to current work being done around changing these processes (including connecting with REBC and attending cultural safety trainings, actively seeking out Indigenous people to be on the board, etc.). E.g., no questions in previous Douglas REB applications pertaining to Indigenous research; eight questions in the newly revised Indigenous section of the Douglas REB application.
- Question about ICCO involvement across the lifespan of the project (from research design to knowledge sharing, including research data ownership, sharing, storage and governance), which is enacting the principles of OCAP®- though OCAP® is not specifically mentioned.
- All new members will be required to take the updated TCPS2 CORE on Chapter 9, and by September 2022 all researchers will be required to have it.

First Nations Health Authority (FNHA)

Note, FNHA is unique from the other REBs in that they are an ICCO. As well, even though FNHA does not have an REB, they do have an interim review process and are able to participate in harmonized ethics review for partner REBs.

- They ask research teams to apply to partner with them before they embark on the project/grant application. FNHA asks to see how the project lines up with priorities they have been given from First Nations communities, and how the study protocol lines up with the seven directives. All research partner requests are reviewed and approved by their Research Executive Committee (REC), which is also the body that reviews and approves ethics for FNHA. Even a request for a letter of support for a project goes through their REC.
- FNHA does look to support in-community ethics review, and also plans to have an REB in-house that will represent the five regions of the province.
- Looks for evidence of a meaningful partnership – both with FNHA and with communities- by talking with any FNHA staff associated with the project. Looks for evidence of implementation of OCAP® (rather than just mentioning the word), evidence of cultural safety, and Indigenous community leadership in the project – across all phases. Cultural safety is one of the main components of the review: look for cultural safety in research team make up, risk assessments, general study design, recruitment and consent.
- FNHA is developing an Indigenous ethics review process, which involves a pre-review by their ethics team, then a collaborative review together with FNHA staff who have volunteered to become ad hoc Indigenous ethics reviewers. They come to consensus on their feedback for the research team in their provisos. Their provisos are reviewed and approved by the FNHA REC, and then posted in RISE. They are also piloting a collaborative meeting with the research team members who are at FNHA to provide their provisos in advance of posting in RISE so that the process is more relationship-based.
- While they don't yet have an REB, they are developing capacity for grant management and self-determination in all aspects of the research process.
- Reviewers must do the TCPS2 updated CORE with Chapter 9 and San'yas Indigenous Cultural Safety Training.

- FNHA is developing an ethics review framework based on extensive community engagement on ethics in 2016.

North Island College

Note, based on the new revised version of their ethics application.

- They want to make their newly revised application more like a coaching piece. Researchers must know that they need to make those relationships solid before the ethics application. The question is asked on the application and asks where the person is situated. They want the researchers to think about who they are and why they want to do the research, and whose lands they are on. They want to see co-creation of studies.
- They acknowledge that sometimes the ethics and protocols are not always a linear process and they allow themselves to be guided by the communities and their wants/needs, while also trusting the communities and the researchers who are a part of these communities to know what ethical protocols are required.

Royal Roads University

- Created guiding knowledge for Indigenous researchers and any researcher who wants to do Indigenous research usually goes through the Director, Indigenous Engagement (who is Indigenous) to receive guidance on the correct protocols for both the lands/communities in which the research is taking place as well as the lands in which RRU is on.
- Engages in knowledge sharing, networking and supporting other REBs and institutions. E.g., SFU regularly connects with the Director who offers guidance in Indigenous research ethics as well as showcases what is happening at RRU.
- Has their own set of guidelines, as explicitly stated in the policies and application, that go beyond the requirements of the TCPS2 Chapter 9.
- Questions on how the principles of OCAP® are developed across the lifespan of the research (development, implementation, analysis, writing, presentation, dissemination).
- Questions on the protection of Indigenous knowledge(s) shared through research.
- Aside from training provided to REB members, they are hoping to build “Indigenous research champions” so they can understand, know, and think critically about how to protect Indigenous knowledge and peoples in the right way.
- The Director and others have gone to Indigenous communities to discuss and share Indigenous research ethics with them to support the development of their own ICCO-based research ethics process.
- They are approaching the vice president and senior administration so that the student approaches the Director much earlier than during the ethics application stage – they are still working on developing this properly and getting faculty members on board.
- They are also working on formalizing the process for students to approach their Director as well as their supervisor for guidance, as they must understand Indigenous research ethics before applying for ethics (not all supervisors/faculty believe there is a need to do this).

Simon Fraser University

- The SFU application form speaks to self-determination between ICCOs (e.g., Nation-specific protocols for recruitment) and the researchers need to consider differing Indigenous protocols within research.
- Asks question about an existing ICCO-based ethical framework: Does the group, organization or Nation involved in this project have a research review process or ethics committee?
- For questions about how the project will support capacity building, a hyperlink is included that takes applicant to the TCPS2 Chapter 9 guidelines.

University of British Columbia

- REB is going through the institution’s Indigenous strategic plan to identify what actions can be

·taken within the board to achieve those goals.

- Currently in the process of building/updating a new UBC website on Indigenous research ethics.

University of Victoria

- The REB does lots of outreach to graduate courses and students.
- They are very strategic in their recruitment. They also send out a call for two graduate students to be a part of the REB, which is always centred on Indigenous research.
- Researchers are to follow UVic's Indigenous Governance (IGOV) policies and practices (i.e., Indigenous leadership).
- Deconstructing Institutional ethics, but this research is very nuanced. UVIC's research should be grounded within the ethical process within the communities in which the research is taking place in. Researchers must speak confidently around the research Indigenous communities want and need. The REB lets the community steer the boat. This has come from years of self and board reflection. The ethical environment is not just what happens within UVIC – they cannot be the experts. The REB know when they need to step back. This is a culture shift and different way of working.
- They are hoping one day to have the online application portal designed by an Indigenous designer so that everything in this process is designed by Indigenous researchers and community; but right now, this is a budget challenge.
- Application questions on Indigenous leadership and/or involvement.
- There are questions in the standard application about Indigenous engagement, which were developed by members of the Centre for Indigenous Research and Community Led Engagement (CIRCLE) (5 years ago). They took the questions Charlotte Loppie drafted and took it to CIRCLE and then CIRCLE independently went out to the local communities to consult with about these questions, which were ultimately reformulated by community. They were then sent back to the REB (the REB itself had no participation in this).

University of Fraser Valley

- Has their own ethical application forms for U. of Fraser Valley – They have a supplemental form which is specifically for Indigenous focused research and was created by the Sto:lo Nation, in addition to the standard form (HREB). The form facilitates thinking that moves away from Western research – the supplemental form is educational and updated regularly.
- They have a meaningful relationship/partnership with Sto:lo, who have their own form and process that has to be completed before going through the University's REB. Sto:lo Nation has a research center (REB collaborates with their research center and ethical processes).
- Acknowledges existence and rights of Indigenous communities to review research occurring with them (i.e., ethical approval either by consent/review or through their own community-led REB).
- Application questions about mutual benefit (reciprocity) as well as Indigenous leadership and/or involvement.
- They have a retreat once a year where there is often an Indigenous guest speaker who shares teachings on Indigenous research ethics.
- They have Indigenous liaisons.

Summary of Ethics Sharing Circles

Purpose

The BC NEIHR's (British Columbia Network Environment for Indigenous Health Research) purpose for completing the Ethics Sharing Circles is to document the ethics review experiences of Indigenous researchers (faculty, including those who are or have participated on a Research Ethics Board (REB) – as a member, vice-chair or chair), Indigenous graduate students and ICCO (Indigenous communities, collectives and organizations) members.

This collaborative project between the BC NEIHR, Research Ethics BC, FNHA (First Nations Health Authority) and University of British Columbia is part of a larger internal review that is gathering information to help inform Indigenous research ethics/ethical processes in the areas of:

- existing research ethics applications;
- current practice of reviewing Indigenous research; and
- education and training for those involved in the ethics review process, and researchers proposing work with ICCOs.

This report provides a summary but not an analysis or interpretation of the information/experiences shared.

Methods

From December 2021 to April 2022, Tara Erb (BC NEIHR Network Coordinator) hosted 2-hour lunches and sharing circles (in-person and online participation) at the University of Victoria, the University of British Columbia, and the University of Northern British Columbia. In addition, information was shared by one-on-one discussions over Zoom and by email, which included participants from other institutions. Unless indicated otherwise, each bullet point in this report represents a single person's response.

Sharing Circles: Using a circle format, attendees shared their research ethics-related experiences, reflections and suggestions. Tara took notes of the discussion to identify current strengths, gaps and barriers related to ethics/ethical processes to inform BC NEIHR initiatives as well as policy and organizational change within REBs/ethical processes.

The sharing circles were guided by the following questions developed by Dr. Charlotte Loppie and Tara Erb from the BC NEIHR:

- As an Indigenous researcher/student, what are your experiences (harmful or positive) going through the ethics review process at your institution?
- What gaps/barriers exist in the current REB process?
- What can REBs do to support Indigenous researchers and graduate students?
- How can REBs ensure that non-Indigenous researchers are culturally safe and held accountable when working with Indigenous people(s), communities, collectives or organizations?
- What do all REB reviewers need to know about Indigenous research ethics? (i.e., core learnings that must be either demonstrated or learned prior to acting as a reviewer)

Positives/Strengths

REBs are trying to embrace complexity

- While still a general feature of current ethics applications, there is an increasing recognition among REBs that a 'one size fits all' approach does not work in every circumstance.
- One challenging issue that the REB did not push back on was questions around what community engagement and consultation actually looked like and how it could be different. There was openness and willingness to listen from the REB when bringing these issues forward.

REBs are trying to provide supports and make provisions

- Overall, there have been improvements over time.
- Institutions moving everything online makes the process of applying for ethics easier and more streamlined. Could this practice be adopted at all institutions? E.g., currently UNBC uses a word document that requires the applicant to type everything in each time. On the other hand, online gives immediate feedback (making revisions very easy) and information from year-to-year can be saved (e.g., if teaching the same course).
- The feedback from the REBs is good and they provide one-one-one support for graduate students to assist with their ethics applications. REBs can come to students and have presentations about the process.
- There is improvement in the support made available for those who are struggling to fill out the forms (e.g., students).
- There is an increased acknowledgement that common Indigenous knowledges exist, and they are making provisions for that.
- Trying to make the ethics process more open/accessible, and less of a mystery.

Approachability

- REBs are approachable and available for in-person or other supports, but not everyone knows or feels that. Many people, including colleagues, are not aware that you can go into the office and get help. There is a need to make it known to more researchers and students that ethics boards are approachable.
- REB always had it so researcher could come and present to the REB. But there has only been 1-2 in all the years that come to present. Wish it were more common – increase conversation between the groups. Come with material and help the REB understand, especially if it is a unique approach.

Personal experiences

- I had positive experiences overall.
- Experiences were entirely positive and felt supported in getting Master's and PhD. I saw the capacity and it fanned the flame to become a researcher and faculty member. The REB does a good job seeking out diverse membership, including Indigenous peoples. They sought me out to be on the board. Also, there are excellent allies on the REB.
- I had to introduce the REB to other protocols, which was a long process. However, it was refreshing to have individuals who actually wanted to understand (open to learning and changing).
- I have completed one ethical review and received approval, and I am working on two SSHRC-funded research projects that also received ethical review approval. What I found going through the ethical review process at my institution was that it was very thorough, and I appreciated the rigor that was expected to ensure researchers were mindful and respectful of Indigenous rights and cultural integrity.

Gaps/Challenges

Fear/hesitance

- This is a hot discussion with more senior faculty in particular– the idea that the REB is trying to stop me from doing my research – and such negative ideas spread to the students. Then there is fear/hesitance from them before even interacting with REBs/ethics processes. This perception that REBs are the bad guys trying to be hard on people and making it difficult to do research is still there in some pockets.

Accountability

- There is an upfront concern from REBs about getting it right, but then little follow-up to see if it was done right. They rely on researcher honesty and compliance.
- The tendency of the focus is to protect the institution. Designed to protect institutions rather than the community.
- What is the institution's responsibility to the community when the researcher(s) cannot or does not want to fulfill their commitment? For example, should ethical breaches have a penalty of no additional granting? It is the Institution's responsibility to think more deeply about it.
- There is so much in the academy about absorbing information, but not enough on how we embody and act on information. There is a huge gap in preparing people to take on responsibility for their actions.
- There is a lack of humility from the institution or academy. We should leave room for mistakes and anticipate harms. We should have a budget and mechanisms in place to deal with them when they happen. Because of the unwillingness to make mistakes and anticipate harm, the academy is not ready to do the deep intergenerational work we are doing or wanting to do (just won't be possible for a while). There is defensiveness just around the word 'accountable'. We deserve to have honest critiques and difficult conversations (it is part of this deep intergenerational work). But there are barriers in place to prevent those conversations from publicly taking place. There should be funding for forums and other opportunities for safe conversations. Examine and re-examine what safety and wellness means. What we think we know and how we learned it– academy is about absorbing information and less about how information affects our bodies and relationships. This gap leaves people unprepared to take on responsibility for the way we act interpersonally. This is harmful and it negatively affects research and how research is conducted. There is a lack of compassion.

Process and decision making

- Lots of back and forth with the REB. They are clearly looking for wording or something specific, and it would be easier if they were more transparent about what it is they are looking for. Clarify what information they want from us. The language is picky and specific. The details can feel patronizing when taken with the concept of self-determination. At the end of the day, it is the communities who are affected because they can't go forward with the research.
- It is confusing when you should contact community. The process of ethics first, then reaching out to the community is an awkward gray area because there should be community involvement from the start– before ethics.
- There are people, including faculty, who are afraid to make an ethics application – seen as a daunting process? It is a notable avoidance – maybe avoiding human research at all costs or trying to get around ethics board.
- Members of the REB can be stuck in their own way of doing things and have difficulty seeing how others are looking at issues. It is more difficult as researchers bring forward Indigenous methods and community-based research, which is not always embraced but challenged. In the past, when qualitative methods came forward, quantitative scientists resisted. It is not as strong a response to Indigenous methods, but it is similar.
- Institutions based in the south of BC do not understand what is happening in northern communities. Then provincial decisions are made that do not resonate or make any sense to northern communities.

- There are attempts to develop strong initiatives in the north, which becomes provincial, and then we never hear about it again. There is a lack of northern community voice. How do you get south-based people, for example, those who live and work in Vancouver, to understand what it is like to live in a northern Indigenous community that is deeply connected to the earth cycles? Those who are in big southern cities are likely disconnected from such worldviews, perspectives, and ways of being, but yet are the ones making decisions for these communities.
- Tendency for a binary approach to looking at things, which eliminates complexity rather than develop ways to deal with the complexity ethically.
- The structure does not allow researchers to be human beings – we expect everything to be locked down and ‘perfect’ before going into community. Institutions do not want to be criticized. But if the research process cannot be open to critique, then it is not collaborative. Expecting perfection is not realistic. There is a lack of humility. The system is structured to make no room for researchers to “be human” and make mistakes. Institutions do not want criticism for researchers not being ready or for bad research practices/processes. We need mechanisms in place to anticipate mistakes and harms (have resources available). This is the institution’s responsibility– they have the resources. Right now, they are policing more than providing the necessary resources. The problem is we do not have a vocabulary that is a real contrast to extractive knowledge/research. And the problem is so systemic– we do not talk about or have the language to grow and garden community knowledge. Maybe just in little pockets. But the academy as a bigger structure doesn’t have that.
- Institutional policies and practices seem to be worse than ethical ones. The ways that institutions set up and structure the research does not work, and that then comes up in the ethics process.
- For ethical research with Indigenous peoples, you cannot just follow only the rules and protocols laid out by the REBs because it is so context-specific and you are bound to miss appropriate protocol. Context-specific is crucial; it matters.
- They struggle with the discrepancies and terminology of relationship and partnership. To go into communities and have the honor of recording truths– those relationships take time to build the trust and involves active listening, which we are not taught in university. Knowing cultural protocols and how we are asked or not asked to participate all takes time. Ethics ask for agreements, but it doesn’t reflect that process and time.

Personal experiences

- Indigenous graduate was told that the language used in their ethics application was “colonial”. Same student was asked questions like: Why Elders had knowledge? Define who an Elder/Knowledge Holder was? Did they have a letter of support from each community in the province? Had they talked to their committee about working with Indigenous community? The same graduate student was required to have pre-approval from an Indigenous person on an academic staff list and send a document about sacred knowledge and sacred artifacts and required to read it. Student found it hard to process an ethics application to do relationship-building work before actual dissertation research work (REB didn’t understand why student wanted to work with people and carry out relationship-building before starting the dissertation– they didn’t understand the need). Student had OCAP® training but was “badgered” about their qualifications to do the work– this student was doing Indigenous research with their own community. Student had heard similar experiences from other Indigenous students in their cohort.
- Not allowed to give tobacco to elders.
- Indigenous students (who are often members of the community) don’t always have the same resources to give as what is expected of non-Indigenous researchers but can give cultural and medicinal gifts (not monetary honoraria). REBs do not always understand that those gifts would be acceptable from a community member. One REB member commented “that it would be better to give money honoraria because Indigenous communities are poor”.

- The ethics form and questions did not fit with what they were trying to do, which was an oral testimony program that records people's testimony– they themselves do not extract any data for their own purposes to reproduce, publish, or do anything with the testimony. They can store it for participants or participants can walk away with it and they keep no record. There were major barriers in trying to communicate in a form to the REB what they were trying to do. No matter what they wrote, it did not convey what they were doing because it was 'new' and there was no researcher 'agenda'. The initial application just kept getting shut down. Eventually they had to do the process in person (x5 meetings). Experience showed clear cultural barriers and cultural protocols between REBs and Indigenous researchers. It took significant time to meet in person to see those barriers come down. The relationship with them had to be built. They say themselves [the REB] that the process did not and could not fit with their program. The application is not set up for Indigenous ways of knowing. They introduced to the REB other protocols. It was quite the process (time and energy). In the end the dialogue was a good experience.
- The suspicion placed on me as a 'Researcher' often feels as though it is stripping me of my Indigenous identity and relation to the community.
- Through the ethics process, student did not hear her community understanding of knowledge. E.g., need to secure anonymity of participants' but knowledge from her community is based on family/clan identity, which is important to identify. How does bad research get through ethics? One example of bad research published (she keeps a copy in her house to remind her about bad research) about her community (Dakelh people). The researcher published 'Elder knowledge', but it was all made anonymous, which is a serious ethical concern for her community. Clearly that researcher did not have enough understanding of her people's understanding of knowledge.
- There is no understanding of the hereditary system and the REBs follow an understanding of Indian Act bands. She left out her accountability to the governance of the hereditary system because she was afraid of REB rejection of it. Instead, she got permission from each 'band', which took her more time and cost her more money.
- REBs make assumptions about being Indigenous or not (when researcher does not self-identify). They assumed non-Indigenous even though the funding opportunity stated Indigenous. They missed that significant detail. The problem is there is pressure in the application to be concise, which means there is no room for identity to make it obvious.

Indigenous recognition, inclusion and leadership (demonstration of or lack of)

- There is a general lack of Indigenous representation on the REBs.
- Indigenous is included in the REB process, but not in a way that reflects our diversity. Still using a one size fits all approach.
- We need to ask how we can make the process more responsive to Indigenous communities?
- When always categorizing Indigenous communities as a collective, it does take away some "individual agency" when from that community.
- A group of Indigenous researchers will submit a proposal and get challenged, for example, because there is no mention of OCAP® or its from superficial/formulaic stance. The meaningful community involvement within the application is not considered (unless stated through OCAP® language). Issues of data sovereignty and doing research in a good way versus OCAP® – the differences between them.
- Communities had developed their own protocols that were dismissed by the ethics board. The REB chair did not see it was important to see what the community had created. All that mattered was approval from institutional REB. The point was missed – how what community wants is important. It is a complete shift that challenges established mentality. The other ways of knowing and learning as well as seeing value in what community wants.
- Ability to use information and language that is common knowledge from your community. E.g., student writing about treaty 6 – had to get research ethics to use common knowledge even though not interviewing anybody and not actual research.

- Communities are looking for research that will benefit them in some way. People out there are willing to participate and have graduate-level students (Masters/Ph.D.) in the community, who have a better understanding of what is involved, engage with them.
- For a lot of people, going to the community and talking to them about what they would like is risky and a big step for them. For example, it can be hard to convince hardline/clinical researchers that there are other ways of gathering knowledge.
- Limited ability to give credibility to the people who are most impacted without framing them as victims. The ethics process can frame Indigenous peoples as vulnerable, at risk, victims, fragile, etc. This is problematic because we end up not involving them in the problem-solving process because of their 'vulnerability'.
- Tendency to treat the community as fragile and in desperate need of protection when it was the community themselves that wanted the research. There was this 'suspicion' of the researcher and a 'forgetting' that the researcher was a member of the community. Fear of causing harm causes over-correction. REBs are nervous about chapter 9 and what it means.
- Can be complex and difficult to apply OCAP® because the knowledge generated "lives" within the institution (not the community). That is a conflict.
- Acknowledgement that the process has improved, but the REBs need better Indigenous representation with decision-making power.
- Separate process altogether for Indigenous research or just make the process safe for all? Create a specific process for only Indigenous-led research and have board specific to it? i.e., not an add on but its own body? Maybe a better opportunity to do better work (bypass the white bureaucratic system altogether)? But then how to still make sure that the system is held accountable to anti-racism and cultural safety?
- Issue of over-consultation- same 3-4 Indigenous people always being asked to help

Community or Organizational Ethics

- Going through two REBs (e.g., university plus a community or organization) at the same time is time-consuming and discouraging for researchers. Indigenous faculty felt that next time they would not do "Indigenous Research" because of the extra time. Whatever processes need to be in place, there is a need for a mechanism to stop them from being so slow that you cannot even do your research. The UNBC REB has rules in place on how long we can take. But for a community or organization, there are no rules in place for how long it takes to respond, and you could be waiting a month or for months. That piece is hard.
- One of the things that is really interesting, as an academic and community member, is that often people dichotomize groups. You are both the insider and outsider. The overlap makes it interesting but also adds to the complexity. Indigenous faculty can get lost and need to be supported by the community. They are working with "bad guy" [the institution] but they are also an insider (community member). Build capacity and as numbers build-up at the institutions, a shift will happen with insider/outsider perspectives.
- Ran ethics by community partners first before going through REB – considered this more important. We need to put agency into the community. Researchers misstep in research because they follow REB protocols but do not always fully understand the community protocol.
- Student created an ethics/methodology process with her community based on her hereditary and traditional governance. It was done to protect intellectual property rights. All researchers who want to work with her community must demonstrate they have gone through their process, understand it, and agree to it. Researchers are held accountable to the community. They have a community-based research committee/council that reviews the research and will negotiate a research contract. She will now first go through this process before she goes through the ethics process at her institution.

- Esk'etemc research policy was developed with student Penina. First, they looked around to see what other people had done (rather than recreate the wheel). They found the framework of Lheidli T'enneh and looked to that, but then found they had to really create their own. There had been so much work around community knowledge and information during the Treaty process (e.g., Elder interviews) and they wanted to capture and include that (all 'paper' documents were digitized). They have a history of knowledge stolen by researchers. One researcher from the University of Calgary stole knowledge from an Elder under the pretext that they were going to write it up for them. They never heard from that researcher again. The family of that Elder tried to find the stolen knowledge but was unsuccessful. So, they decided it was important to develop their own community-based research policy to protect knowledge. They have seen and read bad research done on the Esk'etemc people. The new policy will help to clear up these problems. When reviewing research and research ethics, they prioritize: How will this research benefit us? Is it relevant to us? If it is not, the application is rejected. They will not work with self-serving persons. They have six members on the advisory council/committee. They want to see that the researcher has followed the policy manual. Today they have the first person there doing research (on out-of-care)- a UBC student- who went through their research ethics policy. Dealing with UBC in this context was a problem. There was 3 months of hard negotiating with UBC about the approach and gathering of knowledge (compensation, respect for the protection of knowledge). It got stormy at some points. The student felt afraid to ask hard questions because she felt she would lose her funding- because of issues around possession, ownership, and access to the findings. But Esk'etemc insisted they hold onto the knowledge for so many months (to ensure protection of it). Copyright and release of information is the hardest part to get around because everyone wants rights to the knowledge. It was a huge learning curve for Esk'etemc. They want to be involved in the beginning and the end and then after.
- Respect the need for multi-jurisdictional. There should not be contested space within the university for Indigenous communities, which overburdens them and is unethical. Need to develop MOUs and use ethics terminology that is relevant to the nation- that is folded and respected in context with any REB. Communities have their own expectation of ethics and always have, so you need to include it within the applications. It is frustrating to justify yourself over and over again as an Indigenous researcher- there is fatigue in doing that. We need to grow TCPS2 Chapter 9 and make it relevant to local communities (nuanced).
- Suggestion: Knowing and being aware of community-based ethics that exist and to go through those avenues of consent and approval first. A friend/colleague went through UNBC ethics and Carrier Sekani Family Services and received approval. But when they went to start the research with the community they were shut down. The community rejected the UNBC and CSFS approval (wasn't their process for consent). In the end, they were able to resolve it.
- This province is at the point where they need to create a database of who has already started/created an ethics policy, e.g. These are the communities that already have done this work. Support First Nation communities that want to do the work – connect with the communities that do have it. Does your community have a research ethics policy – willing to share? Create a website. Not currently easily available – it would be great to have a master document.

Indigenous cultural safety and ethical behaviour

- Need funding for more opportunities for safe conversations (e.g., workshops, learning circles, training sessions, etc.). We need opportunities to talk about what safety and wellness means in the context of listening to other people's knowledge and in terms of trying to ground our own knowledge as well as examine what we think we know and how we learned it.
- Lateral kindness: people need to first find their own voice. Third party voice is sought by people who do not have their own voice and so look to outside research for a voice. The process should help community researcher partners to find their voice first (human capacity)- then ethics and the research will be more grounded, and they will have ability to generate grounded knowledge.

- How to make sure that non-indigenous researchers are safe? Many communities have complained when they are not acting in a culturally safe manner. Damage was done in the past and researchers are not always aware of that when entering a community. People need to be aware of those past damages.
- After everything that has happened, researchers are still trying to sneak things through (should know better!). E.g., samples used beyond the initial research proposal. Researchers often not clear on the proposal about the use of data and do not consider community data sovereignty. The researchers do not want to make themselves vulnerable by saying the community will decide what is done. "I don't want to invest my time and then not be able to write my article". Researchers interest comes first over community. We need to help scientists understand these things – data – who do they belong to and do you have permission to use them? There is still a mentality that data are theirs and can be used any way they want. But it is positive when community voice involved. However, they do not see it that way – this is still a challenge.
- Be careful of pan-Indigenizing. Not all Indigenous researchers have a solid understanding of cultural protocols particularly when working with other communities not their own. They can still do harm that gets missed.
- Often the intentions of researchers are good and in the right place but need support thinking it through and making sure there are no gaps and potential harms. People need to have clear understanding of OCAP® principles and Indigenous Cultural Safety. There are so many resources out there about these there is no excuse. There is no reason for applications to be coming in with major gaps in that context. Yet, she has come across these applications still. We need a degree more of self-reflection and reflexivity. We need to develop core principles and education for both supervisors and reviewers.
- We should add an Indigenous aligned policy statement around the 4 Rs (Respect, Relevance, Reciprocity, Responsibility) to the TCPS2. Write the 4 Rs into the applications. Researchers will be able to align their priorities and identities with it. Suggested materials for reviewers: any literature on 'anti-oppressive research' (from field of social work) and Insurgent Research by Adam Gaudry. These materials will provide an understanding of the why to the 4 Rs. The goal is to stop oppressing. The system is not designed for our participation or benefit. They need to understand our struggles with it.
- Lateral violence is not accounted for in a way that is respectful. Problem with not addressing lateral violence– keeps research the way it is– assumes it to be lateral violence free. 'Betrayal blindness'. We study health only when non-controversial. We need to identify and address lateral violence and develop strategies to protect people.

Future Pathways

Protecting community and Indigenous knowledges

- At a minimum, applicants should get a letter from the community for approval of the research. Ethics is not always asking for it and making assumptions that it will be fine. The main concern is protecting institutions, not the community.
- What does community engagement and consultation look like? Who do you get permission from to engage? Are you checking off a box or actually engaging? Reciprocity? Benefits to the community?
- Those who deal with ethical breaches must have some Indigenous knowledge and connections to Indigenous communities.
- Research ethics boards need to have someone who is familiar with Indigenous peoples, research and local communities. What is also problematic about that though? Placing heavy workload on an individual?
- The concept of 'relations' needs to be opened up. When folks are working with land/waters (i.e., not people), there should still be an ethics process and we should be thinking about it in ethical terms (like we would with people). REBs need to think about relationships differently– that the land and waters are our relations. You hear "it's just field work– they're just taking samples– they're don't need ethics", but those are our relations, and you are doing that on communities' territory. We need agreements about what you are taking, how you are using it and storing it, etc.

- How do we define respect? Institutions and nations define it differently. E.g., institutions define sovereign as ownership and control, but my community defines it as being stewards of the land and doing no harm. It is less about ownership and more about reciprocal responsibility. You need permission from both the land and the people. In that case, permission looks different than what institutions would think. There is a fundamental difference here that does not translate well. How can you still be respectful? How to apply OCAP®? Who has the authority to determine the ethics of the research? They can start by inviting the host nations to participate in the process.
- Need to put something in the funding calls/criteria (before ethics) that protects the Indigenous communities.
- Establishing relationship MOUs (shared values and principles statement) with community as part of the ethics process is crucial to a relationship paradigm.
- An REB application challenge is to accept the hereditary system (There is no negotiation with/engagement with the hereditary system).

Accountability

- How to be accountable to host nations? We have them sit on our boards and students in our program present their research to the community. That is very rewarding for students and there is lots of positive feedback from community. They like hearing about all the work that is happening on their territory even if it does not involve them directly.

Increasing approachability

- Make an option for community members to contact the ethics board. Have mechanisms and processes in place for dealing with complaints. Make REBs approachable to Indigenous communities.
- Have more education that demystifies the ethical process.

Complexity and flexibility

- We need to take into account that the researcher's relationship to the community may be unique. E.g., Asking family members, like a parent, to sign an ethics form is uncomfortable and not culturally appropriate.
- Develop user-friendly technologies like fillable forms, etc. so that information can flow quicker, reduce barriers, and feel more flexible. Design a process that will not take the researcher a year to get through, with the understanding that they cannot promise total flexibility – certain rules still have to be met.
- Engage in a paradigm shift and different ontologies etc. Engage with others' perspectives. Talk about land – look at spiritual components – how they make decisions, etc.
- Complexity of urban-context settings because they include different people and multiple hosts. What band to go through for consent and relation-building? Not really possible, but still need to remain accountable and respectful to all the host nations. Thinking of OCAP®- in urban settings who owns, controls, and possesses the data? The knowing mix of urban settings has proven materially difficult.

Resources and resourcing

- We need more supports in general. REBs are shockingly not well supported! There is not a lot of funding, and most do it on the side of their desk. If they were better supported and funded, they could support students better. More supports are what is needed, like opportunities for Indigenous research workshops.
- Need more supports for Indigenous students who are outside of the Indigenous Studies programs (e.g., sciences). In general, we need to do a better job of supporting students doing the applications (i.e., mentorship). The role of the supervisor and mentors should be to engage students and provide clear guidance. You don't know what you don't know.

- REBs are trying to reinvent the process. Some members are very dedicated and working hard to make changes (good allies). The concern are the discrepancies with institutional policies and practices (rather than just ethics). How to make the 'relationality' and customization of it sustainable? We have to think about burnout and uneven pressures. We need to protect both the REB workers and Indigenous researchers and make sure they are not exhausted so that they can give the focus and energy to the projects that need them. This is care work for all parties.
- Mentors need to provide support and mentorship for students and support communities when they want to push back. Indigenous researchers need more support and a varying in discipline (that gets missed- e.g., lots of support in Indigenous studies, very little support in the sciences). Assign point-persons to help go through the process.
- Institution needs to hire more staff and provide more resources to show that this is a priority.
- Develop curriculum based on the 4 Rs in the context of research ethics and ethical review and find a way to have communities represent themselves in their own self-determining way.
- Educate on the 4 Rs and build awareness of historical and contemporary colonial/racist experiences. We need to be careful to not replicate those power structures. This involves broader social-political pieces that we do not talk about enough. E.g., have deeper conversations around OCAP® principles (in the context of community-based) and conversations on multiple levels.

Where to start (comments/questions for further discussion)?

- *How can we find ways to encourage people to discover that REBs are approachable and transparent (humanize them so people do not feel like they are something to avoid)? Challenge for REBS: work to change how people perceive them- put energy into 'public relations' and relationship-building?*
- *How to distinguish between common knowledge that does need approval to share and collective knowledge that should get approval? When are ethics required?*
- *REBs could benefit from more training and familiarity with TCPS2 Chapter 9. E.g., what it looks like in practice.*
- *How can we provide better resources to the REBs?*

References

Government of Canada Panel of Research Ethics (2018). https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html