

Walking Together
Applying OCAP® to College Research in Central Alberta

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KEY MESSAGES

The relationship between the researcher and the community is key to ethical research practice.

Knowing the community is paramount to a successful project, and in order for research to reflect Indigenous principles, the community must also know and trust the researcher. The researcher must be open, genuine, and flexible - behaviours that are often discouraged or made difficult in an academic and bureaucratic environment. Granting agencies and institutions need to find ways to better support researchers as they work to develop authentic, long-lasting partnerships with communities, with an emphasis on acknowledging and allowing for the time this work takes.

A strong disconnect exists between community practices and institutional policies and practices.

This disconnect has a significant impact on both research projects and relationships. Institutions and researchers working within a traditional academic culture therefore need to “take a step away from a colonial, linear mindset”, as one of our collaborators put it, and consider their policies and procedures through a different lens. There must also be a commitment to changing the underlying message that Indigenous communities have to accommodate non-Indigenous ways of knowing, doing, and learning to fulfill non-Indigenous academic requirements.

There is a need to be flexible in how traditional ethical principles are applied and implemented in Indigenous research, and to broaden the consideration of ethical questions to long after a specific research project has concluded.

Much more attention needs to be paid to ensuring future, ongoing positive results of research dissemination and avoiding negative impacts. Researchers and Research Ethics Boards will need to be intentional in their examination of privacy, confidentiality, consent, and acknowledgement when looking at the design of a new project, and may have to consider new ways of doing things in order to properly accommodate individual and community wishes. Research done right also has a significant impact on community resources, so consideration of and respect for community capacity and priorities needs to be part of the ethical assessment of a project, and funding agencies and policy makers need to consider including funding to assist with the resource strain as part of their grant offerings and policies.

Thoughtful and thorough consideration of how language structures meaning and understanding needs to be a part of the research process when Indigenous peoples and communities are impacted.

Language cannot be incorporated in “bits and pieces”. It is a reflection and expression of a particular world view, and words may not translate directly into another language because the underlying concept does not have a direct equivalent or is not understood in the same way. While ensuring that researchers engage with communities in “linguistically appropriate” ways was stressed in the literature and policies, there was an absence of discussion around the practicalities and the importance of doing so. Further work, therefore, needs to be done to provide appropriate guidance to researchers and Research Ethics Boards.

Definitions of “community” are far more complex than the current guidance documents suggest.

The OCAP® principles were created within a First Nations context. The issue of community consent becomes much more complicated when considering research with urban and/or Métis populations, where the definition of community is not as clear, and it is therefore more complex to determine the appropriate members to consult. First Nations, urban Indigenous, and rural and urban Métis communities all exist together. However, each community and group is unique, and the process of seeking both community and individual consent needs to be based on the specific protocols and requirements of the individual community with which a researcher is hoping to partner. Further guidance needs to be provided in policy documents, and funding agencies and academic institutions need to allow appropriate time for community consultation and consent.

EXECUTIVE SUMMARY

The Royal Commission on Aboriginal Peoples (1992) raised awareness within the academic research community that ethical review of research topics, methods, and dissemination strategies related to Indigenous research must go beyond what is normally required for academic study in order to address power imbalances and a long history of problematic research, and to ensure respect for Indigenous knowledge in the research process.¹ In addition to concerns raised around individual and community consent and guarantees of confidentiality, questions still exist around control of research funding, the level of detail provided to participants and communities about potential risks of a project, possible misuse of or de-contextualizing of cultural information, the commodification (by an external researcher) of information collected from a community, and the sensationalization of social problems and limited examination of community or cultural strengths, among others.² Also, as is set out in Article 4 of the *United Nations Declaration on the Rights of Indigenous People*, “Indigenous peoples, in exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs.”³ This right to self-determination extends to the right to control what research is conducted in their communities, how that research is to be carried out, and what is to happen to the data that is collected. It also means that an Indigenous research paradigm can exist alongside and in dialogue with the traditional academic research paradigm, rather than trying to incorporate Indigenous methods into the traditional paradigm.

OCAP^{®i} is a set of principles created during a National Steering Committee meeting of the First Nations and Inuit Regional Longitudinal Health Survey in 1988 to address the historically problematic relationship between First Nation communities and researchers, academics, and other data collectors.⁴ As a set of principles, OCAP[®] aims to secure community rights to and control of their own information, along with ensuring research conducted with First Nations communities maximizes benefits to the community while minimizing harms. However, OCAP[®] was created to address the research process in a health/bio-medical context, and is specifically a First Nations initiative. Questions still exist over the applicability of these guidelines to the social sciences (e.g. qualitative, historical/archival, and participatory action research), as well as how well they fit for all First Nations communities and for non-First Nations communities (e.g. Métis). Is OCAP[®] adaptable to both rural and urban contexts? Do all First Nations know about OCAP[®]? Does it mean the same thing to all First Nations? Do all communities have the capacity to follow OCAP[®]?

Our final research question therefore became: **What is the current academic, government, and community knowledge on the role of institutional Research Ethics Boards in advising both Indigenous and non-Indigenous academic researchers working with Indigenous individuals and communities in Central Alberta on OCAP[®] principles, particularly given differences in language and understanding about the concepts of research ethics?**

Our final research question and parameters for the scoping review were determined, refined, and validated by our collaborators and consultants before moving forward. Collaborators and consultants were invited to participate in the project due to either experiences as an Indigenous researcher, direct experience with research with Indigenous communities, or experience with research ethics or providing support for non-Indigenous researchers. Our initial search resulted in 857 articles, which was narrowed down to a final dataset of 168 articles through the inclusion/exclusion process. The data from the included literature was mapped according to key issues and themes, and gaps were identified. The results of the data analysis and drafts of the report were validated through a consultation process with the collaborators and consultants, and any suggestions and feedback were incorporated into the final report.

ⁱ OCAP[®] is a registered trademark of the First Nations Information Governance Centre (FNIGC). For a full definition please refer to www.FNIGC.ca/OCAP.

Results

- 1. OCAP® principles have not yet been significantly integrated into college or university ethics policies in Alberta.** One possible reason for the limited integration of OCAP® into policy is tied to knowledge gaps in the college/university system. These knowledge gaps result in disconnects between community and institutional cultures coloured by language, political structures, and legal structures, and can have a significant impact on research projects and relationships. As a result, respectful and effective collaborations are weakened in their ability to create effective social change, and questions are raised about Research Ethics Boards' ability to protect the welfare of populations impacted by research. Institutions and researchers working within a traditional academic culture therefore need to “take a step away from a colonial, linear mindset”, as one of our collaborators put it, and consider their policies and procedures through a different lens. Granting agencies and institutions also need to find ways to better support researchers as they work to develop authentic, long-lasting partnerships with communities, with an emphasis on acknowledging and allowing for the time this work takes.
- 2. Each community and group is unique, and the process of seeking both community and individual consent needs to be based on the specific protocols and requirements of the individual community with which a researcher is hoping to partner.** Some Indigenous communities have established forms of governance and relationships wherein people have been given the role of representing the interests of all community members. Failure to recognize these levels of organization when requesting permission to conduct research or inviting communities into research partnerships violates the Ownership and Control principles of OCAP® and risks repeating some of the historical injustices of past research practices. However, there's not much advice offered in any of the documents about how to reconcile a conflict between community and individual consent, when/if such a conflict should arise, nor is there much discussion on how to handle the issue of community consent in non-homogeneous communities or in regions with more than one Indigenous group. The issue of community consent also becomes much more complicated when considering research with urban and/or Métis populations, where the definition of community is not as clear, and it is therefore more complex to determine the appropriate members to consult. Knowing the community is paramount to a successful project.
- 3. There is a need to be flexible in how traditional ethical principles are applied and implemented in Indigenous research, and to broaden the consideration of ethical questions to long after a specific research project has concluded.** Given the importance of the ethical principles of Ownership, Control, and the concern for welfare, much more attention needs to be paid to ensuring future, ongoing positive results of research dissemination and avoiding negative impacts. The academic principle of confidentiality was sometimes characterized both as a barrier to the Ownership principle and as frustrating researchers' attempts to collaborate with Indigenous communities in a respectful and anti-colonial manner. Researchers and Research Ethics Boards will need to be intentional in their examination of privacy, confidentiality, consent, and acknowledgement when looking at the design of a new project, and may have to consider new ways of doing things in order to properly accommodate individual and community wishes.
- 4. To be meaningfully involved in a research project from design through to dissemination, the obligations and responsibilities for the community can be extensive. As a result, resource or research fatigue can be significant challenges.** Collaborative, community-engaged research is positioned throughout the literature as the standard practice for research with and in Indigenous communities. However, full, meaningful research collaborations require a significant resource investment on the part of communities. Funding agencies and policy makers, therefore, need to consider including funding to assist with the resource strain as part of their policies and grant offerings.

Knowledge Strengths and Gaps

1. It was clear throughout the majority of the documents that the relationship between the researcher and the community is key to ethical research practices. However, there are questions around the role Research Ethics Boards play in monitoring both research projects and these long-term relationships. Similarly, the Possession and Access principles of OCAP® were not really addressed in the literature reviewed, possibly because these principles involve activities beyond the scope of the “on paper” project that has typically been the focus of academic Research Ethics Boards. Further consideration of how to either expand the knowledge and capacity of Research Ethics Boards to monitor community Possession and Access or to identify what entities are better situated to do so would start to close this particular knowledge gap.
2. Any researcher or Research Ethics Board will need to work with local communities to draft locally-appropriate research agreements. The templates we found provide a solid foundation from which to work. There was, however, a noticeable gap in the literature around how to reconcile conflicts between the *TCPS 2* and Indigenous ethical protocols. Collaborators and consultants also noted the potential for further discrepancies with the *TCPS 2* and traditional academic practices when we start to tie ethics policies to Treaties, the *UN Declaration on the Rights of Indigenous Peoples*, the *Canadian Charter of Rights and Freedoms*, Provincial Constitutions, and community laws and protocols. All of these legal documents, as well as the Truth and Reconciliation report, contain protocols aimed at reconciling past wrongs towards Indigenous peoples, culture, and communities, as well as ways to forge a future that supports self-determination for Indigenous peoples. How these protocols play out in a research project is currently a significant unknown; but as one of our collaborators noted, the first step is to “accept there are protocols; they are a must”. Further work and research, therefore, is required to better guide researchers and Research Ethics Boards on how all these guiding principles and laws tie together.
3. Collaborators and consultants identified a need for far more consideration of how to contextualize key ethical principles, such as privacy, consent, and confidentiality. Researchers need to be better supported and advised as they collaborate with communities on the specifics of these concepts in research. Further, there is a need for advice from policy makers as to how institutions and researchers are to navigate misalignments between community policies and practices and academic policies and practices.
4. There was some evidence of the inclusion of Indigenous languages and ways of knowing within the literature, and our collaborators and consultants did see evidence of some institutions starting to consider other ways of knowing (for instance, through policies that have been created to facilitate research with Indigenous communities). They stressed, however, that there must also be a commitment to changing the underlying message that Indigenous communities have to accommodate non-Indigenous ways of knowing, doing, and learning to fulfill non-Indigenous academic requirements. They stressed the importance of Research Ethics Boards and researchers understanding the crucial role of language. Language cannot be incorporated in “bits and pieces”; thoughtful and thorough consideration of how language structures meaning and understanding needs to be a part of the research process when Indigenous peoples and communities are impacted. Further work, therefore, needs to be done to provide appropriate advice to researchers and Research Ethics Boards.

Conclusion

Overall, we saw evidence in the literature that OCAP® principles are seeing increased incorporation and application in research projects, but the knowledge about the role that the Research Ethics Board plays, as well as the knowledge about applications specific to the Alberta context, is still quite limited.

CONTEXT

August 2016: Alice sits at her kitchen table, in her house in a remote Cree community in the mountains of Central Alberta. Someone knocks on the door. She opens it to see a young woman with a clipboard - a young, white woman. Her first thought is: *Kee kwai inta we tak?* (Uh oh, what does she want?). She becomes guarded: Is she going to want to come in? Is my house okay? Is it about my kids? The young woman asks Alice if she can have a moment of her time. "May I come in?" Alice worries: Is my house clean enough? Where is she going to sit?, but invites her in anyway, because after all, she's a white woman; have to let her in ... The young woman, a research assistant, walks in, sits up straight at the kitchen table, excited to meet Alice. Alice thinks: *Ota sah keyiu ahwah.* (This is a social worker?) . The research assistant starts to discuss a research project being done in the community. She hands Alice a paper, a consent form, with the logo of the local college on the top. It's a project about a youth after-school program. Alice worries: *Kee kwai maka eete kwee ahmah ochea?* (I wonder what *this* is for?)

This scenario illustrates several practical problems that come up when contemplating research projects with Indigenousⁱⁱ communities, particularly around the superficial involvement of the communities and people as research participants. In our scenario, the Band Council may have passed a Resolution to be involved in the project, but Alice didn't hear anything about it. And if Alice does participate, will the Band Council know what she says? Can Alice refuse to participate? Does consent mean the same thing to Alice as it does to the researcher, to her research assistant, to the Band Council and to the Research Ethics Board which approved the project? Does it mean the same thing to Alice, who is Cree, as it does to someone who is Blackfoot or Nakota?

The Royal Commission on Aboriginal Peoples (1992) raised awareness within the academic research community that ethical review of research topics, methods, and dissemination strategies related to Indigenous research must go beyond what is normally required for academic study in order to address power imbalances and a long history of problematic research, and to ensure respect for Indigenous knowledge in the research process.⁵ In addition to concerns raised around individual and community consent and guarantees of confidentiality, questions still exist around control of research funding, the level of detail provided to participants and communities about potential risks of a project, possible misuse of or de-contextualizing of cultural information, the commodification (by an external researcher) of information collected from a community, and the sensationalization of social problems and limited examination of community or cultural strengths, among others.⁶ Also, as is set out in Article 4 of the *United Nations Declaration on the Rights of Indigenous People*, "Indigenous peoples, in exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs."⁷ This right to self-determination extends to the right to control what research is conducted in their communities, how that research is to be carried out, and what is to happen to the data that is collected. It also means that an Indigenous research paradigm can exist alongside and in dialogue with the traditional academic research paradigm, rather than trying to incorporate Indigenous methods into the traditional paradigm.

OCAP[®] is a set of principles created during a National Steering Committee meeting of the First Nations and Inuit Regional Longitudinal Health Survey in 1988 to address the historically problematic relationship between First Nation communities and researchers, academics, and other data collectors.⁸ As a set of

ⁱⁱ We have used the term Indigenous throughout this report as that is the collective adjective/noun that has been mandated by both the federal and our provincial governments, despite the fact that the Cree Indian people who collaborated directly on this project do not self-identify using this word.

principles, OCAP® aims to secure community rights to and control of their own information, along with ensuring research conducted with First Nations communities maximizes benefits to the community while minimizing harms. The four components of OCAP® are:

- “a community or group **owns information collectively** in the same way an individual owns their personal information...
- communities and representative bodies are within their rights seeking to **control all aspects of research and information management processes** which impact them ...
- First Nations Peoples must have access to information and data about themselves and their communities ... communities and organizations [have the right to] **manage and make decisions** regarding access to collective information ...
- **[physical] possession (of data)** is a mechanism by which ownership can be asserted and protected.”⁹ [our emphasis]

In addition to the guidance provided by OCAP®, frameworks for the ethical conduct of research with Indigenous communities have been incorporated into academic policies, most notably the *Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People*¹⁰ and Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)*.¹¹ The *CIHR Guidelines* were in effect from 2007 to 2010 and provided guidance to researchers and institutions who wanted to conduct health research involving Indigenous peoples in ethical and culturally competent ways. Since 2010, health research involving Indigenous peoples has been governed by the provisions outlined in Chapter 9 of the *TCPS 2*. The *TCPS 2* is the joint research ethics policy statement of three federal research agencies, the CIHR, the National Science and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC), and establishes standards and procedures for research involving humans. In the 2010 revisions to the *TCPS 2*, a new chapter on research involving First Nations, Inuit, and Métis peoples was included. Chapter 9 not only applies the *TCPS 2*'s core principles (Respect for Persons, Concern for Welfare, and Justice) to the context of Indigenous communities (e.g. ethical protocols are to protect the interests of the individual as well as the collective), it also outlines some crucial additional considerations for researchers, including:

- Community Engagement
- Consultation with Formal Leaders
- Ensuring Diversity of Representation
- Critical Inquiry
- Customs and Codes of Research Practice
- Collaboration and Participatory Approaches
- Community Needs and Priorities
- Capacity Building
- Engaging Elders and Knowledge Holders
- Privacy and Confidentiality
- Interpretation of Data and Review of Findings
- Intellectual Property Rights¹²

In addition to these formal policy documents, a number of other key sources have emerged to help guide ethical research in an Indigenous context. The foundational work done by Marlene Brant Castellano in “Ethics of Aboriginal Research” emphasizes the importance of integrating the following principles: “Aboriginal Peoples have a right to **participate as principals or partners** in research; ... [and] Ethical regulations should **include protection for ‘all knowledge, languages, territories.’**”¹³ [our emphasis] The 4 R's of Aboriginal Education have also been adapted by some to help guide appropriate research processes:

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- **Relationship:** Indigenous ways of knowing are based upon relationships between all life forms; all parts of the research process are interconnected.
 - **Respect:** researchers are required to be humble, generous, and patient in co-creating the research process.
 - **Reciprocity:** all research is appropriation and there should be adequate benefits for all parties involved in the research.
 - **Rights & Regulations:** the research process should be collaboratively created based on Indigenous protocols, defined goals, impacts of research, and how the knowledge gathered will be used.¹⁴

Willie Ermine developed the idea of Ethical Space to “create the analogy of a space between two entities, as a space between the Indigenous and Western thought worlds. The space is initially conceptualized by the unwavering construction of difference and diversity between human communities...each entity is moulded from a distinct history, knowledge tradition, philosophy and social and political reality. With the calculated disconnection through the contrasting of their identities, and the subsequent creation of two solitudes with each claiming their own distinct and autonomous view of the world, a theoretical space between them is opened.”¹⁵ In this concept, Ermine is using a definition of “ethics” to refer to the capacity to know what harms or enhances the well-being of people and to stand up for notions of “good, responsibility, duty, obligations, etc.”¹⁶

In recent years, Shawn Wilson’s *Research is Ceremony*, an account of Indigenous research methods from an academic perspective, has often been recommended to researchers. His concept of Relational Accountability is particularly helpful in framing a definition of ethical research: “Relational Accountability... so the way I see it, gaining knowledge is more like being married to someone - you don’t own your spouse or children but you do share a special relationship. It is a relationship that you are accountable to. And therefore it becomes cultural appropriation when someone comes and uses that knowledge out of its context, out of the special relationships that went into forming it. You have to build a relationship with an idea or with knowledge, just like you have to with anything or anyone else.”¹⁷

The principles of OCAP®, Chapter 9 of the *TCPS 2*, and the definitions of ethical research that have been provided from Indigenous perspectives offer some solutions for our scenario:

1. The researcher should find out the first language of the people in the community, and whether that is still the primary language used by the people she will be asking to participate in her study.
2. The research assistant should have a copy of the Band Council Resolution consenting to the project to show Alice that it has community approval.
3. An appropriate person from the community should have the chance to reword the survey questions so that Alice will feel comfortable instead of guarded.
4. The research assistant has to find a way to convey information that doesn’t necessarily translate directly (e.g., in Cree there is no direct translation for the word “ethics” - the concept needs to be described and explained for the specific situation).

Knowledge Synthesis Project

OCAP® and the *CIHR Guidelines* were created to address the research process specifically in a health/bio-medical context. Questions arise over the applicability of these guidelines to the social sciences (e.g. qualitative, historical/archival, and participatory action research). OCAP® is also specifically a First Nations initiative - how well do these guidelines fit for all First Nations communities (for instance, more than one Indigenous community participating in a research project), as well as for non-First Nations communities (e.g. Métis)? Similarly, is OCAP® adaptable to both rural and urban contexts? Do all First Nations know about OCAP®? Does it mean the same thing to all First Nations? Do all communities have the capacity to follow OCAP®?

It is because of all this complexity that we chose to respond to the Theme Question: **“What are the most appropriate and effective protocols and practices for collecting and using data related to Indigenous peoples and communities, in light of the First Nations principles of ownership, control, access and possession (OCAP®)?”**

We chose to further contextualize this question, as we wanted to assess the state of knowledge about the wider applicability of OCAP®, as well as about the specific nature of doing research in Central Alberta and in a college setting. Central Alberta is territory traditionally occupied by a number of different nations, including Cree, Dene, Blackfoot, Stoney, Nakota, and Ojibway, as well as the Métis people, and research in our areas could be done with any combination of these groups in both rural and urban settings. Monitoring ethical research in a college context is unique because:

- Mandates for applied research encourage strong partnerships with communities.
- Due to the size of their institutions as well as the diversity of faculty, college Research Ethics Boards often can or need to spend more time with individual researchers, particularly in the case of faculty from disciplines who have less experience with social science research methodologies. Fewer institutional resources might mean the Research Ethics Board becomes a well-used resource for most research-based questions.
- Teaching-centred institutions frequently engage in a significant amount of integration of the classroom with the community, creating opportunities for student research, but also driving a need for evaluation of campus-community partnerships.
- Sometimes being located in smaller communities (or working with smaller communities) means that communities or representative bodies might lack crucial resources or infrastructure to equally and enthusiastically engage in collaborative research projects.

Further impacting the work of college Research Ethics Boards are the *Truth and Reconciliation Commission's Calls to Action*.¹⁸ Many students are in programs which are training them for employment in the professions that are addressed in the *Calls to Action* - specifically, social work, education, justice, and health care. A common theme throughout the *Calls to Action* involves education of current and future professionals around the history and impacts of residential schools and around effective and appropriate solutions to the systemic inequality of treatment and experiences of Indigenous people. The release of the *Calls to Action*, as well as Canada's signing of the *UN Declaration on the Rights of Indigenous Peoples* that same year, has resulted in a noticeable increase in interest in research that connects these significant national commitments to social justice research as well as research on teaching and learning.

Our final research question therefore became: **What is the current academic, government, and community knowledge on the role of institutional Research Ethics Boards in advising both Indigenous and non-Indigenous academic researchers working with Indigenous individuals and communities in Central Alberta on OCAP® principles, particularly given differences in language and understanding about the concepts of research ethics?**

IMPLICATIONS

The following implications came out of our survey and analysis of the literature and were validated and refined by our collaborators and consultants. Please note that the implications and actions listed should not be limited to their identified group. There is a lot of overlap, and anybody can and should effect change.

Implications and Actions for Research Ethics Boards:

Research Ethics Boards act as the primary check and balance for ethical research in an institutional setting. However, the literature revealed a strong disconnect between community practices and the institutional practices of Research Ethics Boards. In order to address this gap in both knowledge and practice, Research Ethics Boards can:

- Create partnerships with Indigenous researchers, organizations, and communities.
- Ensure there is Indigenous representation among the membership of the Research Ethics Board.
- Require citation of key documents by researchers in their research design.
- Require all researchers to complete OCAP® and TCPS 2 tutorials.
- Incorporate OCAP® and other relevant principles and documents into ethics policies.

Implications and Actions for Institutional Research Offices:

The disconnect between community and institutional practices extends to Institutional Research Offices, whose policies and practices were shown to be barriers to researchers. Institutional Research Offices can:

- Create partnerships with Indigenous researchers, organizations, and communities.
- Provide access to education on Indigenous history, languages, cultures, local communities, etc.
- Support faculty to ensure citation of key documents in their grant applications and research design.
- Ensure communities have been given copies of key documents and can enforce adherence to them.
- Examine and revise relevant policies to better reflect communities' practices and the realities of doing research with Indigenous communities.

Implications and Actions for Researchers:

Individual researchers carry the primary responsibility to create respectful and ethical relationships with the communities in which they work. Researchers can:

- Know the community where they wish to work, including its history, language, belief systems, politics, identification/identity determinants, and representation protocols.
- Know the protocols for doing research in the community, the processes the community has in place for OCAP®, and the capacity the community has for collaborative research.
- Know the laws, including local/municipal/community laws, as well as provincial and national laws that will have an impact on access to participants, access to data, privacy/confidentiality, etc. (e.g. child welfare laws, *Access to Information Act*, *Library and Archives of Canada Act*, *Copyright Act*).
- Read and utilize key documents and have conversations with the community about their capacity and protocols to ensure adherence to them.
- Complete tutorials on OCAP®, TCPS 2, etc.
- Advocate for adoption of best practices and protocols within individual disciplines, including advocating for co-authorship of publications, shared grant holding, shared decision-making, etc.

Implications and Actions for Indigenous Communities:

Indigenous communities and researchers identified lack of capacity to accommodate research as one of their significant issues. In the literature written by them, they recommend that communities:

- Establish research committees and develop criteria for review of research, as well as a community code of ethics/conduct for external researchers.
- Identify community priorities for research.
- Make OCAP®-ready tools available (standards, templates, rules for access to and protection of information).
- Create partnerships with universities and/or colleges and within academic culture.
- Promote development of Indigenous communities as data stewards.

Implications and Actions for College and University Administrations:

The disconnect between community practices and institutional policies and practices also extends to college and university administrations. As the creators of strategy for their institutions, the people responsible for creating and maintaining respectful relationships with the communities in their areas, and especially as they look at ways to respond to the Truth and Reconciliation Committee's *Calls to Actions*, administrations can:

- Create partnerships with Indigenous researchers, organizations, and communities.
- Create a strategic plan for research that encourages projects on topics relevant for the planning of local services and/or that will benefit local communities/groups.
- Create an engagement policy that invests in and commits to maintaining consistent and ongoing relationships with communities and identifies and supports key contact people.
- Support researchers as they engage in new, prolonged processes of engagement and relationship-building with communities.

Implications and Actions for Research Funding Agencies:

Lack of capacity and support was mentioned as an issue for both researchers and communities. To help alleviate the pressures these individuals and groups experience, research funding agencies can:

- Provide funds and resources to support communities that want to learn more about ethical research, OCAP®, and the *TCPS 2*.
- Provide funding to support research capacity in communities (e.g., to hire community-based staff to coordinate research activities).
- Create scholarships and grants for community-led research projects.
- Ensure there is Indigenous representation on funding and grant review committees.
- Require citation of key documents by researchers in their grant applications and research design.

Implications and Actions for Policy-Makers, including the Tri-Council:

While both OCAP® and the *TCPS 2* are seeing significant acceptance by researchers, there are still a number of gaps in the policy information available to researchers and Research Ethics Boards. Many researchers are still using the *CIHR Guidelines*. Therefore, we suggest that policy makers:

- Look at gaps and areas of overlap in existing policies, and work with Indigenous researchers and organizations to try to fill them.
- Clarify the link between the Access and Possession aspects of OCAP® and ethical research protocols. Attention needs to be paid particularly to long-term considerations for the welfare of communities and individuals.
- Look at gaps and areas of overlap in community codes of ethics and/or research agreements and institutional research and ethics policies, and work with Indigenous researchers and organizations to try to fill them.

APPROACH

The scoping review was conducted according to the methodology put forward by Arksey and O'Malley,¹⁹ with some modifications.²⁰ Our final research question and parameters were determined, refined, and validated by our collaborators and consultants before moving forward. Collaborators and consultants were invited to participate in the project due to either experiences as an Indigenous researcher, direct experience with research with Indigenous communities, or experience with research ethics or providing support for non-Indigenous researchers. For a complete list of collaborators and consultants, see Appendix A.

Preliminary search strategies were created based on the final research question, and then piloted to test their effectiveness (complete details of search strategies are available upon request):

- To locate all relevant post-secondary policies, we hand-searched websites for all public post-secondary institutions in Alberta, as well as Alberta First Nations colleges and universities, for information on research ethics and Indigenous peoples. We also tested the websites of several private for-profit colleges but found no evidence that they were involved in academic research.
- To locate all relevant governmental and funding agency policies, we hand-searched a list of federal and provincial websites, both Indigenous and non-Indigenous. We also conducted a number of Google searches using different search strings.
- To locate relevant academic literature (articles, books, theses, dissertations), we conducted extensive searches of 17 literature databases from a variety of disciplines. These searches were supplemented by a number of Google Scholar searches to ensure nothing was missed.

The results of the initial search were brought back to the collaborators and consultants to see if any further refinement to the search strategies was needed. After a second search, inclusion/exclusion criteria for the final study were determined, and these criteria were then validated by the collaborators and consultants. The inclusion/exclusion criteria were determined after the search, rather than at the outset, to allow for changes in our understanding based on our increased familiarity with the evidence.²¹ Documents had to have been published within the last 10 years, have a national (Canadian) or provincial (Alberta) focusⁱⁱⁱ, be written in English^{iv}, and needed to engage with research ethics in an in-depth way. These criteria were independently applied to the search results by two different reviewers in order to reduce bias. Where there were points of discrepancy, the two reviewers met and discussed until consensus was reached. Our initial search resulted in 857 documents, which was narrowed down to a final dataset of 168 documents through the inclusion/exclusion process. For a complete list of included articles, see Appendix B.

The data from the included literature was mapped according to key issues and themes, and gaps were identified.²² These issues and themes were determined by the evidence through a grounded theory approach, specifically a constant comparative analysis, and modified throughout the analysis process.²³ Each document was read and charted with an eye toward information about language and traditional knowledge, community engagement, capacity development, data and results management, risks and benefits of research and inclusion. A copy of our charting document is available in Appendix C.

After the charting had been completed, we held conversations with some of the consultants in order to detail prior experience with research or researchers working on projects in Indigenous communities and to identify which of the themes were of most interest to particular consultants. The results of the data analysis and drafts of the report were also validated through a consultation process with the collaborators and consultants, and any suggestions and feedback were incorporated into the final report.

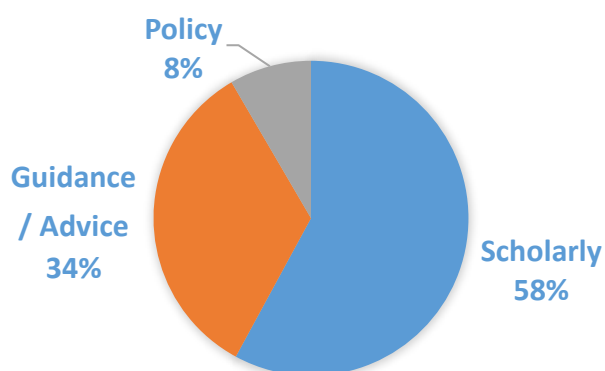
ⁱⁱⁱ Due to the lack of articles with an Alberta focus, we later expanded this criteria to include articles about research in other parts of Canada, in order to have enough data to work with.

^{iv} Note that, because many Métis documents are written in French, this exclusion is a limitation of the study, but was required as no member of our team speaks French fluently enough to work with these documents.

RESULTS

We reviewed a total of 168 documents, including academic articles, institutional websites, a variety of reports, and policies. 117 (69.6%) of the documents reviewed were scholarly articles and books. There were 68 guidance and advice documents and 17 policy documents (e.g. research ethics policies). Note: some documents were categorized as more than one type of document.

Figure 1: Type of Documents



Authors of Documents

Ninety-nine of the 168 documents (58.9%) were written by non-Indigenous authors (or authors who did not identify as Indigenous). Authors who identified as Indigenous created 42 of the documents reviewed (25%). Twenty-four of the documents (14.2%) were authored by a national or provincial Indigenous organization. Twenty-one documents (12.5%) were authored by a college or university Indigenous students' office or research department. There were 16 academic collaborative research teams/co-authors (two or more) where at least one of the team identified as an Indigenous researcher. There were a further 22 documents where there appeared to be a collaboration with an Indigenous community (leadership or a community organization).

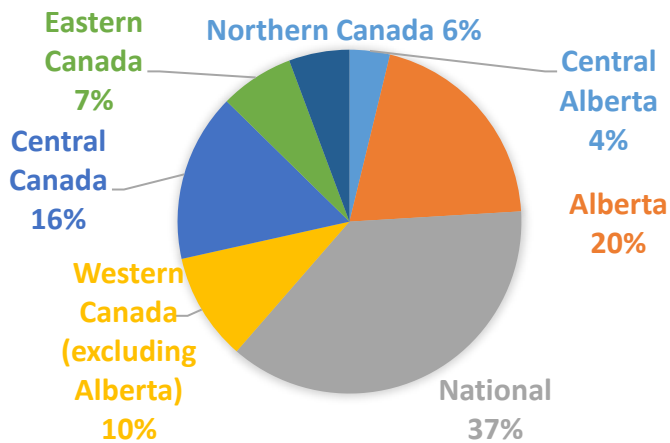
Table 1: Authors of Documents

	# of documents	% of total documents
Academic researcher - Non-Indigenous (or not identified)	99	58.9%
Academic researcher - Indigenous	42	25%
College or University Office (e.g. Indigenous Liaison Office, Research Office)	21	12.5%
National or Provincial Indigenous/Métis/Inuit Organization	24	14.2%
College or University Research Ethics Board	10	5.9%
Federal or Provincial Government	7	4.1%
National or Provincial Non-Indigenous/Métis/Inuit Organization	5	2.9%

Context/Location of Research

Very few of the documents we found were written in or about Central Alberta, confirming a gap we suspected at the outset of the literature search. While we limited our reading of policy documents to those from either Alberta or that had a national focus, as we believed that the advice we read needed to be specific to our context, we expanded our reading of research articles to include those from other provinces in order to learn from other research teams' and communities' experiences, since there was so little local information available in the dataset.

Figure 2: Context/Location of Research



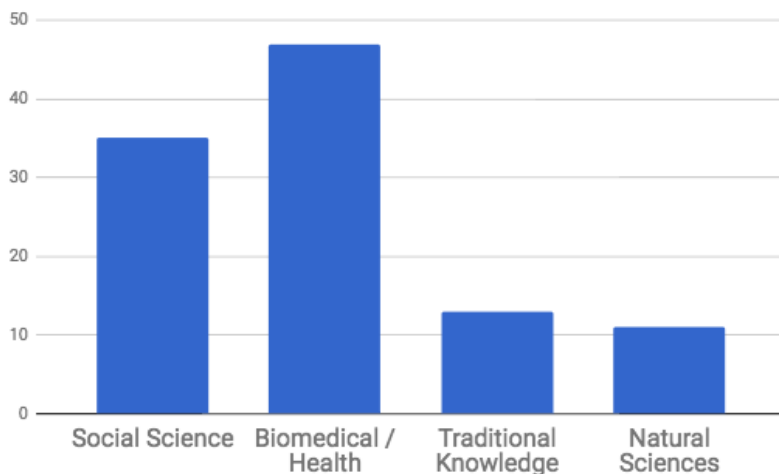
Of the only five documents from Central Alberta, three were in reference to one research project by University of Alberta faculty with the Alexis Nakota Sioux Nation.²⁴ One was the Red Deer College Research Ethics Board webpage on Research with Aboriginal Communities,²⁵ and one was the Voices From the Fire - Collaborative Charter signed by Shining Mountains Community Living Services, Red Deer College, Alberta Health Services, and the Central Alberta Aids Network Society (now known as Turning Point).²⁶ There were an additional 33 Alberta-based documents in the dataset. The majority of the documents had a national focus (59 documents); these included policy, national organization documents, and research projects.

Focus of Research

The documents focused mostly on biomedical/health research; these documents accounted for 47 of the 168 articles (27.9%). Research with human participants with a non-biomedical focus (e.g. sociological, historical, psychological, etc.) accounted for 35 of the documents (20.8%). Thirteen of the research documents focused on Traditional Knowledge (7.7%) and 10 documents involved physical, geographical, or natural science research (5.9%).

While our focus was on researchers working in the social sciences and humanities, we included articles written within a health context both because of the historical context of the OCAP® principles and the *CIHR Guidelines*, and also because the vast majority of the articles reflecting on the implications of doing research using the OCAP® principles came from a health context.

Figure 3: Focus of Research



NOTE: Only 92 of the documents had focus recorded. These documents were mostly research-based but also included guidance and policy documents. Also, some projects fit more than one focus category.

Documents Included in References

51.7% of the documents we read referred in some way to the OCAP® principles, and 48.8% referenced the TCPS 2. The CIHR Guidelines were cited in 18.4% of the documents, 29.7% referenced Castellano’s foundational article, and 13.6% included mention of Shawn Wilson’s *Research is Ceremony*.

Table 2: Documents Included in References

	# of documents	% of total
OCAP®	87	51.7%
<i>Tri-Council Policy Statement 2</i>	82	48.8%
Castellano: “Ethics in Aboriginal Research”	50	29.7%
<i>CIHR Guidelines for Research with Aboriginal Communities</i>	31	18.4%
Wilson: <i>Research is Ceremony</i>	23	13.6%
Community Research Protocols	21	12.5%
College/University REB Policy	16	9.5%

The Truth and Reconciliation reports and recommendations were only cited in two of the documents read, likely because they’re so recent and have not yet made their way into practice.

Our focus for this project was to discover the best practices for adopting OCAP® while also looking for gaps in that knowledge, especially as they relate to the research ethics process. As such, our inclusion criteria enabled us to capture documents that were concentrated reflections on the experience of doing ethical research with Indigenous communities. While there is good evidence of the application of OCAP®, there

were some common concerns and limitations encountered that were highlighted in the literature. The major themes that emerged from the literature review were:

- A disconnect between recommended best practices for conducting ethical research and institutional policies and procedures, including Research Ethics Board procedures.
- Tensions around definitions of community and obtaining informed consent.
- The requirement for confidentiality/anonymity of research participants vs. the desire for acknowledgement and accountability.
- Requirements and constraints of full community participation in research.

Integration of Community Principles into Institutional Policies and Practices

As noted above, 51.7% of the documents we examined made mention of the OCAP® principles. However, these principles have not yet been significantly integrated into college/university ethics policies in the Alberta context. We searched for specific mention of research ethics and Indigenous people/communities on the websites of all public post-secondary institutions in Alberta, and only 11 made any mention at all. When institutional policies do mention research with Indigenous people, most often the default is to Chapter 9 of the *TCPS 2*. See Appendix D for complete details of the analysis.

Only Concordia University and Red Deer College have integrated all or most of the *TCPS 2* articles into policy. The other schools either have only one or two articles integrated into their policies/websites or none at all. When we looked more broadly at evidence of the OCAP® principles within these same policy documents, only Blue Quills University mentioned all four. Blue Quills University likewise had the only truly community-defined policy, in that while clearly incorporating OCAP® and *TCPS 2* principles, it did not explicitly mention OCAP® or the *TCPS 2*.

One possible reason for the limited integration of OCAP® into policy is tied to knowledge gaps in the college/university system. These knowledge gaps result in disconnects between community and institutional cultures, and can have a significant impact on research projects and relationships. The scoping review uncovered several complaints (and unfortunately no specific solutions) about Ethics, Finance, and other administrative policies and procedures being too tied to academic timelines or perspectives, too driven by traditional research protocols, and too focused on the life of a research project as it essentially just exists “on paper” (i.e. Research Ethics Board application to report/journal publication), thus not allowing flexibility or a respectful approach to working with Indigenous communities. Some examples include:

- Finance Departments wanting names for honoraria, which could be a breach of confidentiality.²⁷
- Research Ethics Board rules for confidentiality or de-identifying records conflicting with participants who want to be identified or want acknowledgement for their information.²⁸
- Privacy committees or Research Ethics Boards interpreting the risks-benefits balance differently from the community.²⁹
- The consent form required by a Research Ethics Board being too detailed, not flexible enough, and undermining community ethical consent/approval processes.³⁰

The disconnect between traditional academic and Indigenous community ideologies and realities was also evident in discussions of the relationship building activities that become a key aspect of research in Indigenous communities. These relationship-building activities precede the project and ideally should exist long after the final report is submitted, requiring an expansion of academic policy and ethical oversight to extend beyond the “on paper” account of a research project: “the typical REB process is ‘paper-based’, and reflects a single snapshot-in-time approach reinforcing an emphasis on regulatory mechanics rather than ensuring the ethical conduct of the ongoing research process. This approach does not accommodate the time and relationship factors involved, the nonlinear evolution of the research process, and the importance of equity, action and capacity building essential to community based participatory research and indigenous research methodology.”³¹

The relationship of the researcher and the community is crucial to ethical research. It was the strongest theme in the literature reviewed, and it was further reinforced by our collaborators and consultants. In order for research to reflect Indigenous principles, the community must know and trust the researcher. The researcher must be open, genuine, and flexible - behaviours that are often discouraged or made difficult in an academic and bureaucratic environment. For some researchers, this process also requires them to reflect on the inherent power relationships between them and the communities with which they are involved. The researcher needs to know or learn about the community, including its history, politics, language, and ways of knowing; some of the documents therefore strongly recommended that researchers approach such collaborations as a learner, in addition to their investigator role.³² Researchers also need to engage in self-reflection about their reasons for wanting to conduct research with a particular community, and to locate themselves in relation to the community. While only three scholarly articles addressed this component in detail (by providing reflection questions), this idea was implied in most of the discussions of the principles underlying ethical research with Indigenous communities.

While the *TCPS 2* acknowledges the extensive nature of the relationship-building process (Article 9.11), several researchers identified that there are still insufficient supports available and recommended an extension of funding to accommodate the time and activities involved.³³ One researcher described a situation where the effort to build appropriate relationships resulted in the local Research Ethics Board defining the relationship as potentially coercive due to her pre-established connection to a community.³⁴

The gap between academic and community realities, which is coloured by language, political structures, and legal structures, leads to a misalignment of academic policies with the realities of community-based, anti-colonial research activities. As a result, respectful and effective collaborations are weakened in their ability to create effective social change; as well, questions are raised about Research Ethics Boards' ability to protect the welfare of populations impacted by research. Institutions and researchers working within a traditional academic culture therefore need to "take a step away from a colonial, linear mindset", as one of our collaborators put it, and consider their policies and procedures through a different lens. They need to start to consider OCAP® as a separate, equivalent way of knowing that has meaning behind it, and work to find a pathway between community and institutional ways of knowing. Granting agencies and institutions also need to find ways to better support researchers as they work to develop and work within authentic, long-lasting partnerships with communities, with emphasis on acknowledging and allowing for the time this work takes.

Community Consent

The concept of consent is embedded in the OCAP® principles of Ownership and Control, and a strong thread that runs through all of the best practices documents is the importance of "safeguard[ing] the self-determination and autonomy of those involved in research. Those involved make choices regarding their involvement, anonymity, and participation."³⁵ Some Indigenous communities have established forms of governance and relationships wherein people have been given the role of representing the interests of all community members. Failure to recognize these levels of organization when requesting permission to conduct research or inviting communities into research partnerships violates the Ownership and Control principles of OCAP® and risks repeating some of the historical injustices of past research practices.

Discussions with and requests to conduct research made to community leaders or representatives were mentioned in many of the documents (119 documents, 70.8%), as were provisions made for communities to consent to or withdraw from a research project (43 documents, 25.5%). In some instances, these discussions involved a formal request to work with a community; in other instances, these conversations were part of the research design stage. The definition of community leader depended on the community and sometimes the nature of the research project, and leaders included elected officials, Elders, or persons who held knowledge about the subject of the research (18 documents, 10.7%); sometimes projects involved conversations with

more than one such representative (for instance, first Elders were met with, then the Band Council). For some of the research projects, there was a community advisory board or steering committee with whom the researchers were required to work to design and get approval for their project (11 documents, 6.5%).

There certainly was not any sense in the documents that community consent would overwrite individual consent, and the individual's right to consent and to be identified was reflected on in detail in six documents.³⁶ However, there's really not much advice offered in any of the documents about how to reconcile a conflict between community and individual consent, when/if such a conflict should arise, nor is there much discussion on how to handle the issue of community consent in non-homogeneous communities. Both OCAP® and the *TCPS 2* appear to assume agreement within the community.

The OCAP® principles were created within a First Nations context.³⁷ The issue of community consent becomes much more complicated when considering research with urban and/or Métis populations, where the definition of community is not as clear, and it is therefore more complex to determine the appropriate members to consult.³⁸ "Community, in an Aboriginal policy context, is normally understood by identifying 'reserve bands', loosely translated as 'First Nations communities'. ... The problem with this view is that it **conflates community** (formed by the collectively-shared cultural symbols produced within certain sociological, though not necessarily geographical, boundaries) **with place (the land itself)**. Not only is conflating community with place analytically naïve in a Métis context, it does little justice to the complexity of First Nations and Inuit senses of community (where 'reserve communities' often contain enduring links to extended kin and family members beyond the geographical space of the reserve location)."³⁹ [our emphasis] In Alberta, where there are both land-based Métis settlements and urban Métis communities, this complexity is even greater. Métis communities often don't have the same identifiable organization as First Nations communities, especially in an urban context, and organizations who serve Métis communities cannot necessarily speak on their behalf. Therefore, who a researcher should first approach or who to partner with will take some time to determine.⁴⁰ How Indigenous communities are defined in an urban and/or Métis setting is a huge question, and one that went unanswered in the literature we reviewed. In fact, very little of the literature we looked at spoke to the Métis and/or urban experience: only 9 (5.3%) focused on the Métis, and 18 (10.7%) spoke from an urban context.

There were some notations about the ways in which Métis communities are qualitatively different from First Nations communities when it comes to extending research/ethical protocols, especially given the complicated nature of their legal status and self-identification, both individually and as a group. The Métis Centre @ NAHO has proposed a set of research principles that should be considered alongside the OCAP® principles when contemplating research with Métis communities:

- **"Reciprocal Relationships** - Building relationships between researchers & communities, while sharing responsibility & benefits, & learning from each other
- **"Respect For"** - individual and collective; autonomy; identity; personal values; gender; confidentiality; practices & protocols
- **Safe & Inclusive Environments** - research should be safe for all - youth & Elders; gender & sexual identity; aboriginality; & balance individual and collective
- **Recognize Diversity** - within and between Métis communities; in worldviews; in values & beliefs; in geographic orientation & in politics
- **"Research Should"** - be relevant; benefit all; accurate; accountable; responsible; acknowledge contribution; protect Métis cultural knowledge
- **Métis Context** - understand history, values & knowledge; advance Métis methodology & include Métis experts; straddle worldviews; insider-outsider perspective."⁴¹

As one of our collaborators noted, First Nations, urban Indigenous, and rural and urban Métis communities all exist together; the separations are created through political-legal definitions. However, each community and group is unique, and the process of seeking both community and individual consent needs to be based on the specific protocols and requirements of the individual community with which a researcher is hoping to partner. Knowing the community is paramount to a successful project.

Privacy/Confidentiality vs. Acknowledgement

Confidentiality and anonymity for participants are linked to the core principles of the *TCPS 2*, most notably concern for welfare.⁴² Sixty-one of the documents (36.3%) spoke to issues of privacy/confidentiality/acknowledgement, and 18 of these (10.7%) had extensive discussion on acknowledgement vs. confidentiality (including the link between Intellectual Property arrangements and privacy).

In the college/university Research Ethics Board context, when confidentiality is not possible, any risks need to be balanced with the potential benefits of the research. When projects are undertaken that have a direct benefit to the community, there is a good foundation for ongoing discussions about long term impacts on the community when research results are disseminated. For instance, there was one project in the dataset where the community made the decision to reverse their initial request to not be identified in any public reports: “[T]he Wisdom Committee initially chose to omit the name of the community in any external knowledge transfer and exchange activities, but later, because so little published Aboriginal health research is positive in its tone, decided to include the name of the community if the information highlighted positive community attributes or community successes.”⁴³

One theme that was strongly highlighted in both the scoping review and by our collaborators and consultants was the need to broaden the reflection of ethical practice to long after a specific research project has concluded. Given the importance of the ethical principles of Ownership, Control, and the concern for welfare, much more attention needs to be paid to ensuring future, ongoing positive results of research dissemination and avoiding negative impacts. Examples of long term harms to communities include: cultural appropriation by researchers (e.g. sale of traditional medicine, profit from traditional knowledge⁴⁴), stigmatization (community members internalize negative research results⁴⁵), dignity harms (using data without permission⁴⁶), and documenting damage while ignoring change (positives reinforces negative stigmas⁴⁷). Some of the articles invoked the concept of “damaged-centred research,” which is defined by Eve Tuck as research that “document[s] pain or loss in an individual, community, or tribe ... It looks to historical exploitation, domination, and colonization to explain contemporary brokenness, such as poverty, poor health, and low literacy.”⁴⁸ There is emerging scholarship which asks non-Indigenous researchers to reflect on their role in reproducing colonialism⁴⁹ by essentially contributing to the “stockpiles [of] examples of injustice” and the production of “knowledge shaped by the imperatives of the nation-state, while claiming neutrality and universality in knowledge production”, which have been identified as academic practices that have reinforced the dominance of settler colonial knowledges.⁵⁰ There was, therefore, some evidence of attempts to de-colonize the academic research process by “re-visioning research in our communities not only to recognize the need to document the effects of oppression on our communities but also to consider the long-term repercussions of *thinking of ourselves as broken*,”⁵¹ the repercussions being Indigenous communities being positioned as “both singularly defective and powerless to make change.”⁵²

The academic principle of confidentiality was also sometimes characterized both as a barrier to the Ownership principle and as frustrating researchers’ attempts to collaborate with Indigenous communities in a respectful and anti-colonial manner: “While de-identifying records may be consistent with medical and scientific research principles of objectivity and anonymity, it is at odds with Indigenous methodologies, which prioritize acknowledgement - of the past, people, and place ...”⁵³ Acknowledgement of individual community members or the community as a collective is a component of OCAP®: for instance, “Are First Nation(s)

attributed as author/contributor?” is a recommended critical question to ensure the principle of Ownership is addressed,⁵⁴ and multiple articles spoke of acknowledgement as a way of signaling respect for the communities and adding credibility to the results.⁵⁵ However, acknowledgment by way of co-authorship and recognizing the contributions of the community that participated in the research project runs counter to traditional academic research protocols and academic culture. Fifteen (9.5%) documents engaged in some detailed conversation around authorship or acknowledgment of the contributions of community members/participants.⁵⁶ Not all of these documents framed authorship or acknowledgment in terms of Ownership, but they did all reflect on attempts to secure co-authorship or full acknowledgement of either community members or entire communities: “In listing communities as co-authors, it affords the opportunity to recognize this co-construction [of knowledge] and calls into question notions of singular ownership of knowledge.”⁵⁷ One article specifically identified difficulties with naming an entire community as a co-author because it did not fit the journal’s notion of authorship.⁵⁸

Ownership and authorship were also discussed within the contexts of intellectual property and copyright laws,⁵⁹ and the disconnect between the legal understandings of these concepts and community beliefs around communal ownership of knowledge was frequently highlighted. Although none of the articles we read specifically spoke to institutional intellectual property policies, these are also quite possibly a barrier to or in conflict with the principle of Ownership.

Researchers and Research Ethics Boards will need to be intentional in their examination of privacy, confidentiality, and acknowledgement when looking at the design of a new project, and may have to consider new ways of doing things in order to properly accommodate individual and community wishes.

Community Engagement and Resource Capacity: Constraints to doing Collaborative, Community-Engaged Research

Collaborative, community-engaged research is positioned throughout the literature as standard practice for research with Indigenous communities. Of the research articles in the dataset, 72 (42.8%) were identified as community-based, collaborative, or participatory action research and procedures for community involvement in research were mentioned in 108 (64.2%) of the documents. We also looked for references to research projects incorporating local/traditional knowledge into the research design; 57 (33.9%) of the documents discussed the incorporation of community norms, protocols, and customs into study design and/or execution, including:

- Use of a community land-based activity to secure parental consent for participation of children.⁶⁰
- Use of cultural stories for meaning-making.⁶¹
- Use of community protocols for the collection of plants and data.⁶²
- Use of an interview method grounded in Cree values of relationship, sharing, personal agency, and relational accountability.⁶³

In order to guide these interactions and partnerships between researchers and communities, formal research agreements are recommended by a number of documents, including the *TCPS 2* (71 documents, 42.2%). There were two Research Agreements and one Collaboration Charter in the dataset,⁶⁴ as well as three templates for Research Agreements⁶⁵ and one document⁶⁶ that included recommendations for what these agreements should include. Detailed analysis of these documents can be found in Appendix E.

Apart from the typical ethical requirements researchers are obliged to account for in research applications, the most frequently occurring articles/elements of these six agreements/templates were:

- Benefits for community (5 out of 6).
- Role of community members in the research (4 out of 6).
- Statements about confidentiality/anonymity for participants and community (4 out of 6).
- Preparation of final report and/or opportunity for community to revise and approve (4 out of 6).

-
- Benefits for researcher (4 out of 6).
 - Strategy for updating the community on project progress (4 out of 6).

Most of these documents also included statements on the obligations and responsibilities of both the researcher and the community partner. The most common obligations for the researcher were:

- Involve the community in participation of the research process, promote it as a community-owned activity (4 out of 6).
- Ensure research design, implementation, analysis, interpretation, and reporting are culturally relevant and in compliance with standards of competent research (4 out of 6).
- Ensure that the community is fully informed in all parts of the research process (4 out of 6).

The most common obligations for the community partner were:

- Represent interests, perspectives, concerns of community members and of the community as a whole (3 out of 6).
- Ensure that research carried out is done in accordance with the highest standards, both methodologically and from an Indigenous cultural perspective (3 out of 6).

Full, meaningful research collaborations require a significant resource investment on the part of communities. To be meaningfully involved in a research project from design to dissemination, the obligations and responsibilities for the community can be extensive. As a result, several of the scholarly articles highlighted resource and/or research fatigue as a significant challenge. Some articles mentioned that full participation can be “too taxing” on communities, particularly when there are limited resources (time, people, finances).⁶⁷ Other articles stressed the risk or reality of “research fatigue.”⁶⁸ There were not many workable solutions offered, however; what was mentioned (e.g. funding extensions⁶⁹) would only extend the time available to complete the research project, not assist with the scarcity of resources.

Building research capacity within communities is often mentioned as a way to minimize some of the resource strain, but it takes a significant investment of time and funding. Also, when research has an applied focus, developing research capacity is often second to resource and service development within a community (e.g. delivery of essential services). While there were more mentions of research skill capacity development than the development of other skills, there was also a very strong focus on the research skills as training on service or program delivery (rather than knowledge for knowledge’s sake).⁷⁰ Skills associated with a specific service or program delivery were the most common “other skills” developed via research projects.⁷¹ While this skill development will help communities in a variety of ways, it will not necessarily build their capacity to participate in future research projects. Funding agencies and policy makers, therefore, need to consider including funding to assist with the resource strain as part of their policies and grant offerings.

STATE OF KNOWLEDGE

Relationships

Knowledge Strengths

It was clear throughout the majority of the documents that the relationship between the researcher and the community was key to ethical research practices. These relationships must be reciprocal, honest, flexible, collaborative, and equitable. Within the scholarly articles, there was some guidance on how to develop such relationships, as well as discussion of some of the challenges researchers have encountered in requesting and maintaining research partnerships. Our collaborators and consultants further emphasized the importance of researchers having a “direct, personal, and continuing commitment/relationship with the people, the knowledge, and the community.”⁷²

Knowledge Gaps

Following from the expectation that researchers plan for long-term relationships with community partners are questions around the role Research Ethics Boards play in monitoring both research projects and these long-term relationships. As past stigmatization of Indigenous communities was one of the triggers to the development of OCAP[®],⁷³ researchers and Research Ethics Boards need to be better trained in how to reflect on the impact of research in the long term and in particular on ways to be sensitive to how a project may lead to the stigmatization of Indigenous communities and peoples. Similarly, the Possession and Access principles of OCAP[®] were really not addressed in the literature reviewed, possibly because these principles involve activities beyond the scope of the “on paper” project which has typically been the focus of academic Research Ethics Boards. Further consideration of how to either expand the knowledge and capacity of Research Ethics Boards to monitor community Possession and Access or to identify what entities are better situated to do so would start to close this particular knowledge gap.

Another significant question emerging from the literature was the very complicated (and frequently political) process of defining “community.” OCAP[®] principles necessitate that ethical protocols are in place to protect the individual participant as well as the community, but both these and the TCPS 2 appear to assume a simple, homogenous definition of community. In reality, definitions of identity and community are shaped by language, ideologies, political and legal structures, and differences in lived realities. There is, therefore, a need for more exploration into various definitions of community and into how to best tie ethics policies to all the other policies and legislation that impact on Indigenous social, cultural, and political life as they impact on research partnerships and collaborations.

Templates, Guiding Documents

Knowledge Strengths

The scoping review enabled us to capture some templates for research documents (e.g. research agreements, informed consent forms, researcher-reflection questions, best practices, etc.). As all of these templates were either created in collaboration with an Indigenous research partner or authored by an Indigenous researcher or organization, it is clear that any researcher or Research Ethics Board will need to work with local communities to draft comparable “local” templates. The templates we found, however, provide a solid foundation from which to work. Our collaborators and consultants confirmed the value of these documents, and emphasized that once documents have been developed for our region, there should be 100% compliance.

Knowledge Gaps

In some instances, research agreement terms may come into conflict with the TCPS 2 because elements of OCAP[®] seem to contradict academic research practices (e.g. confidentiality, Intellectual Property provisions, subjectivity/relationships with participants, etc.). There was a noticeable gap in the literature around how to reconcile conflicts between the TCPS 2 and Indigenous ethical protocols.

Collaborators and consultants also noted the potential for further discrepancies with the *TCPS 2* and traditional academic practices when we start to tie ethics policies to Treaties, the *UN Declaration on the Rights of Indigenous Peoples*, the *Canadian Charter of Rights and Freedoms*, Provincial Constitutions, and community laws and protocols. All of these legal documents, as well as the Truth and Reconciliation Report, contain protocols aimed at reconciling past wrongs towards Indigenous peoples, culture, and communities, as well as ways to forge a future that supports self-determination for Indigenous peoples. How these protocols play out in a research project is currently a significant unknown; but, as one of our collaborators noted, the first step is to “accept there are protocols; they are a must”. Further work and research, therefore, is required to better guide researchers and Research Ethics Boards on how all these guiding principles and laws tie together.

Application of OCAP®

Knowledge Strengths

Both our collaborators and consultants and the literature stressed that a commitment to OCAP® has the effect of allowing communities to look inwards and reflect on their needs and priorities, sparking community-defined research agendas that can lead to stronger communities. Further, since many of the articles about Indigenous research partnerships invoked the principles and practice of community-based, participatory action research, there is a potential applicability of OCAP® to research with non-Indigenous groups/communities, with similar positive long-term impacts.

Knowledge Gaps

There needs to be more guidance on mediating the identified disconnects between OCAP® and academic policies and standards. For instance, if confidentiality is a myth in small Indigenous communities, as one of our collaborators noted, what does this mean for ethical assurances of the protection of privacy? Further, when Ownership of the knowledge necessitates acknowledgement, how does the concept of confidentiality then apply at the level of the community? Collaborators identified a need for far more consideration of how to contextualize and come to a common understanding around key ethical principles - e.g. privacy, consent, confidentiality, ownership - and researchers need to be better supported and advised as they collaborate with communities on the specifics of these concepts in the research activity. Further, there is a need for advice from policy makers as to how institutions and researchers are to navigate misalignments between community policies and practices and academic policies and practices.

Indigenous Languages and Ways of Knowing

Knowledge Strengths

There was some evidence of the inclusion of Indigenous languages and ways of knowing within the literature. The importance of being able to interact with participants in their language of choice, as well as the medium of choice (i.e. oral vs. written), was identified in some of the scholarly articles. Further, our collaborators and consultants did see evidence of some institutions starting to consider other ways of knowing (for instance, through policies that have been created to facilitate research with Indigenous communities). They stressed, however, that there must also be a commitment to changing the underlying message that Indigenous communities have to accommodate non-Indigenous ways of knowing, doing, and learning to fulfill non-Indigenous academic requirements.

Knowledge Gaps

While ensuring that researchers engage with communities in “linguistically appropriate” ways was stressed in the literature and policies, there was an absence of discussion around the practicalities of doing so. From a researcher perspective, several questions remain: Will I have time to get data translated? Will I have funds to work with translators? How do I find an appropriate translator? Will I have time to have an appropriate language user assist with the analysis of the translated data? Will I be able to publish an article with a title

written in an Indigenous language? From a Research Ethics Board perspective, additional questions also need exploration: How will the researcher assess the accuracy of translated data? Can the Research Ethics Board extend its “ongoing review” further into the dissemination process to ensure that research results go back to the community in their own language?

Our Collaborators and Consultants stressed the importance of Research Ethics Boards and researchers understanding the crucial role of language. Language cannot be incorporated in “bits and pieces”; thoughtful and thorough consideration of how language structures meaning and understanding needs to be a part of the research process when Indigenous peoples and communities are impacted. Further work, therefore, needs to be done to provide appropriate advice to researchers and Research Ethics Boards.

ADDITIONAL RESOURCES

Context Documents

The following documents provide useful context and background to the issues discussed in this report:

- Carlson, Elizabeth. "Anti-Colonial Methodologies & Practices for Settler Colonial Studies." *Settler Colonial Studies* 7, no. 4 (2017): 496-517. doi:10.1080/2201473X.2016.1241213.
- Castellano, Marlene Brant. "Ethics of Aboriginal Research." *Journal of Aboriginal Health* 1, no. 1 (2004): 98-114.
- Tuck, Eve. "Suspending Damage: A Letter to Communities." *Harvard Educational Review* 79, no. 3 (2009): 409-427.
- Wilson, Shawn. *Research is Ceremony: Indigenous Research Methods*. Black Point, NS: Fernwood Publishing, 2008.

OCAP® Education

The following documents and online courses provide a good introduction to the principles of OCAP®:

- First Nations Information Governance Centre. "The First Nations Principles of OCAP®," 2017. <http://fnigc.ca/ocap.html>.
- First Nations Information Governance Centre. "The Fundamentals of OCAP®," 2017. <http://fnigc.ca/training/fundamentals-ocap.html> (note, there is a fee associated)

Policy Documents

The following documents could prove useful for filling some of the identified gaps in policy:

- Blue Quills First Nations College. "Blue Quills First Nations College Research Ethics Policy," 2009. <http://www.bluequills.ca/wp-content/uploads/2012/03/BQ-Research-Ethics-Policy-09.pdf>.
- Flicker, Sarah, Robb Travers, Adrian Guta, Sean McDonald, and Aileen Meagher. "Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards." *Journal of Urban Health* 84, no. 4 (2007): 478-493. doi:10.1007/s11524-007-9165-7
- Métis Centre @ NAHO. "Ethics," 2017. <http://www.naho.ca/metis/research/ethics/>.

Research Agreements

The following documents provide useful advice for creating research agreements with communities:

- Central Alberta AIDS Network Society, Métis Local 845 of Métis Nation of Alberta, Red Deer College and Alberta Health Services – Central Zone Health Research Collaborative, and Shining Mountains Living Community Services. "Voices from the Fire: Vision in Truth Collaboration Charter." Red Deer College, 2009. <http://rdc.ab.ca/node/2198/attachment>.
- Cuerrier, Alain, Ashleigh Downing, Elisabeth Patterson, and Pierre Haddad. "Aboriginal Antidiabetic Plant Project with the James Bay Cree of Québec: An Insightful Collaboration." *Journal of Enterprising Communities: People and Places in the Global Economy* 6, no. 3 (2012): 251–70. doi:10.1108/17506201211258414.
- First Nations Centre (FNC). "Considerations and Templates for Ethical Research Practices." National Aboriginal Health Organization, 2007. http://www.naho.ca/documents/fnc/english/FNC_ConsiderationsandTemplatesInformationResource.pdf.
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- World Health Organization. "Ethics and Health." Accessed September 10, 2017. http://www.who.int/ethics/indigenous_peoples/en/index6.html.

KNOWLEDGE MOBILIZATION

The following knowledge mobilization activities are planned for the next year, in order to share the findings of the scoping review and start to engage in conversations to initiate change.

Audience	Planned Activity	Timeline
Local Indigenous Communities	Initiate meetings to discuss findings and begin the process of developing ongoing research partnerships, beginning with Maskwacis Cultural College.	September - December 2017
Research Ethics Boards	Present findings at conferences and workshops, such as the Canadian Association of Research Ethics Boards Conference and Annual General Meeting.	January - June 2018
	Publish articles presenting findings in appropriate journals.	January - June 2018
	Hold meetings with local Research Ethics Boards to discuss findings and possible resulting changes to policy and practice.	September 2017 - June 2018
	Attend a local research project's knowledge mobilization activity.	September - December 2017
Researchers	Present findings at conferences and workshops, such as Congress of the Humanities and Social Sciences.	January - June 2018
	Publish articles presenting findings in appropriate journals.	January - June 2018
	Create an online resource toolkit, including questions to consider and templates for local researchers.	October 2017 - June 2018
	Bring in a speaker knowledgeable on Indigenous research methodologies and ethics.	January - June 2018
Institutions	Present document, along with recommended policy changes and questions, to the appropriate groups at our local institutions.	September 2017 - June 2018

CONCLUSION

What is the current academic, government, and community knowledge on the role of institutional Research Ethics Boards in advising both Indigenous and non-Indigenous academic researchers working with Indigenous individuals and communities in Central Alberta on OCAP® principles, particularly given differences in language and understanding about the concepts of research ethics?

Our focus for this project was to discover the best practices for adopting OCAP® while also looking for gaps in that knowledge, especially as they relate to the process of research ethics review. While there is good evidence of the application of OCAP®, there were some common concerns and limitations encountered that were highlighted in the literature. The major themes that emerged from the literature review were:

- A disconnect between recommended best practices for conducting ethical research and institutional policies and procedures, including Research Ethics Board procedures.
- Tensions around definitions of community and obtaining informed consent.
- The requirement for confidentiality/anonymity of research participants vs. the desire for acknowledgement and accountability.
- Requirements and constraints of full community participation in research.

Our mapping of the literature revealed several strengths, but also some gaps in the state of the knowledge:

- There are questions around the role Research Ethics Boards play in monitoring both research projects and long-term relationships between researchers and the community.
- There was a noticeable gap in the literature around how to reconcile conflicts between the *TCPS 2* and Indigenous ethical protocols.
- There is a need for far more consideration of how to contextualize key ethical principles, such as privacy, consent, and confidentiality, and a need for advice from policy makers as to how institutions and researchers are to navigate misalignments between community policies and practices and academic policies and practices.
- Further work needs to be done to provide appropriate advice to researchers and Research Ethics Boards in understanding the crucial role of language and how it structures meaning.

Overall, we saw evidence in the literature that OCAP® principles are seeing increased incorporation and application in research projects, but the knowledge about the role that the Research Ethics Board plays, as well as the knowledge about applications specific to the Alberta context, is still quite limited.

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APPENDIX A: COLLABORATORS, CONSULTANTS, AND CONTRIBUTORS

Walking Together: The following collaborators and consultants were involved in creating our final research question, as well as in interpreting the results of the scoping review. Consultants were invited to collaborate due to either their experiences as an Indigenous researcher, direct experience with research with Indigenous communities, or experience with research ethics or providing support for non-Indigenous researchers.

Collaborators:

- Victoria Cardinal-Widmark, BSW. Indigenous Services Coordinator, Red Deer College. Woodland Cree Woman. Wabasca, Alberta. Fluent Cree speaker affiliated with Bigstone Cree Nation.
- Lloyd Desjarlais, BA. Indigenous Student Services Generalist, Red Deer College. English and Cree Language. Treaty Status Indian.
- Michelle Edwards Thomson, MLIS (University of Alberta). Librarian, Red Deer College. Third generation Canadian (descendant of English, Irish, Scottish, Welsh, and French settlers). English language speaker.
- Krista Robson. Chair, Research Ethics Board, Red Deer College. PhD Sociology (Queen's University). Has worked on one collaborative research project with an Indigenous organization and Indigenous researchers. Fifth generation Canadian (descendant of Scottish, Irish and English settlers in the 1820s - 1830s); English language speaker.

Consultants:

- Nadette Agecutay, Program Director, Red Deer Native Friendship Centre, Red Deer.
- Darel Poul Bennedbaek. B.A. (University of New Brunswick Saint John), MLIS (University of Alberta). Danish, English, Norwegian, Swedish, little bit of German. Non-Indigenous; Danish Citizen, Permanent Resident of Canada. Assistant Librarian, Burman University, Lacombe.
- Wendy Cameron, B.A. Sociology with Honours, (University of Calgary). Worked on two collaborative research projects with Indigenous students. Second generation Canadian (descendant of Scottish, Irish, and Lithuanian people); English language speaker.
- Erika Goble, PhD (Secondary Education, University of Alberta), is the Manager of Research and a Researcher at NorQuest College. Research interests include the intersection of aesthetics and ethics, the phenomenology of practice, and relational ethics. Developed and facilitated educational programming for the exhibit *Sanaunguabik: Traditions and Transformations in Inuit Art*. Fourth generation Canadian and descendent of Ukrainian, Swedish, and American settlers; English and French language speaker.
- Diane Harms, Director, Applied Research, Lakeland College. BSc. Biochemistry (University of Saskatchewan). Review and approve research projects at Lakeland College and those that access Lakeland student populations including those with Indigenous populations. Fourth generation Canadian (descendent of Ukrainian and French settlers). Speak/Read/Write English; Spoken French only.
- Tracey Louis, BSW, MSW, RSW. Coordinator of the Indigenous Social Work Diploma program, Maskwacis Cultural College. Sessional Instructor, Red Deer College, Maskwacis Cultural College, University of Calgary (Edmonton campus). English language speaker. Indigenous - Plains Cree Nehiyaw from Akamikk Montana in Maskwacis, Alberta. I have worked all my life with Indigenous communities.
- Doris MacKinnon, Program Coordinator/Instructor, Red Deer College. PhD History (University of Calgary). Language(s) spoken English; French. Non-Indigenous. Descendant of French and Scottish settlers (1600 - 1700s) and Indigenous peoples. Archival and oral research with Métis people in support of dissertation.

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- Raye St. Denys: Executive Director, Shining Mountains Living Community Services, Treasurer, Canadian Aboriginal AIDS Network, English Language Speaker, Métis woman of Cree descent. Have worked on multiple research projects with Aboriginal communities as Collaborator or Knowledge User.

Research Assistants:

- Lindsey Brinen, Bachelor of Arts (Sociology, Minor in Psychology - University of Calgary/Red Deer College). English Language Speaker.
- Patryk Siergiej. Bachelor of Arts Psychology student, University of Calgary/Red Deer College. Member of Canadian Psychological Association, American Psychological Association and Canadian Counselling and Psychotherapy Association. Polish and English language speaker. Born in Poland.
- Cree Stoney, Bachelor of Education student, University of Alberta/Red Deer College. Plains Cree of Treaty 6; Ermineskin First Nation; Maskwacis, Alberta.

Other Contributors:

Heather Alexander, Erin Booth, and Anne Marie Watson all provided valuable input during the report writing phase of this project.

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APPENDIX C: CHARTING DOCUMENT

Title of Article or Document.

Author(s).

Source/author. Check all that apply:

- Academic researcher - Aboriginal
- Academic researcher - Non-Aboriginal/Not Identified
- College or University Research Ethics Board
- College or University Office/Dept. (e.g., Research Office, Aboriginal Liaison Office)
- Federal Govt.
- Provincial Govt.
- National Non-Aboriginal/Métis/Inuit Organization
- Provincial Non-Aboriginal/Métis/Inuit Organization
- National Aboriginal/Métis/Inuit Organization
- Provincial Aboriginal/Métis/Inuit Organization
- Other:

Researcher relationship with community. Check all that apply:

- Aboriginal researcher - own community
- Aboriginal researcher - other community
- Non-Aboriginal researcher

Type of Document. Check all that apply:

- Policy
- Guidance/Advice Document
- Scholarly article/book/conference proceedings
- Other:

Community/Context/Location (if research, location of research; if other, community context and/or audience). Check all that apply:

- Central Alberta
- Alberta
- National
- Urban
- Rural
- Métis settlement/reserve
- Other:

If research study, methods used. Check all that apply:

- Community-based/collaborative/participatory action research
- Interview/focus group/qualitative
- Survey, quantitative
- Scholarship of teaching & learning
- Document analysis
- Secondary analysis of previously collected data
- Policy/program/service review
- Research team
- Single researcher
- Other:

If research study, who are the participants/what is focus of research? Check all that apply:

- Human
- Animals
- Physical/natural sciences
- Traditional, cultural knowledge
- Bio-medical/health
- Other:

What they reference (in article or bibliography). Check all that apply:

- Tri-Council Policy Statement (TCPS2)
- Castellano article: Ethics of Aboriginal Research
- OCAP (Schnarch, B. OR National Aboriginal Health Org)
- Shawn Wilson: Research Is Ceremony (book)
- College or University Research Ethics policy
- Community Research Protocols
- Other:

REB Approvals (if academic research). Check all that apply:

- Institutional REB
- Community REB
- Community approval
- Other:

Language & Traditional Knowledge. Check all that apply:

- Research material in community's language
- Interpreter used
- Reports/results returned to community in appropriate language
- Incorporates local/traditional knowledge into research design/execution

Things to note re: language & knowledge.

Community engagement. Check all that apply:

- Relationship building activities
- Research agreement created
- Community engagement plan created
- Authority, leaders, Elders, political officers (rural)
- Leaders, Elders, organizations (urban)
- Norms, protocols, customs
- Community involvement as partners/researchers (design, analysis, communication)
- Project initiated by community

Things to note re: community engagement.

Capacity development. Check all that apply:

- Research skills developed
- Other skills developed

Things to note re: capacity development.

Data/results management. Check all that apply:

- Community review of data
- Community review of publications
- Possession of data, information
- Intellectual property (agreement, decision-making)
- Community makes decisions about data
- Ownership of data, information
- Access to data, information

Things to note re: data/results management.

Risks/benefits. Check all that apply:

- Address possibility of harm to individuals during research project
- Address possibility of harm to community during research project
- Address possibility of harm to individuals after completion of research project
- Address possibility of harm to community after completion of research project
- Right to withdraw from research
- Risks/benefits equitably distributed among researchers and community
- Research benefits; reflects community priorities
- Privacy, confidentiality, anonymity addressed

Things to note re: risks/benefits.

Inclusion. Check all that apply:

- Varied representation of community members in research
- Critical inquiry; special protocols (critical inquiry = research on leaders/government)

Things to note re: inclusion.

Major themes. Check all that apply:

- Gender
- Challenges Faced/Solutions tried
- Opportunities Realized/Unintended benefits
- Relationality (e.g. relationship building)
- "Ethical Space"
- Other:

Things to note re: major themes.

Things to note not covered above.

Your initials.

APPENDIX D: INTEGRATION OF TCPS 2 AND OCAP® INTO RESEARCH ETHICS POLICIES

Integration of TCPS 2 Principles into Research Ethics Policies

	Community Engagement (9.1, 9.2, 9.4, 9.10); Collaborative Research (9.12)	Respect for Governing Authorities (9.3); complex Authority Structures (9.5)	Recognize diverse interests (9.6); Critical Inquiry (9.7)	Respect for Customs & Codes of Practice (9.8)	Research Agreements (9.11)	Mutual Benefits of Research (9.13)	Strengthening Research Capacity (9.14)	Recognition of Role of Elders (9.15)	Privacy & Confidentiality (9.16)	Interpretation & Dissemination (9.17)	Intellectual Property (9.18)
Athabasca University											
Bow Valley College	✓				✓	✓		✓			
Concordia University	✓ 9.1,9.2, 9.4,9.10, 9.12	✓ 9.3, 9.5	✓ 9.6, 9.7	✓ 9.8	✓ 9.11	✓ 9.13	✓ 9.14	✓ 9.15	✓ 9.16	✓ 9.17	✓ 9.18
Grande Prairie College						✓					
MacEwan University	✓ 9.1, 9.2		✓ 9.6								
Mount Royal University					✓						
Red Deer College	✓ 9.1,9.2, 9.10, 9.12	✓ 9.3	✓ 9.7	✓ 9.8	✓ 9.11	✓	✓ 9.14	✓ 9.15		✓ 9.17	✓
University of Alberta	✓								✓		
University of Calgary											
University of Lethbridge	✓									✓	✓
Blue Quills University	✓	✓		✓		✓	✓	✓	✓	✓	✓

9.1 = requirement of community engagement in Aboriginal research

9.2 = nature and extent of community engagement (determined jointly by researcher & community)

9.4 = engagement with organizations and communities of interest (e.g. representative bodies, service organizations, communities of interest)

9.10 = requirement to advise REB of plan for community engagement

✓9.X = refers directly to TCPS 2 articles, or uses almost the same wording

✓ = references the general principle/s

Integration of OCAP® Principles into Research Ethics Policies

	Ownership	Control	Access	Possession	OCAP in general	Misconduct policy	Gifts of Reciprocity/Elder Protocols	CIHR	Links to TCPS 2- Ch. 9	Other resources linked to	Traditional Knowledge/Ceremony	Credit / acknowledgement
Athabasca University							✓					
Bow Valley College		✓										
Concordia University		✓						✓				
Grande Prairie College												
MacEwan University		✓										
Mount Royal University												
Red Deer College		✓						✓	✓	✓		
University of Alberta		✓					✓		✓	✓		
University of Calgary					✓		✓		✓		✓	
University of Lethbridge		✓							✓			
Blue Quills University	✓	✓	✓	✓	✓	✓					✓	✓

APPENDIX E: RESEARCH AGREEMENT COMPARISONS

	Voices from the Fire / Canadian Aboriginal AIDS Network	Aboriginal antidiabetic plant project with James Bay Cree	First Nations Centre @ NAHO	Tl'azt'en Nation Guidelines	Centre for Indigenous Peoples' Nutrition and Environment	Kahnawake Schools Diabetes Prevention Project
Statement of purpose of research ¹						
The results of this research may be used to						
The research has the following objectives and/or aims to answer the following questions ¹						
Who will manage the project and decide how results get used						
Role of community members in the research						
How information will be gathered ¹ , recorded, analyzed, reported						
How information will be shared, distributed and stored ¹						
Statement about confidentiality/anonymity ¹ for participants and community						
Access to, restrictions on the use of data during and after the project, including terms and conditions for future use of data ¹						
Protecting information that Elders will share						
Informed consent from individual participants will be obtained in these ways ¹						
Description of the levels of collective consent required, how it will be obtained ¹						

Preparation of final report/opportunity for community to revise and approve ¹						
Format for presenting findings to the general public						
Benefits for researcher ¹						
Benefits for the community ¹						
Risks for the community ¹						
Measures to minimize risks						
Funding: researchers have received funding from/funding agency has imposed the following criteria, disclosures, limitations, reporting responsibilities ¹						
Dissemination of results: results will be disseminated to the following stakeholders and in the following manner						
Future publication or dissemination of results shall not be undertaken without consultation with the community						
Data Ownership ¹ : the individual owns his or her personal information, while the community owns the collective data						
Intellectual Property rights retained by the community (including copyright) ¹						
Conditions of data stewardship and use of data after completion of project						

Communication with the media/other parties (funding) will be handled in these ways ¹						
Project progress will be communicated to the community in these ways ¹						
Acknowledgments: those who contribute to the research shall be acknowledged						
Review process for publications, presentations						
Dispute Resolution process ¹						
Term & Termination: the agreement shall be effective as of/shall terminate on/process for termination ¹						
Principles of research						
Collaboration values						
Relevance of research to both parties ¹						
Type, level, frequency of interaction between researcher and community ¹						
Precise time commitments required from community members involved in the research in various capacities, and amount of financial or other compensation (if any) ¹						
Respective financial and logistical responsibilities of the partners (e.g., salaries, equipment, office space, accommodation, supplies, transport) ¹						

¹Ethics and Health” (World Health Organization)

External Researcher - Obligations & Responsibilities	Voices from the Fire / Canadian Aboriginal AIDS Network	Aboriginal antidiabetic plant project with James Bay Cree	First Nations Centre @ NAHO	Ti'azt'en Nation Guidelines	Centre for Indigenous Peoples' Nutrition and Environment	Kahnawake Schools Diabetes Prevention Project
Do no harm to the community						
Ensure research priorities and objectives are to the benefit of the community						
Involve the community in participation of research process, promote it as a community-owned activity						
Ensure that a representative cross-section of community experience and perceptions is included						
Ensure the research design, implementation, analysis, interpretation, reporting, publication, and distribution of its results are culturally relevant and in compliance with the standards of competent research						
Undertake research that will contribute something of value to the community						
Ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation, etc.						
Agree not to sensationalize problems; will strive to present a balanced portrait that also focuses equal attention on wise practices						
Be a steward of the data until the end of the project if requested or appropriate						
Promote the dissemination of information to society at large if desired and appropriate through both written publications and oral presentations						

Be involved in any future analysis of the data after the data is returned to the community, if requested						
Abide by any local laws, regulations and protocols in effect in the community or region, and become familiar with the culture and traditions of the community						
Within their respective role as researchers and community representatives, advocate and address health, social or other issues that may emerge as a result of the research/act as a resource to the community on topic of study						
Ensure that community is fully informed in all parts of the research process, including its outcomes through publications and presentations, and promptly answer questions that may emerge						
Communicate equally with all partners in all issues arising in the project						
Support the community by providing resources (e.g., research funding to support community research coordinator)						
Abide by their own professional standards, their institution's guidelines for ethical research, and general standards of ethical research						
Agree to stop the research project in the following circumstances (e.g., if community leaders decide to withdraw their participation; if the researchers believe that the project will no longer benefit the community)						

Community Partner - Obligations & Responsibilities	Voices from the Fire / Canadian Aboriginal AIDS Network	Aboriginal antidiabetic plant project with James Bay Cree	First Nations Centre @ NAHO	Tl'azt'en Nation Guidelines	Centre for Indigenous Peoples' Nutrition and Environment	Kahnawake Schools Diabetes Prevention Project
Represent the interests, perspectives and concerns of community members and of the community as a whole						
Ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective						
Recommend capable and reliable community members to collaborate or to be employed in the project						
Keep informed about the progress of the project						
Help in leading the project toward meaningful results						
Communicate the results of the research to other communities, and share ideas as well as program and service development for mutual benefit and involvement						
Serve as the guardian of the research data during and/or after completion of the project						
Offer external and community researchers the opportunity to continue data analyses before the data are offered to new researchers						
Maintain a policy of open public access to final reports of research activities except in cases involving information deemed to be confidential and/or sensitive						

Voices from the Fire is a Collaboration Charter, not a Research Agreement.