General comments on this chapter:

The additional, arguably excessive, length is due in large part to the integration of materials that were developed separately. A prime example is the section on research involving aboriginal peoples. This could have been shortened considerably for inclusion in the draft. Furthermore, some sections have footnotes and/or references while others do not. The document needs greater consistency in these regards.

Chapter 9: well done. Some principles may also apply in other parts of the TCPS.

I would like to offer my comments for consideration regarding Chapter 9 of the TCPS Draft: Research Involving Aboriginal Peoples. First of all, I was VERY impressed with the draft chapter: I thought that it was very comprehensive, allowed for flexibility given the diverse nature of Aboriginal communities (both urban and on reserve), and provided practical examples of the application of said policies.

Chapter 9. This is the most contentious of the chapters in this draft document. My personal perception is that this is a very political consideration and that there has been insufficient communication with aboriginal peoples to insure that they feel included in the development of defendable guidelines. In principle, it seems to me that if we adhere rigorously to the guidances in other chapters that this special consideration may be redundant. I believe that the issues have been covered broadly in other chapters. I do understand the political issues, but I am somewhat confused by the differences especially between Canadian and US guidances, where documentation of ethnic origin of clinical trial participants is required to demonstrate adherence to equal access as research participants by previously under-represented groups. NIH has a special form that the review panel completes to insure that this guidance is followed. In my participation in the NIAID panel related to the AIDS international research program, this issue seems to have been addressed by formation of community committees that address many of the issues raised in Chapter 9. I do understand that the approach to this matter is difficult, but I am concerned that investigators may not pursue important research issues in these communities if the administrative burdens become extremely prolonged.

In general, we applaud PRE for the work that has been done in preparing this guidance for ethical review of aboriginal research.

We are also delighted to see the inclusion of more explicit procedures and values for work with Aboriginal Peoples and qualitative methods. There is a question to be raised, however, whether this tends to normalize Euro-Canadian research and quantitative methods?

In our opinion, this is an excellent Chapter and reflects the fulfillment of the current TCPS promise to hold discussions and consultations with affected peoples and groups before setting policies. Our congratulations and thanks to those who drafted this Chapter.
Why don’t all three councils adopt the existing CIHR provisions in this area? Why try to re-invent the wheel with yet another set of rules and procedures.

Stylistically this chapter reads very differently than other chapters. For example in this chapter, there are many mentions of named groups, initiatives and incidents. This raises the question of whether these mentions will be periodically updated.

In general, the language used lacks urgency and strength. In most cases the use of the word “should” should be substituted by the word “must”. Researchers should provide clear justifications for disregarding guidelines and these should be communicated both to the REB and to the participating community in question.

Far too often communities are not aware of their research rights. This document fails to address this problem in that it is written primarily for academic audience.

Research participants’ rights and protection in the research process, to be enshrined in the TCPS revisions, are of special concern to the people in Saskatchewan and the North, particularly with respect to Aboriginal research and/or research with people in remote areas. The TCPS has been termed the human rights protection for research subjects and these are among the most vulnerable of research subjects.

The committee is also to be congratulated for expanding the document to include guidelines for Aboriginal and qualitative research. These are much appreciated by REB’s who have been feeling around in the dark for some years on these issues.

We are pleased to see the recognition in this document of the particular challenges and requirements of research involving Aboriginal peoples in Chapter 9.

We would like to commend the Secretariat on Research Ethics for providing such an opportunity and for including Aboriginal-specific ethical guidelines (chapter 9). We believe this is a step in the right direction to ensuring Aboriginal communities, individuals and traditional, ecological and sacred knowledge are protected.

The addition of this chapter is welcomed and a large improvement over the previous version. As a living document this is bound to change over time, but this is indeed a vast improvement.

These guidelines have been long in coming and will be useful to REBs.

Very good improvement on previous version of TCPS. Important emphasis on many issues.

\[\text{Congratulates you on the addition of this chapter.}\]
The Panel has taken a very important step by including a chapter on research involving Aboriginal peoples in the new TCPS. This not only recognizes that Aboriginal peoples have been subjected to harm in the past by research, but affirms that researchers who choose to work with them must be aware of the unique ethical context in which Aboriginal research takes place. This draft mentions many of the essential issues, such as involvement in the research process, privacy and data ownership issues. We do, however, feel that there are shortcomings as the draft stands now. These shortcomings centre around the language and terminology used through the chapter, the importance of negotiated research agreements, the role of pre-existing community codes of ethics and research protocols, and harmonization with other current Canadian and international guidelines. We strongly feel that many of these shortcomings can be addressed by expanded community-level consultations.

We have found Chapter 9 to be an informed discussion that concerns some of the challenging issues that arise between communities and researchers. This discussion identifies a number of real issues and complexities without necessarily providing direction. Such ambiguity might reflect the reality of existing experience, or lack of experience for both the Academy and communities with research partnerships. We do not advocate a premature "codification" of procedures, but we do not know how individual REBs will interpret Chapter 9 and fully expect some bizarre results.

<table>
<thead>
<tr>
<th>Article #</th>
<th>Issue Raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.1</td>
<td>Line 3265 Much survey research involves the collection of basic demographic information, including ethnicity (which can include aboriginal as a category) to characterize the respondent population. The intent may not be to seek out aboriginal participants or even to necessarily focus on aboriginal issues. However, if by chance an unexpectedly high proportion of aboriginal individuals responded, this could be important in interpreting and reporting the results. Anticipating this in advance might not be possible and hence the kind of prior consultative provisions of this chapter might be impossible to achieve. This is presumably what Example 5 is intended to address. Should REBs require that researchers demonstrate that they have at least a basic plan to deal with such a situation, should it arise, if they include 'aboriginal' as a category in their protocols?</td>
</tr>
</tbody>
</table>
| 9.1      | • Much improved document overall  
  o recognition of collective interests sets this chapter apart from the rest of the policy – i.e., the “welfare of the collective” (l. 3146) – this is recognition of a different worldview and/or way of being as separate from that of the Western model/paradigm  
  o recognition of cultural maintenance and ensuring full participation in Canadian society as goals within Aboriginal research – this is very good; in fact, any Aboriginal research agenda should be encouraged to prioritize these goals  
  o drawing on international standards is commendable as indigenous groups such as those in New Zealand and Australia appear to years ahead of us in terms of revisioning (or decolonizing) indigenous research – researchers should draw on these best practices to inform their work; moreover, the unique positioning of indigenous researchers is notable as a highly complex positioning that will benefit from drawing on the work of international indigenous scholars (i.e., the work of Linda Tuhiwai Smith)  
  • Despite these strengths, any process for resolving issues of power and/or areas of dispute is absent (e.g., l. 3259 – “may require interpretation or adaptation”) – how is this resolution to be effectively or successfully accomplished? |
We recommend that community groups set up an Ethics Review group of their own and that this group be the first step in the approval process for university researchers. This would allow researchers to adhere to the diverse set of ethical protocols that surround each individual community/cultural group. Once this approval is obtained, the subsequent institutional ERB process should be simplified to ensure that the process does not become too onerous and/or time-consuming for those researchers and thereby discourage future research efforts.

- Importantly, the Métis remain a significant Aboriginal population without “voice” or proper support in the arena of ethics as applied to research processes – there is a real danger of further marginalizing this group without the proper institutional supports in place
- Also, in the case of researcher’s/s’ non-compliance with ethical standards, it should be the case that the community is given the opportunity to try to resolve this issue as a first step but that a process be put in place if there is non-resolution of the issue.

<table>
<thead>
<tr>
<th>9.1</th>
<th>The content found within lines 3372-3375 undermine Aboriginal self-determination and provide insufficient parameters for researchers to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>Determine if all measures available to identify a community research sanctioning body have been exhausted;</td>
</tr>
<tr>
<td>B.</td>
<td>Determine under what circumstances can the value of a proposed research supersede consequences of conducting research without adequate community/collective consent (especially in light on comments made on line 3527-3528)</td>
</tr>
<tr>
<td>C.</td>
<td>Determine if they (the researchers) are in conflict of interest by choosing who has the community authority to sanction their proposed research (especially in the absence of a community-identified authority);</td>
</tr>
</tbody>
</table>

In instances where the community in question lacks adequate resources to sanction and oversee research, a local or regional Aboriginal organization with adequate research capacity (i.e Mi’kmaq ethics watch) must be consulted prior to commencing the research.

| 9.1 | Article 9.1. Roles, responsibilities, and accountability should be included here; all are needed for a productive relationship. |
| 9.1 | 3274-3275. This could be reworded to ‘Aboriginal peoples, knowledges, languages, histories, or cultures.’ |

| 9.1 | 9.1 Applicability of the principles: we were unclear about the meaning of the last paragraph (3276-3280). If an Aboriginal person has been adequately informed about the purpose of the research, has consented to participate, and the research does not pertain to Aboriginal culture, then how can it matter if one or more of the study participants turn out to be Aboriginal? |

| 9.1 | Page 94 line 3623 Member ship in an Aboriginal community is quite specific and I have no difficulties with that. However, I think that use of “Aboriginal identity” as a variable needed consultation may be too restrictive. Many studies, especially preliminary epidemiological and/or genetic ones will request info on basic demographic e.g. age, sex, ethnicity. Aboriginals are not a special group here any more than Africans or Jews or Italian (communities that we do not consult with individually). My concern will be that if researchers drop this variable because they perceive it is too sensitive or the process of obtaining consent too onerous, then very important associations with health or other factors that are unanticipated at the start of the research will be missed. I have had personal experience of this and heard other examples at the session I attended. Further research taking the results to the next step of evaluating the reasons for possible
associations should obvious need “community” consultation. This is commented on appropriately in section 5 page 96 line 3341.

9.1 This clause only asks for consideration by REB. There is no requirement to do so and to do more.

Re: the need for a phrase “Integrity of Indigenous knowledge systems”: suggests a paternalistic view that Aboriginal persons do not have the capacity to conduct research. It is contradictory to the assumption that indigenous knowledge systems exist and have integrity. Moreover this phrase is vague and begs to be defined through characterizations of what makes an indigenous knowledge system and how it is epistemologically unique from other forms of knowledge. The notion of ‘integrity’ in knowledge ‘systems’ risk reification of such knowledge, objectifying it and denying that knowledge is process and forever in evolution.

It is our opinion that it is the responsibility of the community leadership to ensure that their members are educated sufficiently to have the capacity in question. Calls for researchers to provide this capacity risk replicating ethnocentric views of who are and who are not the experts.

9.1 Section D. Research Processes and Ethics Review.

When Articles in this Chapter Apply – Article 9.1

- This list has the same application criteria as the CIHR guidelines; it is one opportunity (there are others) to cite the CIHR document and highlight areas of harmonization.

9.1 3932 à 3938 : Ce paragraphe n’est pas clair. Sa traduction en anglais, non plus.

9.1 THEMES À REVISER/CLARIFIER À L’EPTC :


9.1 In order for researchers to meet the highest ethical standards and not to create disincentives for research through the imposition of ethical standards, it is crucial that appropriate support be provided to researchers within academic institutions and through funding agencies. This is an area where the ethical standards of the Tri-Council and funding programs need coordination as I address this issue in my final comments below.

Article 9.1 Application

Reference is made in this article to demonstrating respect for “Aboriginal rights and cultural heritage.” Although some Aboriginal communities ground research concerns and initiatives affecting their cultural heritage in the assertion of inherent Aboriginal rights or treaty jurisdictions, and the writer and others have developed legal arguments in support of this approach, the scope of constitutionally protected Aboriginal and treaty rights is not clearly defined in law. To date we do not have legislation or case law that clearly recognizes Aboriginal or treaty rights to protection and control of cultural heritage. Given the challenges and controversy associated with increased Aboriginal participation in research and control over products of research originating in their communities there is a potential danger that the language of “rights” will be narrowly construed by researchers and REBs to refer only to existing, recognized rights in Canadian law. Therefore both in the discussion of the policy preceding these articles and in all articles I suggest referring to Aboriginal rights and “interests” in cultural heritage.
to avoid narrow rights based approaches to the interpretation of ethical obligations.

It is not clear what is meant by “research conducted on a defined…territory.” My question is defined by whom? Traditional territories as defined by Aboriginal peoples extend beyond boundaries recognized in Canadian law (e.g. reserves) and overlap. A suggestion is to link the definition of territory to that adopted by the participants’ community. This will include traditional territories that are not necessarily given formal recognition in Canadian law and policy and extend ethical obligations accordingly. See also my discussion of Article 9.3 below.

9.1 Reference is made to research involving “cultural property.” Again this invites a narrow legalistic interpretation as cultural property is defined in domestic legislation concerning international movement of cultural objects and international treaties concerned with trade and recovery. Our research and that of others has demonstrated that the concept of property is not necessarily understood or consistently applied between western and indigenous legal systems and among Aboriginal communities. In the discussion of ethical concerns (lines 3199 – 3215) you define the broader concept of cultural heritage, including cultural property, with reference to the United Nations Declaration on the Rights of Indigenous Peoples. Use of the broader concept of “cultural heritage” is important because “cultural property” to varying degrees is incomprehensible, inappropriate, and inadequate when understood as a western legal, social or economic concept and applied to some forms of aboriginal cultural heritage. For consistency with your general discussion of ethical concerns and clarity in the adoption of your definition of cultural heritage, I suggest any time the phrase “cultural property” is used it be replaced by “cultural heritage.” Comments on defining cultural heritage will be elaborated in the submissions from and are also contained in the Introduction attached.

9.1 It is not clear what is meant by a “significant number of Aboriginal individuals.” The significance of the number may vary with the nature of the research being conducted. For example there may be few people, who have the authority within a community to discuss matters being investigated, but the information shared and how it is used could impact on a larger population. To suggest numbers are significant is, I respectfully suggest, adopting a Eurocentric approach to the issue of impact. The reference to a “significant number” should be removed and that REBs should be required to consider these articles in chapter 9 any time research involves Aboriginal participants. It may be decided that community engagement is not necessary or need not be as extensive, but in order to fulfill the goals of the policy the rebuttable presumption should community engagement is always appropriate when there are Aboriginal participants in a study unless established otherwise by the researcher.

9.1 Our experience is that this flexibility of application is extremely important because of the diversity among Aboriginal communities concerning understandings of cultural heritage, laws and protocols for sharing and control over information, and the desire and interest to engage at various stages of the research program. Concerns for protection and control of research and products of research varied among communities with some having protocols similar to those adopted by academic institutions for research involving human participants and others requiring greater consideration of collective interests and control over use, sharing and communication of information (e.g. by elder panels, ceremonial societies). Preliminary meetings concerning a wide range of issues from use and control of research data to processes for maintaining academic integrity and the integrity of indigenous knowledge took approximately one and a half years prior to the submission of and were largely funded by . All researchers that received funds from the project were bound by the broad ethical principles governing the project as well as those specific to the community with which they worked.

9.1 3251-56 Does Article 9.1, at lines 3251-56 mean that Chapter 9 requires something other than “Concern for welfare, respect for autonomy and respect for the
equal moral status of all humans”, the principles articulated at the beginning of the policy? (47-51)?

Scope of application (Application section for Art. 9.1 All the bullets are identified as “a” Shouldn’t they be numbered or lettered differently in sequence?

| 9.1 | 3261: “Article 9.1 (a) Research is conducted on a defined First Nation territory, Inuit land claims territory or Métis settlement;” does not include Aboriginal individuals residing an urban setting, a large group more and more the topic of research reviewed by REBs. In particular REBs need guidance on the need for, and the methods for assessing, community consent in urban settings with diverse Aboriginal representation. |
| 9.1 | 3276: “cultural accommodations to Aboriginal people” whose participation becomes known only when the research is conducted. This may not always be appropriate, and the consultation suggested could compromise confidentiality. In addition, some Aboriginal people might find this paternalistic and researchers may find this onerous and impractical. This statement should be elaborated or dropped. |
| 9.1 | 3251-3256: “Article 9.1 Researchers and research ethics boards should consider whether application of the core principles of this Policy require interpretation or adaptation in the context of proposed research involving Aboriginal participants, to demonstrate respect for Aboriginal rights and cultural heritage, the integrity of Indigenous knowledge systems, and the diversity among and within Aboriginal communities.” |
| 9.1 | 3257-3260: “Protections for human research participants set out in this Policy apply to research involving Aboriginal people, with the provision that application of the principles and requirements may require interpretation or adaptation, in situations such as the following:” |
| 9.1 | 3268 and 3283 Further guidance is needed at lines 3268 and 3283 where it states that additional interpretation and adaptation needs to be in place where: “there is a reasonable expectation that the research population will include a significant number of Aboriginal individuals”. How is “significant” defined? Does this apply even if Aboriginality is not a variable of interest? How does this reconcile with lines 3276-80 where Aboriginality is discovered only after data is collected? |
| 9.2 | The first issue occurs on pages 95 and 96, lines 3302-3305 and 3330-3332. On page 95 under the list of examples of Aboriginal involvement point 2 there is given the example of, |
“Research involving Aboriginal people who comprise a sizable proportion of the study or community and where Aboriginal-specific conclusions are intended. Example: a comparative study of access to public housing in Prince Albert, Saskatchewan.”

I have no problem with this example in itself but rather with the so called “Proportionate community engagement” suggested in the new draft:

“The tribal council representing local First Nation communities may partner with the Prince Albert city council to sponsor, implement and use the results of the housing study.”

The problem with this so called proportionate community engagement is that it is not proportionate at all. The choice of Prince Albert as the example is particularly troubling as this is the urban centre with the highest concentration of Métis people in Canada at 17% of the total population (Teresa Janz, Joyce Seto and Annie Turner, 2009)! The choice of engaging the local tribal council as the representative of the Aboriginal population in Prince Albert eliminates half the Aboriginal population from the community engagement process. Perhaps choosing Prince Albert was an unfortunate mistake but I think that it shows an underlying (albeit unintentional) invisibility of the Métis to researchers, ethicists, and government policy makers.

How can this be solved? My suggestion would be to find what community organizations and/or Métis political bodies could be engaged in this process in concert with the local tribal council. Métis people have core housing issues in many urban centres as well as First Nations people.

Reference:

9.2 I also appreciated your specific examples in 9.2, but I wonder about the feasibility of some of them for graduate students. It's one thing for a prof with a big research grant to be able to convene a committee to advise the District Board of Education for a study of student retention in high schools, but is it going to be possible for a PhD student with limited time and resources? I'm not saying that there should be different ethical standards for grad students vs. faculty, and I do think the TCPS does a good job in highlighting flexibility in ethical research, but I also think that the proportion of community research also depends on how many resources the researcher has available. I guess what I'm trying to say is that everyone should absolutely be involving Aboriginal peoples/communities in such work, but the extent of the involvement might also depend on other factors.

9.2 Ce chapitre représente un progrès très considérable, si on le compare au contenu de l’EPTC en vigueur. La reconnaissance du rôle des communautés autochtones et de l’autonomie individuelle constitue la base des considérations contenues dans le chapitre 9. Cette orientation doit être maintenue fermement, car elle reflète une diversité culturelle à respecter et des droits individuels inaliénables. Les suggestions faites aux chercheurs paraissent pertinentes et réalisables sans que des coûts exorbitants soient engagées. Les exemples des listes A et B des pages 106 et 107 apportent un éclairage utile, parce qu’il est concret. Par ailleurs, la
In regards to the Inuit and research there seems to be an emphasis on the Inuit land claims offices. The fact is that there are a number of offices that oversee the research and applications for research licenses. Nunavut Research Institute is run by the territorial government and while this office shares information with the Inuit land claims organization in Nunavut – Nunavut Tunngavik Incorporated (NTI) – researchers doing research in Nunavut do not necessarily have to consent to working with the Inuit land claims organization – as implied throughout the text. It is of course preferable that collaboration is with the Inuit land claims organization. This also is the case in Northwest Territories – where Aurora Institute oversees the research processes in that territory. Again, the office is run by the territorial government and share information with Inuvialuit Regional Corporation and the latter office is land claim organization. In case of Nunavik (Arctic Quebec) research licensing does indeed go through the land claim organization. The Inuit in Labrador/Newfoundland organized research under their public government (which in this case is land claimed based).

The strong emphasis on the land claims organization does little to mention the new non-government organization in all Inuit regions. They should be mentioned as well.

L. 3283–3285 – the implication is that a pre-research phase is necessary to achieve the best outcomes – can this be stressed with stronger language/terms, or in a procedural way?

L. 3291-3293 – “Engagement with the relevant community throughout the research process is the preferred means of ensuring that the ethical protections incorporated in a project respect the identities, interests and circumstances of participants” – Agreed; the ethical process is an ongoing process or a best practice of community approval that should be regarded as a process continually engaged in rather than a preliminary phase.

L. 3354 – in reference to “evidence of community engagement” – can examples of such evidence be provided to potential researchers to clarify what is meant by this phrase?

L. 3357-3358 - define what is meant by “ongoing relationship with a community” – What exactly does this encompass? What are the specific parameters (ie, employment, family connections, long-term friendships…)?

L. 3368-3371 – “the least organizationally developed communities are the most vulnerable to exploitation and should be supported in expanding their capacity to participate rather than suffering dilution of ethical safeguards” – Specifically, how can this be accomplished? Could a guidebook be published in this area or could targeted programs help address this gap? This has clear policy implications under the Canadian Charter of Rights & Freedoms.

Page 95, Article 9.2, 3282-3288: Should also refer to page 117, 10.6.

Page 95, Article 9.2, 3282-3288: What is meant by “managing the project”. Clarification is needed here to indicate whether the researcher should be ceding control of the study to the community and under what circumstances? Also, in the context of engaging with the community to determine the parameters of the
study, some guidance as to when exploration ends and data collection is considered to have begun would be helpful.

9.2 Line 3360 Add
Make the point here that by engaging with community leaders, the relevance/appropriateness/desirability of the research question itself can be more assured; also that the translation of the knowledge gained into practice is likely to be more assured and timely.

9.2 We would ask that there be clarification to article 9.2 (lines 3357-3359) where a researcher may have an ongoing relationship with Knowledge Holders in an Indigenous community, and particularly, in defining who has to provide approval of the research. Doing research in their own Indigenous communities (“insider” research), and we want to be sure that existing relationships are treated appropriately from an ethics perspective.

9.2 3282-3288. The idea of informing REBs seems wishy-washy. The use of ‘preferred’ on line 3292 should be strengthened – engagement/interaction with the community is a necessity, not a preference.

9.2 3344-3347. Is there REB follow-up if approval is not required?
9.2 3348-3353. Research involving collection and analysis of tissues from animals generally involves Aboriginal peoples (hunters and trappers) who gather the information.

9.2 3361-3371. Given this situation, what advice is there for researchers and REBs?

9.2 3385-3386. Who might advice be sought from?

9.2 9.2 Community engagement: Another situation that might be relevant to discuss occurs when Aboriginal and other cultural groups are asked to self-identify as part of the gathering of demographic data; in such cases, it needs to be clear whether the information will be used for purposes other than describing the sample.

9.2 General Requirement to Inform REBs on Community Engagement – Article 9.2
Chosen examples provide good illustration of the spectrum of Aboriginal involvement, however lists A and B should be read across items and not linearly. Consider combining the two lists so that each example on the spectrum of Aboriginal involvement is followed immediately by its corresponding example of community engagement. A table format could also be a good way to visually represent the spectrum and all corresponding examples.

9.2 Line 3354: “evidence of community engagement may vary”: this is a good opportunity to draw attention to how TCPS harmonises with existing protocols within agencies or communities and sets out the minimum standard.

9.2 En vertu de l’article 9.2, lorsque, dans une étude, un participant s’identifie comme autochtone au cours de la collecte de données primaires, la consigne selon laquelle il faut « s’interroger sur l’opportunité de demander l’aide d’un intervenant bien au fait de la culture des participants pour interpréter ou valider la conformité aux protocoles » (lignes 4010-4012) peut mener à des difficultés d’interprétation. Il serait notamment utile de clarifier ce à quoi réfère la notion de « protocole » pour éviter des interprétations restrictives qui pourraient biaiser l’étude. Le Sous-comité suggère donc de préciser le cinquième exemple de participation de la communauté selon une approche proportionnelle (lignes 4008-4016). L’on constate par ailleurs que l’article 9.2 ne balise pas très bien les responsabilités des chercheurs et des CER pour assurer la participation de la communauté, ou du moins l’inclusion de l’avis des communautés concernées (lignes 4025-4032). En l’absence d’instances représentatives (lignes 4048-4052) un CER peut-il préciser lui-même ses exigences.
Considering space limitations on research proposals: how can we expect researchers to cover these issues in a satisfactory manner in a proposal to granting councils, while also addressing the theoretical framework and methodological issues and remain competitive relative to less ethically ‘questionable’ proposals? It is not sufficient to say that the selection committee are not required or consider ethical questions – research ethics most often end up being informal evaluation criteria for selection committee members, when they are reviewing proposals that cause worries on the ethics front.

Community - how will it be defined? Options are the narrow sense of 1) geographical location, 2) recognition as a member of a band (and then one needs to ask who provides this recognition - the individuals' self-identification, the bands means of determining who is in and out (which at times goes by blood quantum, which suggests ethics issues itself), FN identity as defined by the Indian Act (clause 6.1 and 6.2), etc.). Will urban members be included? What about people with Aboriginal ancestry?

Who in the community will represent that community? Not all Aboriginal community leaders enjoy full or strong support from their community. In fact, band elections can take place as frequently every two years, which means that the leadership can change at any time after permission is given. Moreover, there are stories of distrust of some community leadership, which can result in communities in question being divided along family ties or otherwise. Do you want to promote traditional cultural values such as community consensus or merely leadership approval or a 50%+1 support? University REBs should take steps to become aware of any political issues in a specific community in which research is proposed to be able to determine what best constitutes community consent.

With respect to the ‘level of aboriginal participation’: we ask that more thought be put into this issue. Our reasoning is illustrated by the following example: a well-known statistical agency did a survey on children (including Aboriginal children). In designing this survey and how it would be rolled out, it went the route of striking an implementation board. However, no members of any representative body, such as the Assembly of First Nations, were made board members, yet this agency claimed it had Aboriginal participation. How can this be considered valid, if there are only one or two Aboriginal board members that have no official capacity as representatives of Aboriginal peoples? Note that we are NOT saying that members of the Assembly of First Nations must be involved. Rather we are suggesting that every project should involve Aboriginal participation based on its size and scope and regional dimension. That is, there should be national representatives for national studies of a significant size, etc.

The last sentence of 9.2 uses three words that imply measurement: ‘extent’, ‘appropriate’, and ‘proportionate’. There is a significant potential for problems with respect to how these things are measured and determined to be of ‘extent’, ‘appropriate’ or ‘proportionate.’

| 9.2 | Considering space limitations on research proposals: how can we expect researchers to cover these issues in a satisfactory manner in a proposal to granting councils, while also addressing the theoretical framework and methodological issues and remain competitive relative to less ethically ‘questionable’ proposals? It is not sufficient to say that the selection committee are not required or consider ethical questions – research ethics most often end up being informal evaluation criteria for selection committee members, when they are reviewing proposals that cause worries on the ethics front. |
| 9.2 | Community - how will it be defined? Options are the narrow sense of 1) geographical location, 2) recognition as a member of a band (and then one needs to ask who provides this recognition - the individuals' self-identification, the bands means of determining who is in and out (which at times goes by blood quantum, which suggests ethics issues itself), FN identity as defined by the Indian Act (clause 6.1 and 6.2), etc.). Will urban members be included? What about people with Aboriginal ancestry? |
| 9.2 | Who in the community will represent that community? Not all Aboriginal community leaders enjoy full or strong support from their community. In fact, band elections can take place as frequently every two years, which means that the leadership can change at any time after permission is given. Moreover, there are stories of distrust of some community leadership, which can result in communities in question being divided along family ties or otherwise. Do you want to promote traditional cultural values such as community consensus or merely leadership approval or a 50%+1 support? University REBs should take steps to become aware of any political issues in a specific community in which research is proposed to be able to determine what best constitutes community consent. |
| 9.2 | With respect to the ‘level of aboriginal participation’: we ask that more thought be put into this issue. Our reasoning is illustrated by the following example: a well-known statistical agency did a survey on children (including Aboriginal children). In designing this survey and how it would be rolled out, it went the route of striking an implementation board. However, no members of any representative body, such as the Assembly of First Nations, were made board members, yet this agency claimed it had Aboriginal participation. How can this be considered valid, if there are only one or two Aboriginal board members that have no official capacity as representatives of Aboriginal peoples? Note that we are NOT saying that members of the Assembly of First Nations must be involved. Rather we are suggesting that every project should involve Aboriginal participation based on its size and scope and regional dimension. That is, there should be national representatives for national studies of a significant size, etc. |
| 9.2 | The last sentence of 9.2 uses three words that imply measurement: ‘extent’, ‘appropriate’, and ‘proportionate’. There is a significant potential for problems with respect to how these things are measured and determined to be of ‘extent’, ‘appropriate’ or ‘proportionate.’ |

| 9.2 | 3942 : «...les chercheurs doivent expliquer au comité d’éthique». Il s’agit ici davantage d’une obligation. |
| 9.2 | 4066 : Le début de cette phrase est trop général. La phrase devrait plutôt mentionner le devoir du chercheur de solliciter des avis. |
| 9.2 | The importance of obtaining culturally informed consent and engaging with the community prior to the actual research activities through community events (e.g. feasts, celebrations, informal meetings) and planning meetings can not be overstated in terms of relationship building; clarity of the research program including goals, outcomes, and conduct of the research; and conflict resolution and avoidance. Some of the costs associated with this process were avoided in our research |
by drawing on existing relationships between researchers and communities of interest or by having communities seeking to work with whom they had a prior relationship and that met the levels of expertise necessary to, or were willing to work with experts, able to carry out our mutual goals.

The comments that follow arise from challenges we encountered in applying the core values and principles discussed above. They also arise from a concern for both certainty in knowing when the policies in this chapter are to be invoked, and flexibility of application of core principles in a manner that is both cognizant of the diversity of Aboriginal communities and opinions of the academic community on matters such as universality of knowledge, control over research outcomes, and “ownership” of research. They also take into consideration issues we encountered in the REB process and raised by elders and other knowledge keepers who participated in the Protection and Repatriation Project. I expect some of the issues I raise have already been the subject of debate.

9.2 Article 9.2 General Requirement for Community Engagement

Concerns relating to reference of “defined communities” and “significant numbers” also arise in the articulation and application of this article. The importance of flexibility is reflected in the notion that the “nature and extent of community engagement should be appropriate to the type of community.” However, I am not sure what is meant by “type” of community. Consistency with the policy articulated suggests an appropriate amendment would be “the protocols of the participants’ community.”

Again I have concern about reference to a “significant number of Aboriginal participants” and for the reasons stated above suggest this qualifier should be removed. It should simply refer to “Aboriginal participants.” However, if this is done I suggest that this article include a requirement that researchers inform the REB how they will engage the community or why such engagement is inappropriate given the number of participants and community affected. Helpful examples would be those that demonstrate where such engagement may not be appropriate (e.g., research that incidentally affects a small proportion of Aboriginal participants but is not intended to single out or describe Aboriginal people in the study such as the effectiveness of therapies to control blood pressure).

9.2 3282 Article 9.2 “In research proposals involving one or more...or a significant number of Aboriginal participants...researchers shall inform the research ethics board of how they have engaged...the community in approving, advising on or managing the project”

As the IAPRE notes, Aboriginal populations are not homogeneous. Where Indigenous people live in cities, it is not apparent who would represent the appropriate community body.

In the example 4 (lines 3311-3315), it is equally plausible that there may be more than one service agency. If the researcher chooses only one, the researcher risks being accused of being biased; if the researcher includes all of the agencies, then the researcher risks having the project being caught in the political differences of the agencies.

There is a potential for conflict between Article 4.1 on inclusiveness and the intent of Article 9.2. As noted in lines 3446 to 3452, the “principle of control asserts
that First Nations peoples ...have a right to control all aspects of research and information management...”

And what of the case where the project is a population survey, how does the researcher select the representative community?

In practice, the extensive consultations implied by chapter 9 increase the cost of including Aboriginal subjects, even where the eligibility for participation is as a result of 3268, “the research population will include a significant number of Aboriginal individuals”.


9.2 It is good that Article 9.2 recognizes the diversity of ways in which Aboriginal individuals are involved in research projects.

9.2 3287 Further guidance is needed for Article 9.2. How will the REB know that the research will involve significant numbers of Aboriginal participants? Would a behavioural board make a different determination than a health science board? And how will the REB know that the researchers are sufficiently engaged. There is an assumption in Chapter 9 that most research with Aboriginal communities should and will be community based participatory (CBPR) research, which is very intensive, time consuming and complex. Not all research lends itself to this type of methodology and not all CBPR research is fully directed from the community. Chapter 9 needs to better reflect the diversity of ethically sensitive research with Aboriginal participants.

9.2 3285 Further guidance is needed for the last sentence of Article 9.2. How do REBs and researchers determine to what “extent community engagement should be appropriate to the type of community and proportionate to the level of Aboriginal involvement in the research”. Experienced researchers working with Aboriginal populations have an understanding of this but for new researchers and REBs this will not be clear. (See 3354 for possible definition).

9.2 3289 This statement provides a useful recognition of diversity between urban and rural dwelling Aboriginal peoples. Further clarification is needed about community collaboration with urban Aboriginals as their membership may cross-cut many traditional band or tribal groups.

9.2 Pages 95 - 96 give many useful examples of research involving aboriginal communities and where various degrees of ethics review is needed.

9.2 3325 List B indicates at which level community engagement may/may not be appropriate. This is useful because REBs are now seeing more community-based research.

9.2 Regarding obtaining community consent: It is still not clear how to deal with community consent when research is not about a community. The scope of these examples is too broad to be useful.

9.2 3321-4 This example regarding natural science research does not involve human participants and should be removed. See contradiction with the statement in line 3787-89 on the last page (pg.108) of this chapter.
9.2 3348 List B item # 6: Remove this example because it does not involve human tissue and does not require ethics review.

9.2 3354-3360: This discussion on community engagement appears to be the TCPS’s working definition of community engagement. This should be moved much earlier in this document and could be even be repeated or cross referenced.

9.2 3361-3371 Further clarification is needed here. It is unclear where the responsibility rests to establish increased ethics review infrastructure. It should be made clear that the TCPS isn’t saying that research can’t be conducted in those locations. This statement ignores the sensitivity, experience and longstanding community engagement built by some established researchers. It could also be construed by Aboriginal persons in those communities that the TCPS is paternalistic in its recommendations.

9.2 3369-71 It is stated that “the least organizationally developed communities are the most vulnerable to exploitation and should be supported in expanding their capacity to participate rather than suffering dilution of ethical standards”. Who is responsible for this capacity building and will the Tri-Councils be providing funds to assist researchers in capacity building? It suggests that researchers are untrustworthy.

9.2 3379 PRE should create a website that serves as a clearinghouse for researchers to find ethics guidelines and such groups as the Assembly of First nations or Mi’kmag Ethics Watch of Nova Scotia.

9.2 Page 97, line 3361 refers to “small remote communities and urban populations have the most limited organizational resources to advise or collaborate on research. The least organizationally developed communities are the most vulnerable to exploitation…” At our video consultation with PRE this sentence was brought up operationally about expanding capacity. Does this entail capacity building along with what else goes on with research?

9.2 3282-3288: “Article 9.2 In research proposals involving one or more Aboriginal communities or a significant number of Aboriginal participants, researchers shall inform the research ethics board of how they have engaged or intend to engage the community in approving, advising on or managing the project. The nature and extent of community engagement should be appropriate to the type of community and proportionate to the level of Aboriginal involvement in the research.”

There may be cases where research only involves one person or a small number of individuals simply because these are the only living experts (e.g., elders) in the community on the topic of study (e.g., language or traditional plant medicines). Thus, it is not just the level of Aboriginal involvement, but the cultural significance of the research focus that should trigger the need for community engagement.

9.2 3289: “First Nation, Inuit, Métis, urban and rural communities differ significantly from one another, and they are characterized by increasing internal diversity. Engagement with the relevant community throughout the research process is the preferred means of ensuring that the ethical protections incorporated in a project respect the identities, interests and circumstances of participants.”

Clarify what is meant by throughout the research process, i.e., determining research questions, collecting data, interpreting results, and disseminating the findings.
<p>| 9.2 | 3298-3353: The format of Lists A and B (i.e., that they are separate lists) makes it difficult to follow the connection from the example of Aboriginal involvement to what is considered proportionate community engagement. The example of Aboriginal involvement should be followed directly by the relevant example of proportionate community engagement, instead of being separated into the two lists. |
| 9.2 | 3384-3353: Reference should be made to the Scientific Research Licence required for research in NWT. |
| 9.2 | 3354-3357: “The evidence of community engagement in a project may vary from a formal agreement setting out terms of co-management, to verbal approval of the proposed research in a group setting (which should be recorded), to informal advice from an ad hoc committee.” Replace “recorded” with “documented” since recorded implies audio or video. |
| 9.2 | 3368-3371: “The least organizationally developed communities are the most vulnerable to exploitation and should be supported in expanding their capacity to participate rather than suffering dilution of ethical safeguards.” Clarify who has the onus to support communities in expanding their capacity to participate – the researcher or some other entity? If the researcher, is this feasible? Shouldn’t this onus more reasonably rest on the institution of the researcher? |
| 9.2 | 3372-3375: “Where Aboriginal participants or communities do not designate an organization or individuals to represent their interests, the responsibility for securing culturally informed advice on ethical protections rests with the researcher or the sponsoring institution.” This is important but a tall order. Are there any general resources available to researchers and their institutions to assist in their understanding of how to go about securing culturally informed advice on ethical protections in such circumstances? |
| 9.2 | 3382-3386: Is it the function of the REB to ensure that advice has been sought to ensure that cultural perspectives are acknowledged? |
| 9.2 | Historical research. There needs to be additional consideration of the socially situated and political nature of historical interpretation which can have serious impacts on Indigenous communities. The lack of ethical review of historical research removes historical researchers from the ethical safeguards which other researchers must rightfully follow. While it may be “good practice” to consult those who may be affected by historical research (page 98, line 3385-3386), it is still left to the discretion of the researcher to do so. |
| 9.2 | The Draft does not address the issue of group consent. We note that Article 9.2 requires the researcher to inform the REB but does not require the researcher to obtain community consent, and the related Application aims to minimize the influence of the group on individual autonomy. We note that in Article 9.4 there is a requirement for free and informed consent of individual participants, in addition to group engagement, where appropriate. Thus, the focus of the Articles is on individual free and informed consent and consultation with communities. We support the CIHR Guidelines in outlining a two-stage consent process involving first the community in recognition of its jurisdiction then the individual. |
| 9.2 | 33 | Research must demonstrate the potential to benefit the community. To suggest that research “can benefit” (line 3183) the community makes this feature seem optional and subject to the researcher / REB’s discretion. The importance placed on maximizing community benefit from scholarship should equal that of... |</p>
<table>
<thead>
<tr>
<th>Section B</th>
<th>methodological rigor and that scholarly excellence. For those who would resist this on the basis of so-called academic freedom (opportunism), I would urge that they research something else, or at the very least, they reflect on their motives for doing Aboriginal research. If Aboriginal people need not be the beneficiaries of Aboriginal research, than who is?</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.3</td>
<td>Re. 9.3, I assume the consultation of leaders/administrators needs only happen if the research goes beyond the one person being interviewed on the Aboriginal territory? For example, if a researcher is collecting oral history from a granny and three aunts-—ie. asking them about their life experiences—this does not need permission from authority figures? If it does, then I find this troubling since the research, while having to do with Aboriginal peoples, is not about community knowledge in general, but rather the life histories of a few individuals.</td>
</tr>
<tr>
<td>9.3</td>
<td>Sometimes who the leaders that should be consulted in a community are not so evident. notes that there may perhaps be issues in managing the different viewpoints within a community, from liberal to traditional. Although there is guidance to REBs in how to manage these different expectations, our members felt that this section lacked sufficient clarity.</td>
</tr>
<tr>
<td>9.3</td>
<td>Out of respect for Aboriginal culture and their right to self-determination, collective consent should be mandatory. Where and when collective consent cannot be determined, research should not proceed unless there are exceptional circumstances that warrant this omission. The cost of proceeding without adequate community support is well documented. It includes: i) increased Aboriginal community resistance and distrust of the research community; ii) ethnocentric representations of Aboriginal reality and iii) minimal community uptake and benefit from scholarship. If the purposes of these new guidelines is truly to improve relations between Aboriginal and academic communities as a precursor to culturally competent scholarly excellence, there needs to be a more equitable balance of research power.</td>
</tr>
<tr>
<td>9.3</td>
<td>Ongoing consent procedures should be discussed in this section.</td>
</tr>
<tr>
<td>9.3</td>
<td>3409-3411. Videoconferencing, web-based interview/communications, and on-line archives could be added to this list.</td>
</tr>
<tr>
<td>9.3</td>
<td>We find that the TCPS section regarding surveys should mention those specifically targeting Aboriginal peoples (or other ethnic/vulnerable groups). If the survey does not specifically target any one or group of vulnerable groups, this could be lightened. Otherwise, we would question how 9.3 is substantially different from 9.2, other than to be more specific. We suggest that 9.3 and 9.2 be rolled together. Moreover, we suggest PRE further consideration of the word 'consult' with has specific legal connotation as a result of the Haida Decision (cf., Haida Nation v. British Columbia (Minister of Forests), 2004 SCC 73, [2004] 3 S.C.R. 511).</td>
</tr>
</tbody>
</table>
| 9.3 | Research on First Nation, Inuit or Metis Territory Requires Consultation
Line 3387: is ‘territory’ the appropriate word choice for this subtitle as it is politically contentious and, as the document later points out (line 3461), Metis are among the groups “without a land base…”. The term also excludes subgroups such as urban Aboriginal populations. “Communities” may be a better word choice. |
| 9.3 | 4068 : Ce titre devrait plutôt insister sur le devoir du chercheur de consulter les dirigeants officiels ou les administrateurs de l’entente sauf dans le cas des articles
17

9.7 et 9.8 car à la lecture des applications, il s’agit davantage d’examens, d’approbations, de gouvernance et de surveillance des travaux de recherche. Le libellé des lignes 4068 et 4069 devrait être changé pour tenir compte du ton donné par le contenu de l’application de l’article 9.3.

9.3 4084 : Quel sens prend l’expression «collaborer à la recherche» dans cette ligne?

9.3 THÈMES À RÉVISER/CLARIFIER À L’EPTC :

-- Consentement : Le consentement collectif des autorités locales des communautés des Premières Nations est exigé avant de démarrer un projet de recherche. Il est un pré-requis au consentement individuel.

-- Recherche sur le territoire : Il est impératif d’obtenir les autorisations appropriées au sujet de la recherche sur le territoire auprès de la nation ou de la communauté concernée.

-- Recherche historique, généalogique, analytique : Il est essentiel de consulter et d’impliquer les nations et les communautés dans ces types de recherches au même titre que les projets de recherches qui nécessitent une cueillette d’informations. Les données recueillies et les résultats issus de ces recherches doivent être réacheminés aux nations et communautés concernées.

-- Représentation : Les représentants officiels des membres des nations et des communautés des Premières Nations sont les conseils de bande élus démocratiquement au sein des communautés. Ces représentants sont la voix de l’ensemble des membres de leur nation, et ce, peut importe le statut de résident ou non résident des membres.

9.3 Article 9.3 Research On First Nation, Inuit or Métis Territory

Although the principle of consultation with Aboriginal governments with authority over defined territories is an important general principle, it is necessary to define “government” and “designated territory.” For example, one could refer to governments recognized in Canadian law and policy with respect to reserve lands, Métis settlement lands, and land claim settlement areas or areas subject to land claims. However, this would exclude traditional forms of government over traditional lands which extend beyond legally recognized boundaries to which ethical obligations arguably continue to flow if we are to take the idea of collaboration seriously.

A second concern is that in matters of cultural heritage authority may be delegated to a different body, or it may be necessary to have permission of the government (otherwise research on the land could be trespass) and the culturally appropriate authority which may or may not be officially designated by band council resolution or some other means. Again here your principle of being culturally informed of appropriate community authorities and structures is crucial (such as Mi’kmaq Ethics Watch and Mookakin Cultural Foundation of the Kainai Nation).

9.3 Guidance is needed on how researchers and REBs are to determine which leaders it is appropriate to consult in communities where the legitimacy of leadership is in dispute.

9.3 Page 98 Line 3387 onward. The guidelines do not really address the problem of governance where there is conflict between Aboriginal groups as to who speaks for them e.g. a local body made up of several First Nations may want to have a consultative role for any and all of its members re their participation in research, but this may be at odds with the individual community, whose leaders may feel the decisions should lie with them. This can be a difficult situation for both
<table>
<thead>
<tr>
<th>9.3</th>
<th>XI. Expand discussion on research approval by formal community authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.7</td>
<td>Clarified articles and expanded application (specifically 9.3 and 9.7) is needed to provide guidance on how to navigate the issue of blocking research for perceived illegitimate reasons. For example, when a male-dominated community authority blocks research on domestic violence against women. Two questions are salient. The first is, “Who constitutes a legitimate community authority from whom approval to conduct research must be sought?” The Indian Act or settlement agreements set out the politically legitimate political authorities for some Aboriginal communities. Care must be taken, however, to not conflate political authority for genuine moral authority in the community. In many cases, this will indeed be the political authority. We propose changing article 9.3 to include other types of community leadership, especially Elders.</td>
</tr>
</tbody>
</table>

The above-mentioned domestic violence example shows that there may be a need to circumvent some types of community authority to protect vulnerable individuals within the community. Hence the second question, “When can the formal community authority be circumvented?” Exact circumstances and mechanisms under which this legitimately and ethically can happen need to be spelled out. Such can occur when community political bodies lack moral authority to decide in the community's best interest or are not acting in good faith. Also, an option to partner with non-community specific organizations (e.g. a national Aboriginal organization working on violence against women) should be included. However, any exception to the partnership norm must be phrased so that researchers do not view it as an opportunity to escape the partnership framework when it becomes inconvenient. We propose modifying article 9.7 state that the formal community authority may be circumvented when it lacks moral authority and fails to act in “good faith” for the interests of community members. |

Finally, we suggest including articles 9.3 and 9.7 in one section on this issue. Article 9.3 can state the requirement to partner with community leaders. Article 9.7 can then spell out the exceptions to this rule, only operating within the spirit of the principles presented throughout chapter 9.

| 9.4 | Similarly, research circumstances that might qualify for waiver of fully informed consent in non-Aboriginal Research (e.g. Articles 1.1 and 3.8 in Draft TCPS) should not qualify for such a waiver in the Aboriginal Research Context, especially if they involved Traditional Knowledge, Intellectual, Cultural and Heritage Property, the Environment, Biodiversity, Human Bodily Tissues and Genetic Testing, and the Biotic and Non-Biotic Environment, including Sacred Sites, which are specially valued and protected in the Aboriginal Context. Any Articles, Provisions or General Principles in the Draft TCPS permitting waiver of fully informed consent in Non-Aboriginal Research should definitely not be applicable to Aboriginal Research where fully informed consent (both individual and collective) shall always be mandatory. The Draft TCPS should make this distinction clear and explicit in both general and Aboriginal sections of the TCPS. |

| 9.4 | I appreciate that the TCPS does not specifically request written consent (from individuals or authorities), but could this possibly be made more clear? REBs who do not have much experience dealing with research involving Aboriginal peoples seem to focus on written consent (in my experience), which led to an Aboriginal student of mine being unable to use her own grandfather's knowledge in a class paper. |

| 9.4 | Line 3424-3425. The statement that “any undue influence on the exercise of autonomy should be mitigated wherever possible” is an error. No undue influence on autonomy should be accepted by researchers or REBs. Perhaps a better wording would be state that researchers and REBs should work to eliminate such undue
influence. This acknowledges that elimination of all influence by communities may not always be possible, but puts a clearer burden on researchers and REBs to address it.

| 9.4 | We found article 9.4 redundant in light of the provisions in Chapter 3 of TCPS. One could add emphasis on Aboriginal persons in chapter 3 and remove this article here, unless we are speaking of a different cultural interpretation of informed consent in this case (and in consideration of oral cultures). |
| 9.4 | 4117 à 4120 : Il arrive souvent que la conformité à un groupe relève du choix personnel et conscient du participant. Dans ce contexte, la question du libre exercice de l’autonomie du participant ne devrait pas se poser. |
| 9.4 | 9.4 Free and Informed Consent |
| | I agree it is important to maintain the principle that “community or organizational agreement” can not replace “free and informed” consent of individuals. I have not had the opportunity to review Chapter 3 in detail but suggest “informed consent” is more complex in this context and offer the following suggestions. |
| | (1) Oblige researchers to inform individual participants about the mechanism for community authority review and/or approval as part of the principle of informed consent; |
| | (2) Respect for different knowledge systems and appropriate payment for elder knowledge should be taken into account by REBs in assessing issues of payment for participation and voluntariness. |
| | (3) Given increased concern about appropriation of cultural knowledge, misrepresentation, and use of data concerning human participants and matters of cultural heritage, researchers should be obliged to (a) discuss ownership of data, use of data (including possible secondary uses), and copyright with appropriate community authorities; and (b) if requested and where possible and appropriate given the nature of the research, to find alternatives to sole institutional and author ownership that are more inclusive of community collaboration and control of outcomes of research. |
| | (4) Although written or recorded consents are preferred, there should be flexibility for REBs to approve mechanisms for evidencing consent that are more culturally appropriate to the communities and individuals engaged in the research. |
| | (5) In matters of cultural heritage researchers should be obliged to take reasonable steps to inform themselves of individuals with the capacity to speak to the issues being researched in accordance with the laws and protocols of the community |
| | Each of these issues is discussed in further detail in the Introduction and Preface to First Nations Cultural Heritage and Law attached to this submission. Of particular concern is the fact that elder knowledge is not well understood by academic institutions and the implied hierarchy of knowledge associate with treaty elders as “human subjects” and “informants” rather than individuals that bring knowledge that is different, but equally important, as that offered by academic researchers. The dilemma of compensation raised by western ethical frameworks is the delicate balance between coercion and consent. However, honoraria approved for this kind of research is based on a scientific health/psychology model and is woefully inadequate recognition of the expertise being shared. Similar problematic assumptions about the value of knowledge and participation result in a legal regime that places control over research outcomes in researchers, their employers and their funders. Meaningful respect for difference and interpretation of principles of “concern for welfare, respect for autonomy, and equal moral status of all humans” in a manner cognizant of the distinctiveness and diversity of Aboriginal communities calls for increased control by Aboriginal participants in |
use of data and research outcomes. There should be an ethical obligation at least to discuss these issues as part of informed consent and the limits within which researchers work. As a result of such discussions in our research we often co-authored with indigenous organizations, obtained cooperation of publishers in releasing copyright on certain works, and decided together about proper storage and use of research data. I refer you to the Preface and Introduction attached for further detail. See also my comments on Article 9.9 below.

9.4 Consider adding information here about the appropriateness of obtaining verbal consent in certain research settings and how ethnographic research should be accommodated. The guidelines need to cover situations in which community consent might be sufficient (e.g. elders’ permission to watch a community ritual, elders’ consent to be in the community for participant observation). In addition, it would be helpful to add that this does not preclude research in communities that have not adopted local ethics codes.

It was useful that there is a cross-reference to Chapter 3. It might also be useful to include a cross-reference to Chapter 10 on qualitative research. In both instances, cross-references should be bi-directional.

9.4 This chapter is suffused with a very strong stress on aboriginal communities, as if they are consensually-based entities without divisions according to status, wealth, gender, or other such criteria—unlike any other community anywhere in the world. While I agree that the interests of aboriginal groups must be protected, given their long suffering under colonial and assimilationist policies, there must be some statement that aboriginal leaders or elders do not have the right to veto research in which individual aboriginals might be interested in participating. With regard to Article 9.2, for example, the possibility of not engaging with the community in some situations must be allowed; for example, if all the community leaders are members of extended family x, and do not want extended family y’s circumstances to be investigated, the researcher must be permitted to circumvent the community leaders and go directly to family y. With regard to Article 9.4, the statement that in no case can community consent substitute for individual consent should be supplemented by a statement that in no case may community representatives block researchers’ access to individuals who wish to be research participants despite community disapproval.

9.4 a. 9.4: Good (lines 3420-3425)

9.5 Article 9.5 – who is the final authority or decision-maker if project decisions cannot be reconciled between divergent groups? Can the researcher be empowered to walk away from a non-productive project? Perhaps a clause in the research agreement would help facilitate this.

9.5 Article 9.5. Aboriginal peoples have their own cultural code of ethics that originate and apply in their communities (sometimes known as ‘knowing your manners’). These codes of ethics are often unwritten and orally shared. These codes must be acknowledged and respected by all researchers and REBs, and take precedence. The community research protocols that have been developed are meant for external agencies, as above. An expression of trying to negotiate space between the real community protocols and demands of external agencies would be useful. There is a report by [AFN] for the AFN that gets at this. If a community does not have a formal written protocol, it is nevertheless important that the researcher try to understand and respect traditional and cultural protocols. When in doubt, the researcher/REB should ask. Seeking advice externally implies communication, outreach, and building/ maintaining relationships with Aboriginal organizations and communities.

3439-3458. OCAP is one ethical model, but traditional protocols within a community should prevail. Local cultural codes exist and apply even when the
organizationally derived research protocols are engaged (e.g. OCAP, NAHO). It is possible to do ethical research in Aboriginal communities respecting these unwritten protocols without OCAP. Discussion of responsibilities by both the researcher and the communities is needed.

9.5 3463-3466. It is not clear what this contributes. Aboriginal consultation protocols could be used as guides or principles. The Metis Nation Council has developed a set.

9.5 3467-3474. This is why relationships need to be negotiated from the start. OCAP, or any other single protocol is not always possible or desired, but these need to be negotiated.

9.5 9.5 Respect for community ethics codes: When there is a fundamental disagreement between the requirements of the community and the REB that cannot be resolved by negotiation and discussion, how will the dispute be settled?

9.5 Moreover, the assertion that these groups/communities should have control over all aspects of research and information management processes that affect them (p. 99) is crucial to the decolonization of North American scholarship.

9.5 When reviewing this article, we asked what is meant by “take into consideration” – it requires that an REB only consider these codes/protocols and do no more.

9.5 It was at this point in our discussion we began to wonder if the generation of a glossary of terms in the TCPS was in order: this emerged as we asked what is the difference between ‘code’ and ‘protocol’.

9.5 Respect for Community Ethics Codes and Protocols

Lines 3437 and 3469 to 3474: the advice to “seek to harmonize any differences between protocols” and “being prepared to reflect on what is essential… and on what degree of flexibility…” is laudable in principle but lacks practical tools for application. Considerably more responsibility will now fall to REBs to inform themselves of the local research ethics needs and whether these are being met. Will there be any REB training around this issue?

9.5 Line 3459: additional description of ITK processes would balance the lengthy explanation of OCAP in the preceding paragraph.

9.5 4122 et lignes suivantes : L’article 9.5 fait ressortir l’idée que seules les communautés des Premières nations dotées d’un code d’éthique sont organisées pour recevoir des fonds, contracter des ententes de recherche, accueillir et protéger les recherches conduites auprès des communautés. Cela laisse à penser qu’il serait non-éthique de conduire une recherche avec des communautés autochtones qui ne sont pas à même de protéger leurs intérêts. Ce qui irait à l’encontre de la culture scientifique sur la nécessité de conduire des recherches sur des groupes ou des communautés plus difficiles d’accès.

9.5 THEMES À REVISER/CLARIFIER A L’EPTC :

-- Protocole : Les nations et les communautés des Premières Nations qui possèdent un protocole ou des lignes directrices à l’égard de la recherche devrait avoir la latitude d’exiger l’application de leur protocole local en substitut à tout autre protocole suggéré par l’équipe de recherche.

9.5 Article 9.5 Community Ethics Codes and Protocols

I agree with much of what is said in this section but caution that often such protocols do not present themselves in a manner with which western academics are most familiar. They are not always written down and may be evidenced through action and ceremony. Again the principle of being culturally informed is
imperative and it is essential to acknowledge compliance with law and protocol may still be required absent formal written codes and protocols. There should be an obligation on the researcher to take all reasonable steps to be informed of oral and performance based protocols as well.

9.5 3433-3438 It is good to see that the drafters have used the word “harmonize” but it would be helpful to clarify what harmonize means in this context. This should be cross-referenced to the discussion at lines 3467-74 or the two sections should be brought together. Greater guidance should be given regarding whether/when this Policy will be overturned or trumped by local ethics codes.

9.5 Ownership, Control, Access and Possession (OCAP). Include a cross reference to line 3564.

9.5 3439-3458 With regard to confidentiality and data security: Provide further guidance about how the researcher will be able to ensure confidentiality of personal information entrusted to her/him if the data is owned by the community. See also line 3447 where it states that the “community has a right to control all aspects of the research”.

9.5 3459 Add a reference to the Inuit Tapiriit Kanatami guide. Do you mean the reference at the end of this chapter at line 3810?

9.5 3461-3466: the purpose of this section is unclear and not well integrated to the previous discussion.

9.5 3463 Do the drafters mean research protocol or research ethics codes generated by these groups?

9.5 3467-3474 While this statement recognizes the problem it doesn’t give research ethics boards enough useful guidance. The suggestion of maintaining respectful relationships is a good but should those relationships break down what recourse do these boards have? If there is an impasse, will legitimate and useful research be slowed down or halted?

9.5 3437 Harmonizing the TCPS with local Aboriginal Ethics Codes: Further guidance is needed what is meant by harmonization and how REBs should harmonize the differences between the TCPS and a local Aboriginal research ethics codes.

9.5 3447 Ownership, Control, Access and Possession of Research Data: Further clarification is needed to understand how the statement that the “First nations peoples, their communities and representative bodies have the right to control all aspects of research” is reconciled with other statements in this policy that participants do not have veto power over research. How will this assertion be reconciled with the undertakings researchers enter into with the funding agencies that support their research?

9.5 3427-3429: ADD TEXT: “Article 9.5 Where prospective participants signify that a community ethics code, GUIDELINE, POLICY or RESEARCH protocol is in effect, researchers and research ethics boards shall take into consideration the code, GUIDELINE, POLICY or RESEARCH protocol that applies in the territory or organization.”

9.5 ADD TEXT: “The similarity, divergence or overlap of such code, GUIDELINE, POLICY or RESEARCH protocol with this Policy, and clarification of mutual expectations, should be considered by all parties AND USED AS THE BASIS OF NEGOTIATING MUTUALLY-AGREED TERMS in advance of launching a particular project.”

It is insufficient to only suggest “consideration” by all parties – it is vital that the considerations then be used to inform negotiation of mutually-agreed terms, preferably taking the form of a written research agreement.
9.5 3439-3466: These three paragraphs intend to describe applications in First Nations, Inuit and Métis, respectively, but the intent is not clear at the onset. Subheadings or bolded key terms at the start of each paragraph (i.e., First Nations, Inuit and Métis, respectively) would help orient the reader.

The single sentence paragraph on Inuit Tapiriit Kanatami (lines 3459-3460) needs additional context to make it clear why (among the many guides, guidelines, codes, etc in existence) only this one is highlighted. It may be clear to those who already work with Inuit communities, but it will not likely be clear to those who don’t.

9.5 3469-3474: ADD TEXT: “Having reference to parallel codes, GUIDELINES, POLICIES and RESEARCH protocols in institutions and communities is likely to pose questions of which code should prevail when expectations and/or requirements diverge. Maintaining respectful relationships will be dependent on all partners being prepared to reflect on what is essential to achieving common goals and on what degree of flexibility is consistent with their core values.”

It is also essential that all parties involved are fully aware of their own and each others’ institutional, professional and community obligations, since these will sometimes be non-negotiable. The CIHR Guidelines (p.12 second para) notes: “Ensuring that all parties are aware of and understand existing institutional, professional and community standards will be important to achieving consensus.” A similar statement is needed in the TCPS.

9.5 VI. Researchers must apply community research protocols or codes of ethics

Article 9.5 is too weak requiring researchers to only “consider” community ethics codes or research protocols. In many cases, such codes or protocols have resulted from many years of discussion and experience with research. The requirement to merely consider them is neither sufficient nor respectful of the community's voice. Community ethics codes or research protocols must be followed by researchers who wish to engage in research with a community where such exists. We therefore propose strengthening the language of article 9.5 to clearly state this requirement.

9.5 9.15 Article 9.5 requires that researchers “take into consideration” community ethical standards. This suggests that the TCPS code of ethics supersedes community ethics in that researchers must “comply” (as oppose to “consider”) with the latter. Not only is this problematic with respect to self-governance, it provides researchers and REBs with a great deal of interpretational discretion that may place them in a conflict of interest when demonstrating collective consent and guideline compliance.

9.5 9.15 In the Protection and Repatriation Project, applications of the above values and principles were discussed, elaborated, and negotiated on a community specific basis at preliminary meetings conducted with First Nation participants and appropriate community authorities. Aware that our procedures had to be consistent with existing Tri-Council Policy on Research Involving Humans we carefully documented rationale for offering different interpretations of requirements such as “free and informed consent” arising from First Nation protocols, laws (often referred to as “customary laws”), and collective interest and responsibility. These were included in detailed REB applications and required in some instances subsequent applications and elaborations.

9.5 9.15 4. RESOLUTION OF DISPUTES

Notably absent from this section is a provision to address appropriate intercultural dispute resolution. A theme that runs through your recommendations is that meaningful engagement with appropriate authorities and participants seeks to find a common ground, anticipate differences, and agreement on process. However,
your policy does not address procedures that can be taken in the event of conflict. The Tri-Council should explore the creation of a dispute resolution mechanism that seeks to resolve conflict in a manner that gives equal weight and respect to Aboriginal and academic ways of knowing and ethical norms. When research relationships break down, Aboriginal participants are most often disadvantaged in that the only recourse they have is against geographically distant institutions that have vested interests in supporting the researcher and tend to rely on legal rather than ethical arguments in face of conflict. To engage in dispute resolution in a meaningful way is costly and may involve legal intervention. These and different cultural norms create significant imbalance of power.

The matter of independent, cost effective, and interculturally legitimate dispute resolution in this context requires significant research, consultation, and planning. However, I suggest it is a necessary next step for the Tri-Council.

9.6

The Second issue I have is located on page 100, lines 3475-3497. Particularly Article 9.6:

“Researchers should consider entering into research agreements with those Aboriginal communities who have adopted ethics codes or protocols, as a means of clarifying and confirming mutual expectations and commitments between researchers and communities.”

I believe this whole article is dangerous and should be eliminated entirely. This article seems counter to one of the main principles of doing ethical research in Aboriginal communities, specifically, building community capacity. If you make the suggestion that researchers should partner with and engage those Aboriginal communities that have adopted ethical codes or protocol you are essentially suggesting that researchers engage with communities that already have the capacity to do research with researchers. This runs the risk of eliminating those communities that have the greatest need for capacity building and likely for research to benefit their community.

I believe, and have the backing of several Aboriginal researchers, that this process is already occurring because it is easier for researchers to engage established communities than it is to go through the long and difficult process of engaging non-established (in a research sense) Aboriginal communities. What occurs (and indeed is occurring) is that a few Aboriginal communities have much research done in their communities whereas others have none and no capacity to start the process of beginning research in their communities. Researchers DO NOT need to be encouraged to continue in this tendency as they are already doing this.

I can understand the reasoning that went behind this article but as I have already said I think it sets a bad precedent, indeed, instructs researchers to engage only those Aboriginal communities that already have the capacity to engage in research processes with researchers, whether Aboriginal researchers or not.

How will this be solved? I am tempted to suggest that the article could be rewritten to get across the intended point without the unintended, but I will not. I think that the best bet would be to eliminate this article entirely. I do not doubt that if the community in question has this capacity in place it will make the research process for the community and the researchers easier and potentially more respectful and ethical, but I will reiterate my point that researchers already know this
and do not need to be encouraged in this manner.

9.6 L. 3475 – “research agreements” – is there a template to work from?

9.6 There is a focus on protocols rather than relationships. The ethical interactions underlie the work, and this is really the focus.

9.6 We found that article 9.6 should be combined with article 9.5.

9.6 Article 9.6 refers to research agreements. Further guidance should be offered to researchers regarding whether they are strongly recommended, when to develop such agreements and for what purpose.

9.6 Article 9.6 Research Agreements

I have not had time to consider this in depth. The only issues that come to mind are those which are associated with all contracts such as the expense of engaging proper legal advice incurred by Aboriginal communities and ensuring the necessary authorities sign (e.g. it may be necessary for the researcher’s employer to sign).

9.6 VII. Research agreements should be considered in all cases

The research agreements mentioned in article 9.6 should be considered in all cases, and not just research with those communities who already have research protocols or codes of ethics. As the article mentions, said agreements are a means of clarifying and confirming expectations. It would be unfair to deny the useful process of developing research agreements to those communities with less formal research structures. Nevertheless, these agreements should only be considered when it is culturally appropriate for the community. In some cases, communities may prefer oral agreements over written ones. This should be respected. We thus propose removing from article 9.6 “with those Aboriginal communities who have adopted ethics codes or protocols”.

9.6 The relationship that is developed and initiated by researchers is often instrumental and paternalistic rather than genuine and humble. Likewise, researcher interest in building a reciprocal relationship with Aboriginal communities is often neglected once data collection and analysis is completed. Since research implementation and knowledge translation remains a relatively low academic priority (not to mention that it is poorly rewarded by academic institutions), greater emphasis on such activities is needed at the ethical guideline level.

9.7 Section 9.7 has made my day! This was a MAJOR problem that I encountered with the REB at my former university. I think this section is really great. Is it possible to perhaps add Cultural Centres as a medium through which community approval can be obtained? I know several Aboriginal communities with very developed Cultural Centres and this kind of gets around the political issue of going to the traditional chiefs versus the band council (if you go to one, you'll sometimes tick the other one off and the Cultural Centre can sometimes be a bit more of a neutral zone--obviously, this depends on the community).

9.7 L. 3522-3528 – divergent groups in conflict – puts too much onus on researcher – there should be further safeguards or procedures put in place to protect all
parties involved in research, including that of the researcher

| 9.7 | Line 3522 Change  
|     | “conflict” to “tension” |
| 9.7 | There are also questionable statements of fact in the chapter on aboriginal peoples. What is the source of the statement on p. 101, lines 3508 ff, that traditional leadership structures are legitimate while leadership established under the Indian Act is not? Is this always the case? This statement appears to present as fact particular ideological or political beliefs about legitimacy in aboriginal communities.  
|     | Furthermore, the injunction not to conduct research on aboriginal peoples which could result in stigmatization of whole communities could result in both denial of academic freedom and non-generation of research findings that might have a beneficial effects on aboriginal or non-aboriginal populations in the longer term. “Stigma” is a loose term; what one individual or group considers stigma another might consider necessary scientific information. If, for example, a particular indigenous population suffers from a disproportionately high rate of HIV/AIDS or tuberculosis, this could be considered by some people as stigmatizing and by others as information that a particular health, social or economic problem requires immediate remedy.  
|     | Along these lines, as well, why should researchers always avoid deepening divisions in a community? (p. 101, line 3523). Sometimes it is a good idea to deepen a division. Would we advise researchers on caste divisions in India, for example, to avoid conducting research that might make clear to Dalits their subordinate position in society? This injunction seems to deny to aboriginal individuals the autonomy that the draft claims is one of its key principles. Aboriginal individuals are not supposed to be allowed to think in ways that might deepen the divisions among them, although non-aboriginals are permitted to think that way.  
| 9.7 | Again a focus on ethical and respectful relationships is called for.  
| 9.7 | 3508-3521. There is not necessarily documentation of cultural and traditional protocols, and diversity exists within traditional structure.  
| 9.7 | 3524. The phrase “the good offices of trustworthy persons” needs clarification.  
| 9.7 | The application section to article 9.7 addresses conflicts between specific interest groups within a community. It proposes that the “where alternatives to seeking approval of formal leaders are to be pursued, researches should provide a rationale and document the nature of the process…” We take this as suggesting that the researchers should take the initiative and seek ‘unofficial’ sanction for their research and, of course, justify their plans to REBs. We would point out that such activities 1) belong to the community leadership (i.e., keeping in lines with Canadian Constitutional rights to self-determination, which includes, de facto, conflict resolution); and, 2) run a risk of accomplishing exactly what this article would avoid: deepening divisions within a community by by-passing the leadership; it risks the researchers being told to leave the community and not return, thus effectively killing the research, and is potentially contrary to Common Law provisions regarding contractual obligations.  
| 9.7 | Community Engagement at Variance with Operative Protocols  
|     | This topic is a welcome inclusion in the discussion as it highlights the need to understand the heterogeneous nature of communities. However, again much responsibility falls to the institutional REBs, who may not have the cultural background (i.e., when to defer to Elders or traditional societies over local authorities |
or TCPS standards?).

9.7 4217 à 4222 : Il serait plus opportun de dire : « S’il faut recourir à une solution autre que les protocoles des communautés... le chercheur doit décrire...».

9.7 4256 à 4258 : Lorsque les risques sont plus grands que les avantages attendus de la recherche, quelle devrait être l’attitude du chercheur?

9.7 Article 9.7 Community Engagement At Variance With Protocols

I have only had time to consider this article briefly. I am not sure what is meant by “Operative protocol” and if this is referring to the community protocol. If so I stress the importance of making it clear protocols will not necessarily be in the formats with which we are most familiar. Some of the information you include here actually speaks to compliance with, not variance from, protocol. The problem may be an assumption that protocols in writing might conflict with laws and leadership structures recognized within and indigenous legal order. In that event the word “variance” is problematic as the latter may be the “correct” protocol.

9.7 3499 Should the word ‘ethics’ be inserted between the words ‘organization(al)’ and ‘protocol’?

9.7 3499-3502 Article 9.7 should be shortened and written in plain language to clarify the meaning. “Shall” sounds too proscriptive for these guidelines and sounds more like regulations.

9.7 3503 -3531 This application section describes situations that might arise but would be more helpful if more practical advice was provided.

9.7 3515-3521 It is useful that this policy recognizes that prospective research on vulnerable persons (e.g., women and youth) may be opposed by community leaders (the very people who are in a position to approve the research project). At lines 3522-3528 it is suggested that the researcher search out “the good offices of trustworthy persons who have moral authority in the community” to find ways to go forward with the research and preserve respect for all parties. This may not lead to resolution on some contentious issues. In effect the REBs could now be put in a position of vetoing important social science research that could improve the quality of life of vulnerable populations because the gatekeepers oppose it. The notions of justice that are discussed in Chapter 4 concerning research on women (especially subsections B, C and D related to women and vulnerable persons) are potentially in conflict here. Also see line 3471 that discusses which code (TCPS or local ethics code) will prevail. This should also have a link to other parts of this Policy that cover risk and benefit.

9.7 Article 9.7, particularly the section about “problem-solving on-site” suggests that researchers must be prepared and trained to problem-solve. A neophyte student researcher who does not have a supervisor with Aboriginal research expertise may not be well-equipped. Also, what band is to give approval for a geographical area where there are four bands?

9.7 3524-3225: ADD TEXT: “The good offices of trustworthy persons who have moral authority in the community can often be enlisted to find ways to proceed with research that preserves respect for all parties. However, in some cases the risks involved simply outweigh the benefits to be derived from proceeding with the research AND THE RESEARCH SHOULD NOT BE UNDERTAKEN.

9.7 3499-3500: This is an important addition.

9.8 Lines 3545-46 and 3549ff. – Such an example seems out of place in a document such as this, if only because the project may end long before the next revision of the TCPS.

9.8 I also like the section (9.8) that allows for the critical examination of "public institutions or persons in authority" since such analysis is clearly a crucial part of
scholarship and may not always be positive in nature. I'm thinking, for example, of the numerous women who regained status in the mid-1980s as some discriminatory elements of the Indian Act were removed, but then returned to their home communities only to find out that the band council would not recognize them as members (because band lists being regulated by the band and not the Indian Act). Certainly, the surrounding context must be explored (i.e. the band not having enough of a land base to include these women and their children, etc.), but we can obviously see why gaining approval from the band council to support such research could be problematic! All this to say, I wonder if this section might be expanded beyond only "public institutions or persons in authority"; that is, I can think of other instances where critical examination may not yield nice/happy conclusions outside of the public/authority sphere, and I think these are important issues to explore regardless (and can indeed benefit the community in the long run).

9.8 L. 3559 – “NWAC acts as its own ethical review body” – if examples exist, can we draw on these models to set up our own community ethics review body? How can this sharing of best practices be facilitated?

9.8 3543-3563 While the story of the Sisters in Spirit project is interesting in its own right, the inclusion of such a story about a contemporary research project raises potentially difficult issues if, for example, someone challenged the ethics of this particular project (or any other project named in TCPS). The response to such a challenge might be that the project can’t be unethical since it is included as an exemplar in TCPS. I would suggest that such accounts be included in parallel publications but not in TCPS.

9.8 3549-3563. What is the community here? This paragraph mentions responsibilities. It might be helpful to provide an academic example of research of this nature that demonstrates this principle.

9.8 9.8 is considered redundant in face of 9.1.

What is meant by the ‘usual requirement’? This is considered vague and, as such, meaningless.

9.8 Article 9.8 Critical Inquiry

Here I only caution that we need to consider more fully what is meant by “academic integrity” and “rigour” in the context of collaborative research that seeks to respect different ways of knowing. Credibility in academia has commonly been understood as deriving conclusions free of influence by “participants” but this idea of critical inquiry and credibility may be at odds with the objectives of collaborative work. Critical inquiry should be understood as engaging not just academic tools but those within the communities with whom we partner (e.g. mechanisms for validating veracity of elder knowledge). I think it would be helpful to point this out to researchers.

9.8 3549-63 this is interesting information but seems rather long and should be shortened or better integrated into the previous discussion

9.8 3533-3536: This too, is an important addition.

9.9 Confidentiality in small communities

Ethics review lays a great deal of emphasis on protecting the confidentiality of individuals. When conducting community based research with participatory models such as sharing circles, confidentiality goes pretty much out the window.
<table>
<thead>
<tr>
<th>Line</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>3571</td>
<td>Insert … respect the privacy …</td>
</tr>
<tr>
<td>3575</td>
<td>It would seem appropriate, in Chapter 9, to acknowledge more strongly that in Indigenous research, research participants may want to be acknowledged by name, as it is often considered respectful to thank people who have contributed their knowledge. This point is made in Chapter 9 (p. 103, lines 3588-3589) with respect to qualitative studies or life histories but could be more strongly stated.</td>
</tr>
<tr>
<td>3570</td>
<td>What does ‘partnered research’ mean here? If this is research carried out by a researcher and community, it seems like these arrangements should be negotiated rather than the researcher informing. The application should also address situations where consent is difficult to obtain due to use of methodology such as participant observation or ethnography. How is data managed when individuals might not know that the research is taking place? Information technology could use more attention, as the new technologies do not truly protect data. Specific mention could be made of PIPEDA (Personal Information Protection and Electronic Documents Act).</td>
</tr>
<tr>
<td>3572</td>
<td>Privacy and Confidentiality</td>
</tr>
<tr>
<td>3565</td>
<td>Line 3565: does the reference to “community-based” research collaboration mean CBR in the strict sense (including CBR methodologies and objectives), or is the term being used loosely to denote any type of research that involves a particular community? If the latter (which is likely the case), consider using a descriptor other than “community-based research” as the specific definition of this term may inhibit broader uptake of the directive by all researchers, especially those who do not self-identify as CBR practitioners.</td>
</tr>
<tr>
<td>4305</td>
<td>Il faudrait plutôt dire : «…de la communauté doivent examiner, dès les premiers stades de la conception de la recherche».</td>
</tr>
<tr>
<td>9.11</td>
<td>Article 9.9 Privacy and Confidentiality</td>
</tr>
<tr>
<td>3569</td>
<td>I have already addressed issues of data control in my discussion of “free and informed” consent. I agree that there should be an obligation to inform all participants about decisions with respect to use and disclosure negotiated with appropriate community authorities. Unfortunately I have not had time to go over Chapter 5 in detail. Although this may be addressed elsewhere, it is important for me to note that anonymity is the norm in medical and psychological research. However, in collaborative research with Aboriginal communities it also often the case that participants wish to be attributed and indeed, to respect the verification process for their knowledge, must also identify the persons from whom the knowledge is derived. There needs to be sufficient flexibility to address this in provisions concerning anonymity and confidentiality. I think you cover this in Article 9.11 Secondary Use of Data, but it applies in other contexts as well.</td>
</tr>
<tr>
<td>3569</td>
<td>Whilst the suggestion to “resolve any inconsistencies” (3569) is reasonable this Policy gives little guidance for doing so.</td>
</tr>
</tbody>
</table>
3570 Application: Researchers should inform communities and individuals what arrangements are made in partnered research to respect privacy of individuals and communities.

3565-72 REBs, researchers and communities are going to need much more guidance.

3580-83 Does OCAP trump individual privacy for Aboriginal participants? It is welcomed to read that that OCAP principles need to be seen in a much larger framework of law and policy to protect privacy.

3584-92 The section on confidentiality needs further clarity.

3593-99 The previous paragraph should be switched in terms of order with this one for greater clarity.

3600-06 The CIHR Best Practices for Protecting Privacy in Health Research dominates this section, but this article is not only about health information. This section could benefit from rewriting to eliminate vagueness and to position this within a broader non-medical research context.

The principle of ownership control, access and possess (OCAP) whilst at the core of this chapter has the potential make create barriers to research. University-based researchers are also bound to the funder’s requirements as well as to their promises of confidentiality made to individual research participants. Further guidance is needed to assist institutions, REBs researchers and Aboriginal communities about how to reconcile OCAP principles with the obligations to funding agencies and standard research practice.

Researchers should inform communities and individuals what arrangements are made in partnered research to respect privacy of individuals and communities.

SUGGESTED REVISION: “Researchers should DECIDE WITH communities and individuals what arrangements WILL BE made in partnered research to respect privacy of individuals and communities.”

Researcher should decide these arrangements with communities and individuals, not simply “inform” them.

a. 9.9: Good that the difficulty with anonymizing data is raised (lines 3584-3586)

Line 3637 – change “or even” to “and” (or “and/or”).

L. 3635-3647 – “Researchers should afford the community an opportunity to react and respond to research findings before the completion of the final report, in the final report, or even in all relevant publications…” – while I agree with the application and intent of this principle, I am wondering how community interpretations and/or responses will be received within the context of a dissertation defense? For instance, will ethnographies of all sorts necessarily become collaborative ethnographies?

o There is a very real need to make the academy aware that different rules of conduct will apply within an Aboriginal context and these processes may have a very real effect on how academic work is structured.

Page 104, 3635: “Researchers should afford the community an opportunity to react and respond to research findings before the completion of the final report…”
How is the REB to monitor this requirement? Suggestions or examples would be helpful here. For example, the researcher could be directed to provide a plan for community consultation prior to dissemination or the REB could require a copy of communication with the community on this issue.

9.10 Line 3624 Correction … work that is necessary …

9.10 3620-3622. Examples should be provided. What tools exist to do this? How can researchers and REBs ensure this?

9.10 I like the point that "if disagreement arises between researchers and the community, researchers should afford the group an opportunity to make its views known or they should accurately report any disagreement about the interpretation of the data in their reports or publications" (p. 104, In 3644-3647). In fact, I think this point should be applied to chapter 10 on qualitative research, too.

9.10 This article talks about the misuse or misappropriation of tangible and intangible property. The question is who defines when something is mis-used or misappropriated: The REB, the researchers, the community, the community leaders, elders, museums, law? This is vague and should be clarified.

We question if article 9.10 means that indigenous knowledge systems/oral histories are not open to questioning or to challenges? It would seem that 9.10 further reifies the notion of knowledge systems as unchanging objects.

9.10 Protection of Indigenous and Cultural Knowledge

Article 9.10: shouldn’t research agreements be required or at least highly recommended especially in the context of highly sensitive issues such as protection of Indigenous and cultural knowledge? Shouldn’t specific mechanisms be identified for such protection?

9.10 Lines 3629 to 3634: originators (if traceable) of traditional knowledge as described in these lines could be consulted to discuss appropriate use and further public dissemination.

9.10 I hope that the above shed light on the diversity of requirement in case of the Inuit and research – but first and foremost I wanted to address the lack of attention on the languages of the Aboriginal peoples in the text, and the role of research in strengthening the languages.

9.10 The other one that I wanted to address is the very fact that Canada as a nation is very much a leader in international context. Many of Aboriginal peoples around the world have no assurance of ethical dimensions in research activities. Canada is one of the few nations around the world that recognizes Aboriginal knowledge as distinct intellectual systems and contributed to creating a notion of Traditional Ecological Knowledge (TEK) or traditional knowledge (TK). In that context, I did not see any mention of Inuit knowledge or Inuit Qaujimajatuqangit – that all need the support from the research community. These are the knowledge systems that are indigenous and are the ones that the new post-land claims government want to re-introduce and use. I see the same trend in First Nations and Métis communities – using varying degrees of the medicine wheel. These knowledge systems simply need to be addressed in the text.

9.10 Further guidance is needed regarding how REBs and researchers will be able to carry out Article 9.10 in practical terms because the acquisition of such knowledge may not be anticipated. Further discussion of this article as it relates to the principles of Ownership, Control, Access and Protection would also be...
useful and the corresponding responsibilities that researchers have regarding the data that they collect.

9.10 3614-19: Define the concept “research product”. (Also see 3616-17.)

9.10 3635-47: Regarding the statement: “Communities consider that their review and approval of reports and academic publications is essential to validate findings, protect against misinterpretations, and maintain respect for Indigenous knowledge, which may entail limitations on its disclosure.” In this instance what do the drafters mean by ‘valid’ and ‘misinterpretation’? Is academic freedom trumped and what happens if disagreements arise?

9.10 3646 It is reasonable that if a researcher insists on staying with a critical approach, and if the community is not agreeable, the researcher has an obligation to state that disagreement in reports.

9.10 3607: “Protection of Indigenous and Cultural Knowledge”

The inclusion of “and” in the subheading is confusing since it implies two distinct kinds of knowledge being discussed, i.e., “Indigenous knowledge” and “cultural knowledge.” What is the intended difference between these? Since there is no single agreed definition of either term, both need to be explained. Or if the intention is to refer to “Indigenous cultural knowledge”, the “and” should be removed. We note that this subtitle is the only place that the term “cultural knowledge” appears in the document (i.e., it is not used anywhere in the text). Introductory information for Chapter 9 uses the terms “Aboriginal or Indigenous knowledge” and “Indigenous knowledge” (p. 93, lines 3205-3215 and 3227-3231). However, the term “cultural heritage” is used (p. 93, lines 3199-3204) and described as including “artifacts, cultural property, collective knowledge and skills, and other intangibles that are transmitted from one generation to the next, such as folklore, customs, representations or practices.”

SUGGESTED REVISION: “Protection of Indigenous Knowledge and Cultural Heritage”

The above seems a more appropriate subheading for this section whereby “cultural heritage” is understood as the broader term that includes cultural property (making it consistent with the introductory text to Chapter 9, as well as common usage).

Further consistency and clarification of terms used in this section are needed.

9.10 3608-3647 “Article 9.10 Researchers should consider, and research ethics boards should review, whether tangible or intangible cultural property of Aboriginal persons or communities is at risk of misuse or misappropriation when collected in the context of research involving Aboriginal participants or communities. Researchers should include measures to mitigate such risks of misuse or misappropriation in the research ethics review proposal.”

The term “tangible or intangible cultural property” should be replaced with “Indigenous knowledge or cultural heritage” so that the broadest category is being encompassed in Article 9.10, and also for consistency with the subheading since it is the first instance where the term “tangible or intangible cultural property” is used so it is confusing in light of its ‘sudden’ appearance (see also our comment about lines 3162-3166 p 92).

9.10 3614-3619: “Researchers should negotiate with communities mutual understandings of appropriate respect for cultural property including Indigenous knowledge,
how to proceed with community review of findings, terms of ownership of research products, and any limits on publication of materials, including how intellectual property rights to research products will be assigned: whether to community sources, to researchers, or to both on a shared basis.”

SUGGESTED REVISION: “Researchers AND communities should DEVELOP mutual understandings of appropriate respect for cultural HERITAGE including Indigenous knowledge, AND NEGOTIATE how to proceed with community review of findings, terms of ownership of research products, and any limits on publication of materials, including how intellectual property rights to research products will be assigned: whether to community sources, to researchers, or to both on a shared basis. THE FINAL AGREEMENT SHOULD BE IN A WRITTEN DOCUMENT.”

Mutual understandings should be developed (not “negotiated”) while how to proceed should be negotiated and represented in a written research agreement.

Some members of our group suggest that the final written agreement should be signed by the researcher's institution and the community's designated representative.

9.10 3620-3622: “REBs should review the measures researchers put in place to recognize and protect Indigenous or local knowledge in the conduct of the project and the dissemination of findings.”

This is the only instance where “local knowledge” appears in the Draft. It is unclear how “local knowledge” is intended here to be different from “Indigenous knowledge,” which is the focus of this section. Certainly there are parallel ethical issues and protective measures that are needed to respect and protect local community knowledge, but these should be placed in context and discussed purposely in relevant sections of the Draft where research involving communities is discussed (especially but not only in Chapter 10).

It is very important that REBs have the appropriate expertise to be able to evaluate the measures proposed from both university and community perspectives. In many cases, this would be an appropriate and vital place for use of ad hoc REB members, as indicated in Article 9.14 (P. 107, lines 3758-3760) “through ad hoc consultation with knowledgeable academic and community advisors, or through collaboration with community ethics review bodies.”

9.10 3635-3647: This entire paragraph applies to all research involving Aboriginal communities, not just to research involving Indigenous knowledge. Move paragraph to p. 100, insert at line 3498. Moreover, this paragraph also applies to community-based research generally, whether or not the communities are Aboriginal.
SUGGESTED REVISION: “Researchers should afford the community an opportunity to react and respond to research findings before the completion of ANY PRODUCTS THAT REPORT THOSE FINDINGS, in the final report, or even in all relevant publications. (See Article 3.2 in Chapter 3 [“Free and Informed Consent”] on information disclosure.) Collaborative research reports are regarded as a product of both community and researcher contributions rather than the sole property of the researcher. Communities consider that their review and approval of reports and academic publications is essential to validate findings, protect against misinterpretation, and maintain respect for Indigenous knowledge, which may entail limitations on its disclosure. If disagreement ABOUT INTERPRETATION arises between researchers and the community AND IT CANNOT BE RESOLVED, researchers should afford the group COMMUNITY an opportunity to make its views known, or they should accurately report any disagreement about the interpretation of the data in their reports, OR OTHER RESEARCH PRODUCTS.

It is not clear what is a “collaborative research report.” Does this mean co-authored or does it refer to any report or product that emerges from the collaboration, regardless of authorship? We support the latter and ask that it be clarified.

Presuming that “disagreement” refers to interpretation, first researchers and community members should seek to resolve the disagreement or misunderstanding. If it cannot be resolved, then opportunities to express all perspectives should be found.

9.10 VIII. Stricter language is needed for control of cultural property
Researchers should not only consider measures to protect cultural property, but must address the issue in a research agreement. Article 9.10 states only the requirement to “consider” such issues. This does not go far enough for this important issue. Before any research takes place, researchers and community must negotiate how cultural property can be used and how the results of any research will be used. This is particularly important when commercialization of results is possible, and it will also lessen the chances for avoid future potential conflict. We propose strengthening article 9.10 to include the requirement to address cultural property issues in a research agreement.

9.10 IX. Potential stigmatization from research results
Chapter 9 must also protect against possible community stigmatization from research results. Too often, communities have been stigmatized by negative or unfavourable research results that have not been put into context. Involving communities in interpretation and dissemination of results can accomplish this. In cases of disagreement over interpretation, the community should be given the opportunity to include their interpretations in any publication and/or intermediate and final report. We therefore suggest expanding articles 9.10 and 9.11 to include the possibility of stigmatization and require protection against it.

9.11 Line 3649 Article 9.11 “…secondary use of data collected initially for other purposes from which personal identifiers have been removed” does not necessarily refer to ‘identifiable’ data which may, by virtue of coding or content enable linkage to individuals. Should this also be included here, as it is in the earlier discussion in Chapter 5 (where identifying and identifiable data are considered equivalent)?

9.11 Lines 633-635 (the Appendix to Chapter 2: Scope and Approach) are in direct opposition to lines 1764-1770 (Chapter 5: Privacy and Confidentiality) and lines 3679-3684 (Chapter 9: Research Involving Aboriginal Peoples). For the sake of clarity, some exception should be noted in the Appendix. Ideally, this might also
include other cases in which a particular group identified by ethnicity, disease status, employment status (e.g. sex workers) or other potentially stigmatizing feature are the subject of the research.

9.11 Line 3684 Insert
… imposed on the use of the data …

9.11 Ligne 4416 (p. 117): Préciser’: Section D’ après 'Vie privée et confidentialité'

9.11 The guidelines:
I am concerned that the guidelines can result in censoring research in which Aboriginal peoples are the subjects. I am also concerned that the guidelines can have a detrimental impact on Statistics Canada’s and other federal agencies’ ability to collect data on Aboriginal peoples. One very important point must be made explicit and very clear. These guidelines must not, and can not, apply to research using secondary data sources. They must be restricted to primary data collection. We have had issues with Research Ethics Boards in selected universities who do not see the distinction between primary and secondary sources of data. The point that needs to be highlighted is that research using secondary sources is using data that have already undergone an ethics review.

9.11 Note Line 3669

<table>
<thead>
<tr>
<th>Research approach with regards to Aboriginal Peoples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. recruiting individual participants, for the creation of a platform to facilitate biomedical research into the causes of cancer and other chronic diseases.</td>
</tr>
<tr>
<td>2. platform is longitudinal (biobank and databases (based on questionnaires)), and will also collect health information through provincial, administrative governmental databases.</td>
</tr>
<tr>
<td>3. data and samples from consented individuals who self-identified as Aboriginal will be stored like any other data and samples.</td>
</tr>
<tr>
<td>4. will only recontact individuals to update the information already collected (i.e questionnaires and physical measures) or to collect new data and samples if necessary. Such recontact has to be consented to in the initial consent.</td>
</tr>
</tbody>
</table>

Questions
1. Through questionnaire, some people might identify themselves as Aboriginal. These participants will not be treated differently by... Should the DV-TCPS address this issue of self-identification as distinct from a “community”?

2. might receive requests from researchers wanting to use data and samples only coming from individuals who identified themselves as Aboriginal. How will the DV-TCPS address this issue?
3. If were to target Aboriginal communities, how will the DV-TCPS address associated issues? Would they be automatically excluded from this type of research? Does a community point of view regarding inclusion in research override individual choices?

Recommendation asks the DV-TCPS to take into consideration emerging novel approaches to research and their possible impact on the inclusion of Aboriginal peoples. At the moment, strict application of the TCPS guidelines would mean either not enrolling aboriginals OR engaging the community at the level of the Assembly of First Nations, which is not practical and is not really what these guidelines were meant to do.

9.11 If the research involves TK, it requires REB review and community consent. TK needs separate consideration.

9.11 Unauthorized use of data is not defined.

9.11 En vue de l’application de l’article 9.11, il semblerait nécessaire, dans un premier temps, de mieux définir en quoi consiste une « représentation erronée » pour une communauté culturelle autochtone. Or cette tâche n’est pas exempte de difficultés et provoque un certain malaise parmi les membres du Sous-comité. Ainsi, l’entreprise scientifique apparaît indissociable d’une position qui peut amener à critiquer la validité de certaines représentations. Le projet scientifique n’est-il pas de remettre en question certains savoirs populaires? Si la « représentation erronée des connaissances autochtones » (lignes 4455-4461) est une éventualité qui devrait être évaluée par les CER, le Sous-comité croit que ce flou épistémique devrait être abordé et mieux circonscrit en fonction d’une protection raisonnable des participants autochtones.

9.11 We find that 9.11 confuses individual and community level data – we note that this article suggests that one can do a community profile of Vancouver but cannot do one of Tsawwassen, which is an aboriginal community and a neighbourhood within Vancouver’s city limits. For this reason we suggest deleting the entire second sentence in Article 9.11.

Furthermore, data is not defined in 9.11 and we find the inclusion of cultural property or representatives of indigenous knowledge of society as 'data' a misnomer. Epistemology has different definitions for data, information and knowledge. This might be a good place to start in clarifying this section's vagueness.

9.11 Secondary Use of Data
Line 3683: in this case the “should” is likely to be very problematic. Researchers deserve complete clarity on whether REB review is or is not required for secondary use of data identifiable as originating from Aboriginal participants or communities. The use of “should” leaves this directive open to interpretation by the researcher who may be more tempted to overlook REB review in the interests of expediency.

9.11 Lines 3686 to 3689: use of a research agreement would be highly relevant in such instances.

9.11 THEMES À RÉVISER/CLARIFIER À L’EPTC :
-- Données secondaires : Dans un concept de partage équitable des avantages de la recherche, l’utilisation des données secondaires doit également bénéficier aux nations et aux communautés.

9.11 Article 9.11 Secondary Use of Data
Unfortunately I have not been able to consider this in detail. However, it strikes me that secondary use of data is appropriately dealt with as a matter of increased control over indigenous knowledge by source communities and thus should be governed by principles concerned with appropriation, misrepresentation and protection of indigenous knowledge. These are areas which the [REB] seeks to explore in further detail as part of the research program.

9.11 Lignes 4432 à 4436, page 118, Utilisation secondaire des données, Article 9.11, Application. Il faut modifier le texte qui n’est pas acceptable dans sa forme actuelle. Dans le cas d’études longitudinales, il faut prévoir d’avance un consentement pour des études ultérieures.

9.11 3649-56 This section seems to be written with health research in mind not the social sciences or life-long research like ethnography. This section needs more work.

9.11 3645 The need for “culturally informed advice” is mentioned. Who provides it? How do the REB and the researchers know it is solid advice? What about the archives of a retiring social scientist collected before implementation of this policy? What if the information is in the public domain?

9.11 3665 The word “impractical” should be changed to ’impracticable’ as in “a degree of difficulty in doing something under present conditions, where the degree of difficulty is greater than would arise if something is merely inconvenient to do but may be less than if something is impossible. (See CIHR Best Practices for Protecting Privacy in Health Research page 40 for the source of this definition.)

9.11 3649-3656 : “Article 9.11 Consistent with the general provisions set out in Chapter 5 (“Privacy and Confidentiality), secondary use of data collected initially for other purposes, from which personal identifiers have been removed, does not require research ethics board (REB) review. Secondary use of data that is identifiable as originating from a specific community, or a segment of the Aboriginal community at large, requires REB review and may warrant seeking culturally informed advice about protection of cultural property or representations of Indigenous knowledge or society.”

Replace “cultural property” with “cultural heritage” for consistency and inclusiveness.

9.11 3669-3678: “Misrepresentation of Aboriginal peoples, unauthorized use of data, and lack of reporting to communities on research outcomes have created ongoing sensitivity about secondary use of data collected for approved purposes. For example, members of Nuu-chah-nulth communities in British Columbia provided blood samples for research on rheumatic disease. They vigorously protested use of the blood components for subsequent genetic research that pronounced on their ancient origins and challenged traditional knowledge about their identity. There are additional fears in First Nation communities that general consent to use health data for purposes other than treatment will facilitate unauthorized government surveillance.”

Another common example of unauthorized secondary use of data that is identifiable as originating from a specific community is the practice of accessing traditional plant knowledge from the published literature to inform commercial development of new products, called “literature-based bioprospecting.” As indicated in our earlier comments on Chapter 5, it is well-known in fields such as ethnobotany that there is a significant amount of traditional knowledge found in the early published record that was not published with the awareness or consent of the original knowledge holders.

This important example should be highlighted following line 3678, to raise awareness amongst the research community that appropriate redress can be found in
<table>
<thead>
<tr>
<th>Paragraph</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Article 9.11, i.e., by “seeking culturally informed advice” before use of such data, to determine if harms or offenses may result and if there benefit-sharing should be explored with the original source community/ies.</td>
<td>9.11 3679-3680: “In light of sensitivity about harms ensuing from identification of communities, potential misuse of cultural property or misrepresentation of Indigenous knowledge…”. Replace “cultural property” with “cultural heritage”</td>
</tr>
<tr>
<td>Article 9.9 stated, correctly, that in smaller and close-knit communities de-identification of data is not sufficient. If REBs cannot look at protocols involving secondary use of de-identified data in research, who will be monitoring whether or not deidentification is sufficient in each case?</td>
<td>9.11 3649-3656: Article 9.9 stated, correctly, that in smaller and close-knit communities de-identification of data is not sufficient. If REBs cannot look at protocols involving secondary use of de-identified data in research, who will be monitoring whether or not deidentification is sufficient in each case?</td>
</tr>
<tr>
<td>Benefits of research Capacity building could be increased in scope to include not only the capacity to increase research, but also nation building and community building.</td>
<td>9.12 Benefits of research Capacity building could be increased in scope to include not only the capacity to increase research, but also nation building and community building.</td>
</tr>
<tr>
<td>Article 9.12 deals with issue that are beyond the purview of research. Rather it has to do with Memoranda of understating between organizations, individual communities and persons not regarding research but ownership of data. Moreover, these issues are already addressed in 9.9 and are redundant here in the face of chapter 5.</td>
<td>9.12 Article 9.12 deals with issue that are beyond the purview of research. Rather it has to do with Memoranda of understating between organizations, individual communities and persons not regarding research but ownership of data. Moreover, these issues are already addressed in 9.9 and are redundant here in the face of chapter 5.</td>
</tr>
<tr>
<td>Benefits of research The statement in earlier policy was stronger and suggests that there must be some benefit to the community but that this benefit can take a variety of forms including those you articulate here. As part of the consent process there should be an obligation on the researcher to discuss benefits of the research to the community. This is a matter that should be negotiated as part of informed consent.</td>
<td>9.12 Benefits of Research The statement in earlier policy was stronger and suggests that there must be some benefit to the community but that this benefit can take a variety of forms including those you articulate here. As part of the consent process there should be an obligation on the researcher to discuss benefits of the research to the community. This is a matter that should be negotiated as part of informed consent.</td>
</tr>
<tr>
<td>The application section for Article 9.12 emphasizes community benefits of research; it would be useful to include discussion of benefits to the individual participant to create a balance. The inherent tension of OCAP principles and notions of personal privacy need further development here and elsewhere in this chapter. There is no guidance on a means of achieving both.</td>
<td>9.12 The application section for Article 9.12 emphasizes community benefits of research; it would be useful to include discussion of benefits to the individual participant to create a balance. The inherent tension of OCAP principles and notions of personal privacy need further development here and elsewhere in this chapter. There is no guidance on a means of achieving both.</td>
</tr>
<tr>
<td>The beginning of this application seems vague.</td>
<td>9.12 3703-07 The beginning of this application seems vague.</td>
</tr>
<tr>
<td>One observation from reviewing applications is about access to data in communities. Researchers are now stating that they will leave a copy of data collected with the aboriginal community. We wonder how does that impact when the person signs the consent, anonymity and confidentiality, and how will the data be used in the future? It’s not dealt with here in this chapter. It only says here that “communities should have data important to their own planning with protections to privacy and confidentiality of personal data as noted in this chapter.” The question is, is this realistically possible in smaller communities? The reality from research experience with Aboriginal communities is that if it’s a small community, person A says something and there’s a good chance person B will know who that is. This needs to be articulated in the chapter. This assumes to be part of the agreement when the researcher gets approval from the community.</td>
<td>9.12 One observation from reviewing applications is about access to data in communities. Researchers are now stating that they will leave a copy of data collected with the aboriginal community. We wonder how does that impact when the person signs the consent, anonymity and confidentiality, and how will the data be used in the future? It’s not dealt with here in this chapter. It only says here that “communities should have data important to their own planning with protections to privacy and confidentiality of personal data as noted in this chapter.” The question is, is this realistically possible in smaller communities? The reality from research experience with Aboriginal communities is that if it’s a small community, person A says something and there’s a good chance person B will know who that is. This needs to be articulated in the chapter. This assumes to be part of the agreement when the researcher gets approval from the community. When we look at the OCAP policy and agreements between individual researcher and band councils, there is a lack of connection between this and the ethics approval.</td>
</tr>
</tbody>
</table>
| 9.12 | 3695-3698: There is overuse of the word “context” in this paragraph: “Autonomous research would enhance the exploration, articulation and application of Indigenous knowledge in its own context, with translation to other contexts following a parallel process. Articles 9.12 and 9.13 specify benefits that may accrue in the context of partnerships between Aboriginal communities and external researchers.”

SUGGESTED REVISION: Autonomous research would enhance the exploration, articulation and application of Indigenous knowledge IN SITU, with translation to other contexts following a parallel process. Articles 9.12 and 9.13 specify benefits that may accrue THROUGH partnerships between Aboriginal communities and external researchers.” |

| 9.12 | 3700-3702: ADD TEXT: “Article 9.12 Communities should have access to data important to their own planning and development processes, with protections for privacy and confidentiality of personal data AND OWNERSHIP PROVISIONS as noted in this chapter.” |

| 9.12 | X. Expand the conception of benefits of research Communities must have access to informed expertise in interpreting results for planning and development purposes, and not just access to data as proposed in article 9.12. Access to data alone is insufficient when the community may lack the scientific expertise to understand it. Researchers are obligated to present research results to the community in lay language and help community leadership to act on such results. For example, when research indicates a high prevalence of diabetes, researchers must be prepared to work with the community in developing an action plan for disease reduction or, at the very least, provide suggestions for the next steps. We propose modifying article 9.12 to include the requirement to provide researcher expertise to the community in understanding results and assistance in taking action upon them. |

| 9.12 | 9.6 Unlike the CIHR Guidelines for Health Research Involving Aboriginal Peoples, there is no emphasis on research design appropriateness (i.e. community-based research) nor is there an emphasis on knowledge translation. The absence of such requirements raises questions about how beneficial research informed by these guidelines will be for Aboriginal communities. |

| 9.13 | A related concern with respect to Clinical Trial Budgets in Article 11.9 of the Draft TCPS, is the disclosure to REBs of the kinds and amounts of payments and other budgetary details. Such disclosure to the REB should be clearly mandatory in order to control for potential conflicts of interest, and any inducements paid to the researchers or institutions for the recruitment of subjects should be disclosed to the research participants or subjects as well. Unequal distribution of benefits and rewards versus risks is an ongoing concern for Aboriginal Communities and research participants when they contemplate partnering or participating in research; these concerns should be comprehensively addressed in the Draft TCPS through these and similar transparency requirements. |

L. 3716 – There is a need to define and clarify who “community Elders” are – these people are community-recognized not self-identified.

9.13 We agree with sharing benefits but disagree with sharing costs. This asks too much in many cases. For example: Some communities are well-off - the Community Well-being index (CWB) shows that 2 of Canada top 100 communities are Aboriginal; however, the opposite is more often the case - the CBW shows that of the bottom 100 Canadian communities, 88 are aboriginal. Asking such communities to share costs may not be too helpful and may result in many communities refusing to engage in research. This is a thorny issue, too: when people invest in something they are more likely to be interested in the results but if they can't afford to invest for any reason, then nothing gets done. We recognizes that this attempts to address or encourage equity but we think more flexibility ought to be allowed to the REBs to use their judgment in such cases, which the evidence shows will be the majority of them.

Moreover, it is not clear what kinds of benefits are being considered here. And one MUST consider that these issues are covered off under the United Nations’ protocol regarding intellectual property (to which Canada is signatory), managed by the World Intellectual Property Organization (WIPO). Does this article propose working in concert with WIPO treaties and provision or does it propose reinventing the wheel?

As regard the phrase “collaborating with ethics reviews” goes: this is vague. Collaboration could be as simple as a footnote in a report or mere acknowledgements of help following a brief telephone conversation. In light of these considerations, ‘collaboration’ becomes meaningless.

9.13 Article 9.13: sharing costs and benefits of research equitably needs to be further discussed, especially the sharing of costs. Training programs to enhance autonomous research initiatives (lines 3724-3725) could be encouraged. Lines 3728 to 3733 are unclear. Encouragement to create Aboriginal REBs could be made in lines 3734 to 3737.

4529 à 4533 : Nous ne voyons pas dans ce paragraphe une suite logique entre le contenu de la première phrase et celui de la deuxième.

-- Cadeau spirituel : Ce passage devrait être approfondi afin de mieux cerner les enjeux reliés à cette démonstration.

9.13 3708-11 Sharing the cost of local Aboriginal Ethics Review: Clarification is need regarding the suggestions that the costs local Aboriginal ethics review be shared

9.13 3724-3737 Some parts of Article 9.13 and the application section while interesting, do not directly relate to the protection of study participants and could be deleted.
by the researchers, institutions and Aboriginal communities. This has serious funding implications especially for social science research that is often unfunded or receives smaller funding amounts. Further clarification is needed to determine if this suggestion means that the researcher’s home institution is responsible for paying for the cost of local ethics review?

9.13 As a minor matter, regarding Article 9.13, p. 106, why do aboriginal communities have to share in the costs of research? No other community of research participants is required to pay part of the cost of the research. What is the Panel getting at here?

9.13 3708-3711 : “Article 9.13 Researchers should endeavour, where appropriate and possible, to share costs and benefits of research equitably…”

Delete “where appropriate and possible” as this is assumed by use of the term “should endeavour.”

We note that this endeavour should be a joint effort shared in a coordinated way by the researcher, the researcher’s institution and the research funder, since personnel and administrative costs of ethics review coordination and project oversight are not typical budget line items in many small grants. This endeavour should be a concerted effort by all involved.

9.13 3722-3725: SUGGESTED REVISION: “Employing Aboriginal research assistants and translators is already common practice in community-based projects THAT SHOULD CONTINUE. Implementing a rational program of training to enhance autonomous research initiatives is less common. WHENEVER POSSIBLE, TRAINING SHOULD BE PROVIDED TO PROMOTE CAPACITY-BUILDING TO ENABLE AUTONOMOUS RESEARCH INITIATIVES.

9.13 3734-3737: ADD TEXT: “Direct funding BY THE GRANTING COUNCILS to community entities conducting research is anticipated in some current programs, although the requirement for ethics review is still met through researcher affiliation with institutions adhering to this Policy, collaborating with the community organizations.”

There are many sources of funding for community-based research outside of the three academic granting councils and outside of the academic system so a slight clarification seems helpful and less presumptive.

9.13 The following are my observations specifically in regards to Chapter 9 dealing with Aboriginal Peoples. I see that no provisions have been made to deliver the research outcomes in the languages of the Aboriginal peoples. Seeing that many Aboriginal languages are disappearing the new knowledge (implied by research) needs to be delivered in the very language of the Aboriginal users. The text addresses minimally the Aboriginal languages and assumes that we continue to deliver the results of research in the non-Aboriginal languages (English/French in this case).

9.14 Consent should be documented. We think that the questions surrounding documentation of consent are handled well. The flexibility of “documented consent,” which allows for oral and written forms is welcome (1237-1238). The TCPS states that “when in doubt about an issue involving free and informed consent, researchers should consult their REB.” (1281-1282), and that the REB “plays an essential educational and consultative role in the process of seeking free and informed consent” (1265-1267). We think that this precipitates a strong argument for the inclusion of an Aboriginal designate on all REBs and that when there is a question of group norms around obtaining consent, a representative from that group should sit on the REB.

9.14 It is problematic that REBs are permitted to render judgment on a proposal without any kind of contact or relation with the affected Aboriginal community (ies) –
especially since this is a precursor to cultural competence. In essence, the entity that is most removed from a particular community reality is afforded the greatest level of research control and authority.

9.14 It might help to provide some direction on how to identify Aboriginal participation and what constitutes ‘relevant’.

9.14  **THEMES À RÉVISER/CLARIFIER À L’EPTC :**
-- Expertise autochtone : Inviter des conseillers experts en matière autochtone à siéger sur des CER. Ne pas se limiter à la consultation de documents de référence lorsqu’il n’y a pas de précédent en la matière.

9.14  **3756-3760: ADD TEXT:** “Article 9.14 Research ethics boards (REBs) reviewing research involving Aboriginal participants and communities on a recurring basis should ensure that they have access to relevant expertise within regular REB membership, through ad hoc consultation with knowledgeable academic and ABORIGINAL community advisors, or through collaboration with ABORIGINAL community ethics review bodies.”

9.14  **3756 This is a welcomed and reasonable recommendation and there should be bi-directional cross-references between this chapter and Chapter 6 on the Governance of REBs.**

9.14  **Section A**

9.14  **Line 3244 requires that REB members consider the context in which the proposed research will be conducted. While it is laudable to direct scholars to a growing body of good Aboriginal scholarship, this does not assure research cultural competence. It has been my experience that many well-versed researchers experience considerable difficulty working respectfully with Aboriginal people – even when they conform with REB guidelines. In fact, their knowledge of Aboriginal research sometimes goes to their head and they assume there are culturally competent. Te guidelines need to provide clearer direction on how a research can/should go about acquiring research cultural competence.

9.15  **Line 3783-3784. The suggestion that conflicts of interest cannot be avoided in small communities (where ethics review and project management may not be separable) should be amended to clarify that communities, researchers, and REBs have responsibilities to find solutions to these circumstances.**

9.15  **" I found the process [doing my research project] very positive; the only daunting part was going over the ethics requirements with community members. At this point in the interview process, the imbalance in power was unavoidable. The language for my ethics requirements was based on suggestions by the ethics board itself, but while it was straightforward it was definitely more formal than the rest of my interview. I would tell community members, “No deception is used in my research and the risk involved in the interview will be no greater than that found in everyday life,” and often at this time worried looks would cross people’s faces. Sometimes, with older community members, you wanted to advise them that perhaps they should have a family member present before they signed it. I was very conscious of my authority/power and felt uncomfortable with it, especially going over the ethic requirements with the elders. Elders’ sharing their knowledge is traditional, offering tobacco prior to asking questions is traditional, but talking about deception and risk is not and, at that moment, I did feel like the colonizer, the outsider.”**

9.15  **Finally, I think it is important, as the document suggests, that REBs find "common ground" with aboriginal governance structures that may have different or unconventional expectations of the research process.**

9.15  **How does 9.15 differ from 9.1?**
Upon reviewing this clause one wonders if it is not a ‘weasel clause’ that will be interpreted as “the REB’s get final word, regardless of the community’s wishes”? If that is the case, it risks failure because if a community decides research will not take place, the current researchers will be asked to leave and future research teams may never be allowed in the community.

9.15 Article 9.15: recommending the creation of Aboriginal REBs would, again, be appropriate.

9.15 This is a noble ideal for which the drafters might provide further guidance for researchers, communities and REBs.

9.15 3780 A possible conflict of interest could occur at the community level if a person responsible for ethics review at the local level is also a person who might be co-managing the study. A bi-directional cross-reference between this chapter and chapter 7 could be inserted here.

9.15 3786 The observation that research that does not have human participants is outside the scope of REB review should either be at the beginning of the chapter or deleted.

9.15 3780-1781: ADD TEXT: “The membership of ABORIGINAL community review bodies will not necessarily duplicate the membership criteria set out in this Policy.”

9.15 3787-3789: “For example, research on the interface between environmental and human systems that does not involve individual participants does not require REB review.”

As noted earlier in our Chapter 2 comments regarding (p.9, line 312-314), it is not clear what is being referred to here. An example should be provided to clarify this text.

Section A. • Line 3160 – 3162: This opening sentence is confusing to me. It talks about how the equal moral status is easily compromised by power imbalances. And then goes onto state that resulting harms are seldom intentional.

• It’s as if in one brief statement, the researchers who wrote these two lines are trying to absolve the entire history of research by saying that “resulting harms were essentially or have been seldom intentional”. It’s like listening to a child give a very insincere apology for doing something that he or she knew was wrong, knew they shouldn’t have done in the first place but yet went ahead and did anyway. This is a major issue with Aboriginal people. The idea that white complacency of their past actions can be justified as simply ignorance is often at the heart of much Aboriginal anger.

• These two sentences are essentially saying that researchers now understand the power imbalances that have occurred between research and subject but that because we didn’t understand that our actions were harmful, the wrongs of past research are somehow justified or forgiven because “resulting harms are seldom intentional”. • This paragraph then goes onto list the “abuses” that have occurred. How can any of these “abuses” ever been anything but intentional?

Section A. L. 3140-3147 – this process aligns with that of participatory action research (PAR) – the methodology, or at least its principles, should be referenced as guiding models to future researchers

Section A. A related issue concerns the status of these documents as “Guidelines.” If they are Guidelines and not mandatory Standards, what are the implications for REBs and researchers not complying with them, and what of the concern for protection of vulnerable research subjects, including vulnerable Aboriginal research
subjects if researchers choose not to follow the non-mandatory “Guidelines”? Should the public, as well as research subjects, be clearly informed that these documents are merely guidelines and may not necessarily be complied with? Should the public in general, as well as community research partners and research subjects in particular, be informed that even if there is compliance with the Guidelines, REB Review may be waived in some circumstances considered minimal risk, and even if REB review is not waived, fully informed consent of research subjects and communities may be waived if deemed for the greater good? Such situations would be of considerable concern to Aboriginal People.

**Section A.** Page 91, 3134-3136: “in Canadian society”. Suggested rewording – ‘in Canada versus other countries and indigenous peoples.’

**Section A.** Line 3120 Grammar
In this chapter, we interpret …

**Section A.** Lines 3154-6 Question
Should “Elders” be recognized here too?

**Section A.** notes that there is a tendency among some ethno-cultural groups to understand well-being (as referenced in Chapter 9) as applying to the community, as opposed to the individual. There was some concern among our members that REBs lack guidance in how this difference in values is to be taken into account; REBs may understand it more as a rhetorical statement rather than concrete guidance, whereas communities may not share the same understanding.

**Section A.** believes that more thought is required in Chapter 9, with regards to requiring permission to use data that is part of a larger study that involves conflicts between the researchers and the communities over scientific findings. In situations where there could be tension between the scientific research results and the assessment and reaction of the cultural community, the REB may experience difficulty in taking these conflicting viewpoints into account.

**Section A.** We have had some discussion on the use of “Aboriginal” and “Indigenous”. We prefer the latter because it is more inclusive, particularly where faculty and students are undertaking research with Indigenous peoples outside of Canada. Indigenous students from other parts of the world, for whom this ethics code will apply. In this regard, it would be appropriate to cross-reference Chapter 9 in Chapter 8 (lines 2990-2995) so that researchers undertaking Indigenous research outside of Canada are aware of the ethical expectations with respect to Indigenous research.

**Section A.** 3124-3128 I am pleased to see the broadened scope of concern for welfare throughout the revised Policy which includes individuals “in their physical, social, economic and cultural environments.”

**Section A.** A. Interpreting the ethics framework in Aboriginal contexts Notes of respect, reciprocity, and relationships suggest the need for ongoing negotiation and consent.

**Section A.** Page 91, 3123: “…involving Canadian Aboriginal peoples…”

**Section A.** In Chapter 2 of the Draft TCPS under consideration, I am concerned about those situations where no REB review will be required. This is a particular concern in Aboriginal Research (Chapter 9 of the Draft TCPS), as Aboriginal people value their Traditional Knowledge, their Intellectual, Cultural and Heritage Property, Human Bodily Tissues and Genetics, Biodiversity (including all livings things) and the Biotic and Non-Biotic Environment, all of which are protected under Constitutional Law and International Declarations and Agreements. Situations which would require no REB review in Non-Aboriginal Research should,
nevertheless, require REB Review in Aboriginal Research, as research involving matters outlined above would conceivably touch on content in the protected sphere for Aboriginal People and thus should not qualify as minimal risk in the Aboriginal context. Such changes and distinctions should be made explicit in the revision of the TCPS in both general (Chapter 2) and Aboriginal sections (Chapter 9) of the TCPS.

Section A. The role of language in involving Aboriginal peoples in research.

We offer the following comments about the presentation of issues in Chapter 9:

The TCPS avoids using the word “spirituality,” although the concept of spirituality is integral to the worldview of Indigenous people and Indigenous-led research. To illustrate: the TCPS states that “concern for welfare includes individual well-being, but broadens the focus of ethics to consider individuals imbedded in relationships in their social, economic and cultural environments” (3126-3128). The spiritual environment in which Indigenous people situate themselves is not mentioned. Even when the roles of Elders in the research process are mentioned (3716-3719), one of their primary roles (spiritual leaders/guidance) is conspicuously absent.

Section A. A concern arises when comparing provisions pertaining to Clinical Trials in Chapter 7 of the Current TCPS with the provisions in Chapter 11 of the Draft TCPS. The role of clinical equipoise has been lessened in the Draft TCPS, with a larger role for placebo-controlled studies. Clinical equipoise requires that a new therapy or intervention be tested against an established effective therapy, whereas placebo-controlled studies would withhold such treatment from the control group. This increased trend towards placebo controls rather than clinical equipoise opens the door to interpret “established effective therapy” narrowly and therefore to withhold treatment that may have some merit from research subjects randomly assigned to control groups. In many cases, this can do harm to vulnerable research subjects, for instance, in the addiction or substance abuse context, where established therapy that may have some efficacy is withheld to those randomly assigned to control groups. Some of the individuals in the control group may suffer further harm from the addiction, even harm to an embryo or fetus as some participants could be in the early stages of pregnancy at the time. Such potential resultant harm could have a chance of being ameliorated if clinical equipoise were the standard. The explanatory comments for Article 11.10 in the Draft TCPS go even further stating “if there are no established effective therapies for the population” leaving the door open to exclude established therapies that have some efficacy but which have not been specifically tested on the Aboriginal peoples of Canada. Such a state of affairs should raise a red flag for all concerned about protecting research subjects from over-zealous withholding of treatment through the vehicle of enhanced use of placebo studies. Aboriginal participants in control groups could be particularly vulnerable, as explained.

Section A. Individual vs. Community Rights

We found the articles in chapter 9 to confuse individual rights from community rights or individual vs. collective rights. Canadian society focuses on individual rights and, as such, we are left wondering how community rights are defined and what do they mean in this social context. This is an important issue as it is often at the root of many different conflicts between Aboriginal peoples and non-Aboriginals and their institutions. For instance, what would happen in the case where a member of an aboriginal community uses one of its traditional images to sell products? Would this violate communal rights to the image? We are suggesting that this confusion between collective and individual rights are symptomatic of a conflict between different world views – the European individualist one and the
indigenous collectivist one.

| Section A. | 3756 à 3758 : Les communautés s’attendent à ce que les recherches proposées soient orientées par leur besoin de renforcer leur capacité à protéger leur culture, leur langue et leur identité. **juge trop restrictive cette conception de la recherche auprès des communautés autochtones. Cette conception pourrait aller à l’encontre du modèle scientifique contemporain et même, à la limite, nuire au développement des communautés et à leur intégration dans la société canadienne. En effet, certaines recherches commandées par la discipline, dont les résultats risqueraient de remettre en question le bien-fondé de certaines pratiques traditionnelles (en santé, par exemple) au sein de ces communautés, ne pourraient tout simplement pas être réalisées.** |
| Section A. | 3760 : La notion de bien-être individuel est plus facile à saisir que celle du bien-être de la collectivité. Comment l’atteinte du bien-être collectif au sein d’une communauté se définit-elle par rapport à celle du bien-être des individus? |
| Section A. | 3769 : Il faudrait définir ce que l’on entend par : «établissement d’objectifs mutuellement avantageux». |
| Section A. | 3778 à 3787 : Il faudrait reformuler ces lignes et revoir l’emploi des concepts d’approbation, d’autorisation, d’acceptation et de participation dans celles-ci. **L’autorisation de la communauté ou du groupe ne peut se substituer au consentement individuel de ses membres. Cependant, il apparaît évident aux yeux des membres que le chercheur doit obtenir prêalablement l’autorisation de la communauté avant de s’adresser individuellement à ses membres. L’autorisation de la communauté suppose qu’elle a approuvé le projet. C’est donc à cette condition première que la communauté accepte de participer.** |
| Section A. | THEMES À RÉVISER/CLARIFIER À L’EPTC : -- Holisme : Le mieux-être individuel chez les Premières Nations inclut la santé spirituelle et émotionnelle au même titre que la santé physique et mentale. |
| Section A. | Early in the chapter a statement should be included that explains to researchers, funding agencies, institutions and REBs that operationalizing this chapter will take additional time because researchers and REBs will need to familiarize themselves with local ethics codes, establish working relationships with communities and possibly negotiate a hybridized ethics review procedure for each project given that it is (3790) “inappropriate to insist on uniformity between community and institutional policies”. |
| Section A. | The preamble of the chapter should also acquaint academic institutions and funding agencies with the fact that the recommendations of Chapter 9 will slow down research productivity when evaluating a researcher’s scholarly progress, the time graduate students need to complete degrees, and evaluations for scholarships and grants. In addition, institutions may be called upon to subsidize the creation and continued operation of research ethics committees or boards in Aboriginal communities where the institution’s researchers conduct research. |
Section A. 3123 A clearer definition of the term Aboriginal for the purposes of this Policy would be useful. What constitutes an Aboriginal person? Does part aboriginality for Métis persons override non-aboriginal heritage? Is self-identification as Aboriginal person acceptable?

Section A. 3126 Key concepts such as Welfare and collective welfare (3137 and 3146) should be cross referenced to Chapter 1 line 57. Interpretation of welfare and balance between individual well-being and collective welfare may differ significantly between Aboriginal communities and in boarder society.

Section A. 3142 A better definition of “engagement” is needed. (Definition at 3354 might be moved here).

Section A. There is no definition of aboriginal peoples in this document. It appears to mean First Nations people in Canada. If that is the definition, it should be clear. All sorts of people in all sorts of situations (e.g. white and black South Africans, Jewish Israelis and Palestinians, a large number of African ethnic groups) define themselves as aboriginal.

This section is by far the most problematic of the draft document. It is suffused with assumptions about the nature of aboriginal society and aboriginal knowledge that may very well not be accurate. It is, moreover, the only section of the document that seems to directly deny researchers the right to academic freedom: article 9.5 (p. 99), for example, states that First Nations people have a right to control all aspects of research that affects them, directly undermining academic freedom.

Section A. This document is a source of reference for neophyte researchers (undergrads and graduate students) and yet there is no historical background to reflect the existing level of distrust in the communities and imbalance of power (e.g. colonial legacy and why research involving Aboriginal peoples is conducted differently than with non-Aboriginal peoples to warrant a separate chapter).

Section A. 3126: “Concern for welfare includes individual well-being, but broadens the focus of ethics to consider individuals imbedded in relationships in their physical, social, economic and cultural environments.”

As we noted earlier, this important statement applies more widely to all communities, not just Aboriginal communities and should be made explicit in Chapter 1 (lines 56-64).

Section A. 3130: “This Policy acknowledges the important role of Aboriginal communities, particularly those that exercise local or regional governing authority, in promoting collective interests that also serve individual well-being.”

Revise to “collective interests, rights and responsibilities” to underscore that Aboriginal worldviews incorporate a sense of reciprocal rights and responsibilities as part of well-being. Use of the word “interests” alone does not adequately reflect this important point.

Section A. 3140-3147: “Where the social, cultural or linguistic distance between the community and researchers from outside the community is significant, the potential for misunderstanding is likewise significant. Engagement between the community involved and researchers, initiated prior to the actual research activities and maintained over the course of the research, can enhance ethical practice and the quality of research by promoting mutual trust and communication, establishing mutually beneficial research goals, and ensuring that the conduct of research is respectful of the well-being of individuals and the welfare of the collective, as understood by all parties involved.”
This well-written paragraph very clearly articulates key elements of research involving any community (i.e., not just Aboriginal communities) and should be given greater profile and emphasis in Chapter 1 of the Draft.

Section A. In sum, if the principles of academic freedom are to apply to all other research except research about aboriginal communities, then this should be clearly stated so that researchers on aboriginal matters know they are operating under a different set of rules than they are used to. Moreover, if individual aboriginals are to be denied the autonomy that all other competent Canadian and other adults are assumed to enjoy, that should also be clearly stated.

Section A. 3149-51: ADD TEXT: “First Nations, Inuit and Métis concerns for their continuity as peoples with distinctive origins, identities and rights IN MANY CASES have led to the development of ethical protocols to guide community–researcher relations.”

Section A. 3152-3155: ADD TEXT: “Community engagement in these situations, particularly when First Nations, Inuit or Métis communities with local governments are involved, may take the form of REVIEW AND formal approval of a research undertaking.”

Section A. 3156-3159: “A key consideration for researchers, research ethics boards (REBs) and participants is determining when voluntary, informed consent of individuals is sufficient and when the welfare of the relevant group is implicated, making community engagement a priority.”

It should be made clear that there are circumstances where permission and collective consent are involved, which may become clear through community engagement, but the point here is that community-engagement may not be sufficient in itself (noting, however, that it is not clear what is meant by community-engagement since it is not defined in the Draft).

Section A. 3161-3162: ADD TEXT: “Resulting harms are REAL BUT seldom intentional.

Section A. 3162-3166: ADD TEXT: “In the case of Aboriginal peoples, abuses have historically included appropriation of cultural KNOWLEDGE AND property such as songs, stories and artifacts, devaluing of Indigenous knowledge as primitive or superstitious, violation of community norms regarding the use of human tissue and remains, and dissemination of information that stigmatized whole communities.”

The use of “cultural property” on its own is problematic since if left undefined it evokes the western legal notion that does not necessarily fully encompass the intentions and subject matter of Chapter 9. For specific advice on this terminology we defer to the written comments of law professor [redacted] and the written comments of the [redacted] submitted by archaeology professor [redacted] that have been contributed as part of this TCPS consultation.

Section A. 3166-3168: ADD TEXT: “Affirmation of Aboriginal rights and respect for community ethics codes and protocols, AND DECISION-MAKING PROCESSES are means to better ensure balance in the relationship between researchers and participants and mutual benefit in researcher–community relations.”

Section A. • Respect for Aboriginal world views, as in CIHR Guidelines Article 1: “Researchers should show respect for Aboriginal world views”

While Introductory text and parts of the Application in the Draft touch upon differences between Aboriginal and non-Aboriginal views, these do not carry the force of an Article, which is directive in nature.
Section A.

5. Diversity of Aboriginal Populations

The Policy Statement clearly and usefully recognizes the heterogeneity of Aboriginal peoples in terms of geography, socio-economic status and political organization: Chapter 9 B: Aboriginal peoples in Canada encompass great diversity. First Nations, Inuit and Métis representatives declare that the term “Aboriginal” glosses over the distinctions among them, as peoples with their own histories, cultures and languages. Communities may be large and urbanized or small and isolated. They may be relatively close to a traditional, land-based way of life or integrated in a market economy. Governance may be exercised by a First Nation band council, an Inuit hamlet council, a Métis settlement council or a regional authority. First Nation, Inuit and Métis people who reside off a reserve, land claim territory or settlement now make up the majority of the Aboriginal population of Canada. They do not ordinarily have a governance or administrative structure to represent their interests. Communities are also becoming more diverse internally, as a result of formal education, employment, mobility and intermarriage with non-Aboriginal persons. However, many of the examples and suggested procedures for engaging with Aboriginal peoples implicitly assume a "community" in a stereotypical, geographic or political sense exists. Similarly, it should not be taken for granted that participatory research is the ideal mode of research and that other research models are inadequate for Aboriginal communities and therefore lacking ethical standards.

Section A.

3861-3950: Many of the principles and practices outlined here apply much more broadly than just to qualitative research.
Protection and Repatriation project. At the time the methodology was developed for the Protection and Repatriation Project many First Nation communities and research bodies had yet to develop, or were in the process of developing, written Aboriginal specific research ethics policies and community and professional research protocols. However the SSHRC Task Force on Native Peoples had recommended some general principles, there were some helpful academic commentaries on decolonizing research methods, and international, domestic, professional and some community guidelines were being developed and refined.1

Although we knew research would engage information gathered from human participants, we did not enter into the Protection and Repatriation project with a set methodology prior to consultation with appropriate community authorities. Rather an approach was guided largely by core values inherent in participatory action research and academic works critical of past research methods. The core values adopted were collaboration through meaningful participation, respect (for individuals, community, and difference), equality (including different ways of knowing), empowerment of participants and inclusiveness with a view to social change concerning protection and control over First Nation cultural heritage. These values were reflected in the following principles which were influenced by, but also extended beyond, the general guidelines of the SSHRC Task Force on Native Peoples in place at the time. They were:

(1) active and meaningful community participation in all stages of the research program including development of broad research questions and design and case study development, reporting, publication, research and activity;
(2) dual validation of work by the academic team intended for publication drawing on community information through input by appropriate community authorities and participants by means acceptable to those affected, including authors, researchers and publishers;
(3) production of tangible benefits for First Nation partners (e.g. training, employment, use of research data and products, communicating issues to a broader public);
(5) compliance with First Nation laws and protocols; and
(6) regular communication throughout. As elaborated below, understandings and applications of these values and principles were discussed, elaborated, and negotiated on a community specific basis at preliminary meetings conducted with First Nation participants and appropriate community authorities.

Section B. L. 3186-3187 – in the past, research has been “carried out by non-Aboriginal personnel” and this has resulted in some serious misunderstandings and wrongdoings – if this is the case, shouldn’t the future directive of “by and with” or “by, with and for” (as per Rock & McNaughton, 2003; Baydala, Placsko, Hampton, 1 As a consequence we included in the published outcomes discussions of First Nation Research Protocols and a chapter on role of ethical codes and community protocols as instruments for protecting cultural heritage. See e.g. the index to Bell and Napoleon, supra note 3 and Kelly Bannister, “Non-Legal Instruments for the Protection of Intangible Cultural Heritage: Key Roles for Ethical Codes and Community Protocols” in Bell and Paterson, supra note 3 at 278.
Bourassa, McKay-McNabb, 2006) be articulated as the future vision of Aboriginal research?

<table>
<thead>
<tr>
<th>Section B.</th>
<th>L. 3195-3198 – Aboriginal people are proposed as “partners in research” – can the wording be changed to reflect the idea that researchers should strive to achieve an ideal of “partners in research”</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>L. 3223-3224 – there are those Aboriginal people that “do not ordinarily have a governance or administrative structure to represent their interests” – high risk groups or vulnerable populations must be seen as deserving of special attention and support in the case of research; they must not be left out because of their lack of capacity. This is especially the case with the Métis population.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>L. 3230 – “researchers should seek” – change to must seek or are strongly advised to seek</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>Page 93, 3194: “They may propose participation as partners…” Not all communities will be interested in forming research partnerships. Some may allow the researcher to proceed without their direct supervision.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>Line 3191 Question Should we here also be expected to reflect on the past, about communities that have been researched without deriving any real/tangible benefit from the research/discovery?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>Line 3189. “racist interpretations” is needlessly inflammatory.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>The following statement is problematic: “Research has a critical role to play in creating the knowledge base for mutually respectful relationships and full participation in Canadian life, with all its responsibilities and benefits” (3173-3175). If “collaborative research” was specified this would be acceptable. The current version implies that research as an academic or institutional endeavour creates knowledge. We would maintain that research done about – and not with - Aboriginal communities (and other communities, for that matter) tends to articulate existing perceptions rather than create new understandings. This sentence should be changed to reflect the co-creation of knowledge, which can have the power to bring into the consciousness a knowledge system and tradition that has existed for hundreds or thousands of years.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>From the perspective of Indigenous experience the following statement insufficiently acknowledges historical context: “This affirmation marks a break with Canada’s colonial past, in which the goal of public policy was to absorb Aboriginal peoples into Euro-Canadian society and erase their distinctive identities” (3180-3182). The goal of past public policy, via the Indian Act and residential schools, was primarily to wrench identity from Aboriginal peoples, or to “kill the Indian in the child.” The absorption of Aboriginal peoples into the Canadian body politic does not come close to conveying the colonial intentions of past governments.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Section B.</th>
<th>The statement that “in the past, research concerning Aboriginal peoples has usually been initiated outside the Aboriginal community and carried out by non-Aboriginal personnel” (3186-3187) does not recognize that this practice continues in the present, and remains a distinctive problem. We suggest instead stating, “Research concerning Aboriginal peoples is too often initiated outside the Aboriginal community and carried out by non-Aboriginal personnel.”</th>
</tr>
</thead>
</table>
Section B. It seems disingenuous to mention the United Nations Declaration on the Rights of Indigenous Peoples (3201-3202), given that Canada is one of only four countries that have refused to adopt it.

Section B. 3176-3182. The idea of nationhood could be expressed here.

Section B. 3205-3215. The paragraph seems to be frozen in time. It is important that there be a recognition that Aboriginal knowledge, like, any knowledge, changes, and a contemporary context for Aboriginal knowledge could be included. In general, it was felt that this is the place where appropriation of knowledge is the most likely to occur. Somewhere in this section it would be helpful to discuss what “traditional knowledge” means.

Section B. 3201. At the moment, Canada is not a signatory to the UN Declaration on the Rights of Indigenous Peoples.

Section B. 3209-3210. The phrase “the right way of living” is not clear; it is perhaps a translation from something that works in an Aboriginal language but does not work so well in English.

Section B. 3211-3215. Should the Convention of Biological Diversity be mentioned? TK is required in some of Canada’s environmental legislation.

Section B. 3224-3226. The last sentence is not needed. This point is made in other places in the document, and need not be included.

Section B. 3227-3231. This paragraph is not clear.

Section B. Overall, I really liked this chapter. I welcomed the notion that aboriginal participants ought to be “partners in all phases of research” (p. 93, ln 3195) and appreciated the suggestion that researchers need to “adapt their conventional practices and broker agreements” (p. 94, ln 3242). The emphasis on community engagement “as a basic expectation” of research with aboriginal groups/communities (p. 98, ln 3394) introduces the respect and sensitivity researchers need to bring to such an arrangement.

Section B. • Line 3174: there’s that “full participation in Canadian life” again. With the added “with all its responsibilities and benefits.” Kind of implies or denotes that there are no responsibilities to being an Aboriginal “citizen” of an Aboriginal community. While I understand that this document is aimed at the researcher, it also, to me, seems to imply the usage of research by Aboriginal people as a means to better their participation in Canadian society. Again, what does full participation mean?

Section B. • 3176 -3182: OK – what’s the point of this paragraph? A nice little history lesson?
• This paragraph should read something like this: “While Aboriginal rights should have always been recognized as inherent, it was not until 1982, through the Constitution Act, that Canada recognized and affirmed these rights….This affirmation…” OR, “The Aboriginal and treaty rights…were finally recognized…” In essence, it is the language in the paragraph that bothers me. And really…what is the point of this paragraph?

Section B. There is very little discussion on commercialization issues which are highly problematic for Aboriginal communities.

Section B. Research involving Aboriginal peoples

While it is very positive that this critically important topic has been included in the proposal, we have some concerns that we would like to bring to your attention. After consulting with some of our members who are specialists in the area, we think that more thought should be given to particular issues regarding social science
research in Aboriginal communities. Many of the examples in Chapter 9 are drawn from medicine or the natural sciences. Some of the challenging issues in social science research are not mentioned and, therefore, will fall to the adjudication of the REBs.

- While we recognize the past history of unethical research practices in Aboriginal communities, we think it is important to respect the capacity of First Nations to make their own views known regarding research in their communities and that, especially for non-Aboriginal researchers, it is the researcher’s responsibility to seek information and knowledge from Aboriginal communities.
- It is also important to recognize that Aboriginal communities are not homogenous. The is concerned that local ethics boards will be left to adjudicate claims from researchers who may be concerned about having to seek the consent of the community’s formal leaders or about sharing their research with those leaders. There should be more reflection about how the community is defined in this document and about how to handle community consent when there are disagreements within Aboriginal communities.
- Moreover, the wonders how land claims mandates, such as those referenced in the document (i.e. the Nunavik and Nunatasiavut agreements), would affect political science research. It is our understanding that those agreements entail research approvals for environmental and wildlife management. We feel that the remit of these agreements should be clearly specified in the guidelines.
- Most importantly, the feels that it is of the utmost importance that Aboriginal scholars and non-Aboriginal scholars who work on Aboriginal issues should be consulted directly regarding the development of ethics guidelines and regarding the role of the local research ethics' boards in relation to these complex issues. These consultations should take into consideration the specific issues that affect social science research, rather than assuming a medical or natural science research model.

| Section B. | 3806 à 3808 : Il est suggéré de supprimer cette déclaration. Le fait que la recherche produise des connaissances de base ne garantit pas nécessairement des relations mutuellement respectueuses ni une pleine participation des communautés autochtones à la vie canadienne. Des conditions inhérentes au fonctionnement de la société, hors du contrôle de la recherche et des chercheurs sont nécessaires pour atteindre cet objectif. La scolarité et l’emploi en sont des exemples. |
| Section B. | 3825 : «de nombreux autochtones redoutent les activités des chercheurs». Il est suggéré de compléter cette phrase par : «ou refusent de participer à la recherche». |
| Section B. | 3828 à 3831. «Les initiatives des communautés s’appuient non seulement sur la reconnaissance des droits inhérents des autochtones», Il conviendrait d’insérer dans cette phrase le texte suivant : «et sur la reconnaissance sociale des connaissances dont elles sont détentrices.» |
| Section B. | The following features of the proposed Tri-Council Policy are consistent with approach and experience. I strongly urge you to maintain these features of your policy but also to interpret and add to their articulation and application in light of the concerns given in part 3 below: |
| (1) | The importance of interpreting ethical guidelines within the broader movement of transforming the relationship between Aboriginal peoples and Canadian society; the Aboriginal and treaty rights of the Aboriginal peoples of Canada; the desire and importance of maintaining collective identity and continuity of cultures; the balance between the individual well being of participants and broader concerns for the collective welfare of the community; and the potential |
imbalance of power between affected individuals, researchers, academic institutions, funding agencies and communities.

(2) The importance of community engagement in addressing concerns relating to protection and control of cultural heritage as understood by affected communities through respect for their laws and protocols and distinctiveness and diversity including their understandings of cultural heritage, research and protection priorities and through meaningful engagement of appropriate community authorities (which may or may not be officially recognized governing bodies) including through culturally informed advice, meetings with researchers prior to the actual research, activities and participation at all levels of the research program including input on interpretation of outcomes and equitable distribution of benefits.

(3) The importance of an intercultural understanding of voluntary informed consent that respects the need to protect and balance the welfare and autonomy of individual participants with the autonomy and welfare of the collective as understood by the parties involved including through compliance with community research protocols.

Section B. The historic background is laid for Aboriginal people’s special position in Canada with respect to self determination. This is important because many researchers ask why there is a special policy for Aboriginal people.

Section B. 3162 It is appreciated that mention was made that harms that may have arisen from research are seldom intentional yet the impression is given (3183-90) that researchers from outside Aboriginal communities never get the information right. It is suggested that wording should be adjusted to note that that there are a great many non-Aboriginal researchers who have conducted ethical research and have developed strong and enduring research relationships with communities, including pioneering community-based participatory models of research of the type that is at heart of this chapter. These should be the ideals to which the drafters of this Policy should be hoping that all researchers will aspire.

Section B. “Aboriginal knowledge” is used throughout this chapter without explanation as to what it is. As far as I can determine, it refers not only to statements of fact that are empirically verifiable according to normal scientific standards, but also to aboriginal beliefs and myths. For example, at p. 105, lines 3673-76, we are told that aboriginals objected to a genetic research program that challenged their “knowledge” about their identity. There is no suggestion here that this knowledge might be inaccurate. Academic freedom implies that any researcher can investigate anything an individual or a group claims to be its “knowledge”; we do not, for example, protect non-aboriginal Christians who insist on the empirical accuracy of their Biblical origin myth from academic inquiry into it, even if falsification of such a myth might undermine their Christian identity.

Lines 3853-54 p. 110 in the chapter on qualitative research state that “Knowledge…is treated as socially constructed.” Yet we are enjoined in the chapter on aboriginal peoples to assume that knowledge is immutable, malleable, and not socially constructed.

Section B. 3174 Painting all researchers with the same brush is not a productive way to create “mutually respectful relationships”.

Section B. 3184 Please clarify “intrusive research” vs. non-intrusive research.

Section B. 3167 References would be useful at 3167 regarding Aboriginal ethics codes and protocols (See also 3236).
Section B. The background information about the diversity of Canadian Aboriginal people and about their cultural heritage that includes artifacts and collective knowledge is very useful and succinctly presented.

Section B. The document refers to culturally informed advice but further clarifications are needed on consultations and advice. Who provides culturally informed advice to the researcher? How is that identified and determined by the researcher, especially a neophyte researcher? How does a neophyte researcher know who is trustworthy and is a moral authority in the community? Who is an elder and who has moral authority? Recruitment process – do we need a two part review process? The possibility of doing research entails actually building relationships in the community and the recruitment process has already begun prior to ethics approval.

Section B. 3170: ADD TEXT: “Aboriginal peoples have rights, RESPONSIBILITIES and interests that deserve recognition and respect by the research community.”

Section B. 3183: ADD TEXT: “Research conducted ethically AND EQUITABLY can benefit Aboriginal people and communities.”

Section B. 3187-3190: ADD TEXT: “Aboriginal people have OFTEN NOT BEEN INFORMED OF THE RESULTS, had little opportunity to correct misinformation or to challenge ethnocentric and racist interpretations. In light of such experience, many Aboriginal people feel apprehensive about the activities of researchers.”

Section B. 3193-3194: ADD TEXT: “Community initiatives are grounded in the assertion of inherent Aboriginal rights AND RESPONSIBILITIES and go beyond protective measures to ensure that research does no harm.”

Section B. ADD TEXT: “APPROPRIATION, COMMODIFICATION AND Commercialization of Indigenous knowledge without INVOLVEMENT OF OR benefit to communities from which the knowledge originated has prompted efforts to protect the interests AND RESPONSIBILITIES of holders of Indigenous knowledge.”

Referring only to commercialization here is too narrow. Knowledge appropriation is the beginning of the ‘chain of production’ that can lead to commercialization. But there are harms that may happen in the absence of commercialization – in fact most traditional plant knowledge that has been appropriated has not resulted in commercial products, yet harms have still resulted. Written as is gives the impression that Aboriginal people are mainly interested in a share of benefits from commercialization. The larger ethical issue begins with knowledge appropriation, and in particular, a lack of understanding by those who appropriate of the spiritual and sacred dimension of the knowledge. This ignorance and the taking of the knowledge out of context and disassociating it from its origins holds the potential for significant harms and offenses, whether or not commercialization is involved.

Section B. 3227-3228: ADD TEXT: “In light of ethical obligations to respect the rights AND RESPONSIBILITIES of Aboriginal peoples as expressed in community codes and protocols…”

Section B. 3230-3231: “…researchers should seek culturally informed advice appropriate to the context when their work involves Aboriginal participants.”

We question if this statement provides a sufficient level of guidance to researchers. We acknowledge it is impossible to be too specific but at minimum the section could elaborate using “such as” and/or through use of examples.

Section B. However, would like to more emphasis on the notion of “equitable partnership” as the framing construct for research with Aboriginal peoples. That is, that researchers must enter into partnership with the communities they want to work with. This means that the community must be involved, as equals, in all stages of
Section C. 9.14

**Ethical Review process**

Who are the peers in this review process? Why do we not have more ethical review processes that are operated by elders and those who are know to be wise by the local community? How qualified are academic review committees to review proposals from communities and aboriginal scholars based on a world view that they cannot understand?

Section C. Line 3234

It is not clear what the status of the CIHR Guidelines for Health Research Involving Aboriginal People (2007) will be with the adoption of this policy. For example, will CIHR funded research still be governed by it? By both? Has there been a systematic cross-referencing between the two documents to ensure that there are no areas of direct conflict between them?

Section C. L. 3242

“divergence “may be unclear, requiring researchers to adapt conventional practice or broker agreements” – again this is a power struggle of who holds the upper hand (ie, decision making powers)? This is where having a community-based ERB would help to mitigate such risks. They should be the first point of contact in resolution of such issues.

Section C. L. 3245

“REBs are reminded that ethical judgment must be attentive to the specific context of a proposed project” – makes the argument for seeking out cultural expertise – Yet, how is this “expert status” determined? By the institution’s REBs? Or the involved community? Again, this is a case where the community under study must dedicate itself to overseeing the ethical adherence of researchers to their principles – relying on an institutionally appointed “expert” who may not have specific knowledge of certain communities and/or their protocols perpetuates a colonial and patronizing tradition of yesteryears.

Section C. L. 3247

“are advised to consult reference documents that provide a fuller exploration of the concerns cited in this chapter” – The Royal Commission on Aboriginal Peoples (1996) should be referenced here as a primary resource in conducting research with Aboriginal peoples in Canada.

Section C. Page 94, 3247-8

indicate that the references mentioned are listed at the end of the chapter.

Section C.

The interface of the Draft TCPS and the CIHR Guidelines for Health Research Involving Aboriginal People should also be clarified in both documents, and the two should be reconciled with each other (in a manner that enhances the rights of Aboriginal research participants), so that researchers are not left in an “Ethical Guideline Limbo or Dilemma”.

Section C.

[Author的感觉] feels that there needs to be harmonization among various documents governing research ethics; more clarity is needed on how various policies of various bodies work together. For example, every institution is supposed to sign a conflict of interest Memorandum of Understanding with the granting councils; how will these integrate with the TCPS? Additionally, how will the TCPS harmonize with CIHR’s guidelines on research with Aboriginal communities?

Section C.

[Author的满意] is pleased that the Draft 2nd Edition contains a more comprehensive chapter on research involving aboriginal communities. However, we are unclear why the proposed chapter does not reference more directly CIHR’s highly regarded Guidelines for Health Research Involving Aboriginal Peoples (2007). It is also
unclear whether PRE consulted widely with aboriginal communities and associations in the development of this chapter.

In addition, some researchers have expressed concern whether the principles contained within this chapter will be extended to other communities (e.g., recent immigrant communities in our urban centres or communities such as those representing individuals with HIV/AIDS.). ** believes that it is important to take account of the particular situation and status of aboriginal communities but would caution against generalizing the provisions of this chapter to research with other groups.

Section C. The document refers only in passing to CIHR Guidelines for Health Research Involving Aboriginal People (at: http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf ), a CIHR policy that has been approved and that is being implemented. We propose that these Guidelines be referred to more extensively and that key points be more emphasized throughout chapter 9.

Section C. As mentioned in our “General Comments”, the chapter should refer to CIHR Guidelines for Health Research Involving Aboriginal People (at: http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf )

Section C. We have had an opportunity to thoroughly review both the TCPS as well as the Canadian Institute for Health Research’s recent guidelines CIHR Guidelines for Health Research Involving Aboriginal People. While we appreciate many of the points made in the TCPS, we feel that CIHR’s guidelines are more detailed and comprehensive. For example, CIHR’s guidelines have provisions encouraging researchers to show respect for Aboriginal world views and to understand and respect community’s jurisdiction over conduct of research. We feel these are integral aspects to any set of ethical guidelines because in the past, researchers have come into communities with very little understanding or respect for their worldviews and this has resulted in communities being exploited; having their traditional, ecological or sacred knowledge used in ways that are not intended because the researcher(s) did not understand or respect their worldviews. This exploitation has lead to Aboriginal people across Canada to be hesitant to engage in research. We are slowly seeing this trend change thanks, in part, to Aboriginal academics and to guidelines developed by the Assembly of First Nations and the National Aboriginal Health Organization (OCAP).

Section C. 3246-3248. The SSHRC report by McNaughton and Rock (2003) should be referenced here.

Section C. Another important omission from the TCPS is the issue of biological sampling. The CIHR guidelines state in Article 12.1: Researcher should recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research. This issue is not addressed at all by the TCPS. Again, we feel that it is the right of the Aboriginal community or research partner have a right to their data and biological samples and to be able to negotiate what the data/samples are used for and who has access to them through a data sharing or research agreement.

Section C. I have not exhausted all of the issues outlined in the attached chart, but I hope that you understand the importance of these issues to Aboriginal people. We believe that CIHR’s guidelines overall better meet the needs of Aboriginal populations and strongly encourage you to review the attached chart prepared by CIHR. As a member of the ** at CIHR, I feel that this is an excellent summary of the key differences and reveal where improvements in the TCPS can and should be made. I would like to emphasize that CIHR’s guidelines are not perfect and certainly need to continue to be modified to meet the needs of our diverse Aboriginal population across Canada. For example, I believe there are differences between First Nations, Inuit and Métis people as well as urban, rural, northern, remote, on and off-reserve populations. I have been working diligently with CIHR and I believe that they are willing to adapt and change the guidelines as we continue to move the Aboriginal research agenda forward in this country. I understand the TCPS represents more than just health research, however, I still
feel that the gaps outlined in the attached are relevant for all research with Aboriginal people and I hope you will be able to find a good compromise in terms of integrating the TCPS and CIHR’s guidelines. I sincerely hope that the Secretariat on Research Ethics demonstrates the same willingness as CIHR to work in partnership with Aboriginal academics and communities in order to create the best possible set of guidelines that is respectful to our diverse Aboriginal populations. I would be more than willing to discuss my thoughts regarding the TCPS and CIHR guidelines once you’ve had an opportunity to review the attached summary.

Section C. 3884 à 3887 : « ...peuples autochtones d’obtenir l’assurance d’une recherche précise et éclairée», plutôt » qu’à assurer».

Section C. 3896 à 3899 : La deuxième phrase de la ligne 3896 devrait plutôt se lire comme suit : «De plus, compte tenu de la diversité des communautés et des groupes, les chercheurs et les membres des CÉR qui ne connaissent pas bien le contexte évolutif de la recherche avec les autochtones doivent consulter les documents de référence...».

Section C. THEMES À RÉVISER/CLARIFIER À L’EPTC :
-- Principes - Propriété, contrôle, accès et possession (PCAP) : Chaque nation et communauté est unique en soi. C’est pourquoi chaque nation et communauté définit selon ses valeurs l’interprétation et l’application des principes PCAP.

Section C. THEMES À AJOUTER À L’EPTC :
-- Communications : La maîtrise d’une langue officielle telle que le français ou l’anglais versus le consentement éclairé individuel. Puisque le français et l’anglais demeurent des langues secondes pour la majorité des communautés des Premières Nations, le chapitre 9 devrait inclure un passage au sujet de cette réalité. On suggère aussi que des pratiques exemplaires soient énumérées.

Section C. No reference to good existing documents
o There exist some outstanding documents to draw upon in some areas covered by the TCPS v2, but not employed to enhance the latest version. In particular, the CIHR Guidelines on Research and Aboriginal Health is a validated, well-respected document that ought to be incorporated. It was carefully developed under consultations with the First Nations communities and as I understand it, was widely expected to be the guiding document for Aboriginal research ethics in Canada.

Section C. Research Involving Aboriginal Peoples
In 2007, the Canadian Institutes of Health Research (CIHR) adopted their Guidelines for Health Research Involving Aboriginal People. These Guidelines were developed over a number of years and involved extensive consultations with aboriginal communities, researchers, and institutions. They incorporate the OCAP Principles developed by the National Aboriginal Health Organization and provide communities with protection over their traditional knowledge. We recommend that the TCPS adopt the CIHR Guidelines which have become the standard of practice in the country for aboriginal communities and many researchers.

Section C. The chapter is similar to the CIHR Guidelines for Health Research Involving Aboriginal Peoples. It might be useful to make the overlap and differences clear to researchers and REBs. Researchers, REBs and Aboriginal people would benefit from clearer guidance from the Tri-Councils regarding when researchers are expected to comply with guidelines laid out in Chapter 9 and when they are to follow the CIHR Guidelines for Health Research with Aboriginal Peoples.
Section C. When research occurs in the north and Nunavut, researchers and co-investigators need a license and approval in NW Territories, Yukon. This relates to the National Aboriginal Health Organizations’ OCAP document – “ownership, control, access, and possession” of the data and findings etc. This is overlooked in the chapter.

Section C. 3233-3235: “This Policy provides guidance on issues that have been raised frequently in public consultations on revision of the original version of this Policy (1998), in the CIHR Guidelines for Health Research Involving Aboriginal People (2007)…”

As noted above, we disagree that the Draft provides guidance on issues that have been frequently raised in the CIHR Guidelines – or if it does then the linkages between the Draft and the CIHR Guidelines need to be much more explicit through out Chapter 9.

Section C. 3240-3242: ADD TEXT: “Applying this Policy in a way that accommodates the diversity of Aboriginal cultures and communities is complex. FOR EXAMPLE, the fit between community protocols and institutional policies may be unclear, requiring researchers to adapt conventional practice or broker agreements.”

Section C. 3244-3246: ADD TEXT: “Researchers and REBs are reminded that ethical judgment must be attentive to the specific context of a proposed project. THIS APPLIES TO BOTH QUALITATIVE AND QUANTITATIVE RESEARCH.”

Section C. The Draft professes (p 94, lines 3233-3236) to provide “guidance on issues that have been raised … in the CIHR Guidelines for Health Research Involving Aboriginal People (2007)”. Other than listing the CHIR Guidelines as references in Chapters 9 and 10, and use of information related to when an Article may apply in an Aboriginal context, there appears to be no specific or general attempt to incorporate or refer to the CIHR Guidelines in any substantive way in the Articles. We recommend that a strong linkage between the TCPS and the CIHR Guidelines be made and that reference to specific Articles in the CIHR Guidelines be made when substantive guidance overlaps with, or is absent in, the TCPS Draft. One important example is including reference in Chapter 9 to the sample research agreement provided as an appendix in the CIHR Guidelines.

Section C. As previously stated in the general comments, there appears to be no specific or general attempt to incorporate or refer to the CIHR Guidelines in any substantive way in the Articles. We recommend that a strong linkage between the TCPS and the CIHR Guidelines be made and that reference to specific Articles in the CIHR Guidelines be made when substantive guidance overlaps with, or is absent in, the TCPS Draft. One important example is including a very strong recommendation in this chapter to using the research template agreement provided as an appendix in the CIHR Guidelines. This agreement also includes a commitment on behalf of the researchers to promote community capacity building within the research project.

Examples of other cross-linkages with the CIHR Guidelines that would significantly strengthen the integrity of the new TCPS are:

- Recognition of the notion of collective autonomy, similar to CIHR Guidelines Article 4: “Research involving traditional, sacred knowledge or community members requires prior consultation and consent of the community followed by individual free, prior and informed individual consent.”

Section C. III. Harmonizing with CIHR, National and International Guidelines

Given the extensive work, expertise and community input that have been invested in recent guidelines for researching involving aboriginal (especially the CIHR
guidelines), the TCPS should harmonize with such guidelines unless there is a compelling reason not to. As already stated, the CIHR guidelines were the product of a multi-year effort by CIHR. They currently apply to anybody seeking funding from CIHR for any research involving Aboriginal peoples. It would be awkward to have one set of guidelines for funding rules and another set for ethics oversight, especially if they say different things and become inconsistent in their application. Thus for instance, the draft of chapter 9 would benefit from the specificity and language of the CIHR Guidelines. Another example are the WHO Guidelines on Indigenous health and research (http://www.who.int/topics/health_services_indigenous/en/). More time is needed to bring the language and principles into agreement.

**Section D.**

**Excerpt from Handbook of Critical and Indigenous Methodologies (2008) could serve to help formulate a research ethics template for Aboriginal researchers:**

A critical politics of interpretation leads the indigenous scholar to ask eight questions about any research project, including those projects guided by critical theory:

1. What research do we want done?
2. Whom is it for?
3. What difference will it make?
4. Who will carry it out?
5. How do we want the research done?
6. How will we know it is worthwhile?
7. Who will own the research?
8. Who will benefit? (L.T. Smith, 2000, p. 239)

Indigenous persons must conduct, own, and benefit from any research that is done on, for, or with them. These eight questions serve to interpret critical theory through a moral lens, through key indigenous principles. (as quoted Denzin & Lincoln, 2008, p. 9-10)

**Section D.**

Given the omnipresent inequity in our society, and the very large imbalance in power between big corporate, governmental and institutional researchers, on the one hand, and more vulnerable Aboriginal research subjects and other research participants, on the other hand, ensuring protection for research subjects through the REB process is an uphill struggle. It requires constant vigilance and strong, protective ethical guidelines and standards, as REB members may even inadvertently be influenced to favour the more powerful parties who can at some point reward or advance them. The dynamics of REBs are a study in themselves, a very illuminating process, as they are not immune from all of the weaknesses to which humans are subject. Some REB members do move on to more prestigious positions that vulnerable research subjects cannot provide them. Even the consultation process which you have implemented is structured to attract researchers and members of REBs who are researchers, more so than members of the community who may more closely represent the research subjects/participants. In a related vein, I have seen REBs evaluated by the researchers they review, but never by the participants/subjects or community-based research partners. Perhaps research could be done on the topic of REB outcomes and extent of protection accorded to research subjects versus favouring the more powerful research enterprise. Is there a proper balance? How do we obtain a proper balance? Transparent monitoring and reporting, as suggested, may aid in the process of continually striving for a fair outcome.
<table>
<thead>
<tr>
<th>Section D.</th>
<th>Ethics Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lines 62-64 say that one aim of your Policy is to “preserve and respect the broader values with which that individual [the research participant] identifies.” This is extremely problematic. The experience of being a research participant might cause the individual to question her values. For example, a women participating in a research project on spousal abuse might question her previous value that a wife should always submit to whatever treatment her husband metes out to her. Not to allow her this chance undermines your stated commitment to the principle of individual autonomy.</td>
<td></td>
</tr>
</tbody>
</table>

This statement, along with many similar one in the draft, goes overboard to acknowledge the importance of community to an individual without considering that individuals have the right to question community values and to withdraw from the community, and that they have the right to encounter values and critical perspectives from outside the community. P. 13, lines 471-2, states that researchers should “understand the role of the culture, values and beliefs of the populations to be studied,” as if those populations were homogeneous entities within which there were no conflicts over values and beliefs. While it is important not to ride roughshod over communities in the interests of research, it is also important not to have an overt agenda of preserving cultures, values and beliefs, regardless of their content or of the views of the supposedly autonomous individuals who are members of the community.

<table>
<thead>
<tr>
<th>Section D.</th>
<th>Overall, there is little guidance on what constitutes “consultations” and “community processes” throughout the Policy. These can mean many different things. The criteria for ensuring the integrity of these processes and their success are undefined/unspecified.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation: Give some guidance on principles to follow for public/group consultations and suggest at least criteria for gauging success.</td>
<td></td>
</tr>
</tbody>
</table>

| Section D. | Regarding participatory action research, would like to see greater clarity for complex settings where the researcher is working with a community and where the work expresses a community’s voice. The safeguards for the community’s researcher and research participants may involve complex informal relations between the researcher and the community. feels that the document could be strengthened by the addition of a separate section on participatory action research and community-based research, to address issues surrounding anonymity for the REB. The committee suggests that PRE examine the procedures put in place at the University of British Columbia as an exemplar of guidelines for reviewing the ethical issues surrounding these types of research (University Policy #89: Research and Other Studies Using Human Subjects). |

| Section D. | Accountability of REBs and REB Members is a major concern. A valid Accreditation process might address some of these concerns. In extreme cases of harm to research subjects, costly litigation may be resorted to, but expensive litigation is not feasible for most Aboriginal Research Participants and so is not a protection for them; other informed parties who might be concerned would not have legal standing in such cases. Greater transparency is required for research participants and communities to become aware of any infringements of their rights as research subjects. At present, they do not even have a right to see the REB Review |
results. There is definitely a public interest in having greater transparency and accessibility to these results, with protection provided for any bona fide trade secrets. Specifying that one member of the REB be a Member of a Law Society, rather than merely “knowledgeable in the law” (Article 6.4 of Draft TCPS) ensures that someone on the REB, if complaints were lodged, could be held accountable by his or her professional organization at no cost to the complainant research subjects.

Section D. 9.1-9.7 Les approches participatives sont à peine mentionnées dans la section sur les autochtones et la recherche qualitative. Les approches participatives se développent en sciences de la santé notamment via la promotion de l’application des connaissances intégrée par les IRSC. Ces approches sont génériques, et touchent les méthodes qualitatives et quantitatives. Serait-il approprié d’ajouter une section ou une annexe sur ces approches et leurs enjeux spécifiques? Je ne suis pas certain en effet que tous les CER connaissent ces approches et enjeux.

Section D. 9.10 9.9 Observation Article 2.5 exempts “research involving observation of people in public places that does not allow for the identifications of the individuals in research materials…” (370-373). This is essentially repeated in Article 10.2 (4001-4005). The assumption is that individuals in public spaces have no expectation of privacy and also that there is no ethical concern if individuals are not identified. We note that this exemption stands in contradiction with the TCPS statement on welfare (56-85). We believe this position on welfare indicates the need for observational studies to be reviewed, a point the TCPS makes in Chapter 10 (4062-4073), along with raising a number of other important considerations about the implications of observation research (4074-4112).

Our position is that there is a documented history of academic extrapolations from observations causing harm to groups, especially vulnerable groups. Therefore observational studies should not be exempt from REB approval. We offer some contemporary examples of observational research in public spaces that are of concern:

Watching school children. is aware of an observational research study where a professor observed children in school playgrounds. He repeatedly watched them but he did not inform the school administration of his identity, credentials or intent. Needless to say, this caused considerable upset. The bad feeling between the school board and the university involved, interfered with good research relations for many subsequent years.

Aboriginal and ethnic ceremonies. A particular concern is the possibility that culturally uninformed researchers may attend and observe cultural ceremonies and events, without the involvement, permission or review of reporting. This is not culturally respectful, nor in keeping with the ethical concerns for Aboriginal people outlined in Chapter 9.

Vulnerable groups without a voice and/or subject to coercion. The TCPS is concerned at length with capacity to consent (1157-1363; 1418 -1453) and issues in the inclusion of vulnerable persons or groups (1385-1417). Yet the particular vulnerability to public space observation and subsequent pronouncements is overlooked for people who are homeless, disabled, mentally ill, or substance addicted.
What is considered ‘public space? We also have concerns about the conduct of observations without permission and review in sites such as hospitals and courthouses where there is: a) potential for overhearing conversation where privacy was expected or should have been observed; and b) a potential for an un informsed researcher to misinterpret and misreport with harmful consequences.

Section D. What kind of appeals process exists? I know in the past the Tri-Council has not dealt with appeals, but I think this is very important because, in my own experience, my former university’s REB required things of me that were entirely inappropriate for the community with which I was working (and it was not just my supervisor and me who thought so—I solicited letters of support against the REB decision from eminent anthropologists and Aboriginal community members). There was one Aboriginal member on the REB, but I still encountered many problems (not just with my own research, but also for my students).

Section D. Some found this section confusing. Are the articles principles? The principles referred to (3252) are those of the TCPS as a whole, but it is likely that this chapter will be read on its own, and it would be good to embed within it the general principles that underlie the TCPS.

Section D. The creation of Aboriginal REBs could be strongly emphasized.

Section D. Par ailleurs, la définition de la notion de « parrainage », qui apparaît à quelques reprises dans le chapitre 9, semble varier selon les endroits du texte où elle figure (par exemple : lignes 3996, 4052 et 4179). Dans un souci de cohérence, le Sous-comité propose de définir clairement et uniformément ce qui est entendu par le terme de « parrainage » et, bien sûr, de s’assurer de l’adequation entre les versions française et anglaise du document. À cet égard, la possibilité que des individus soient favorables à une recherche, contre l’avis même de leur communauté, devrait également être prise en compte. Alors que le consentement individuel est toujours requis (cf. article 9.4), y aurait-il lieu d’approfondir la réflexion relative à l’équilibre à atteindre entre, d’une part, l’atténuation d’une influence induite exercée par la communauté et, d’autre part, l’ingérence des chercheurs dans la communauté?

Section D. In addition, the TCPS does not address the issue of capacity building and training within Aboriginal communities while the CIHR guidelines clearly state that researchers should support education and training of Aboriginal people in the community, including training in research methods and ethics. Again, we feel that Aboriginal people have been left out of the research process in the past and it is an ethical responsibility of a researcher to work with the community, to the best of his/her ability to train community members in data collection, analysis, etc.

Section D. THEMES À AJOUTER À L’EPTC : -- Identificateur autochtone : Nous suggérons que tous les projets de recherche en général et même ceux qui ne concernent pas spécifiquement les autochtones, ajoutent un identificateur autochtone (Première Nation, Inuit ou Métis) afin d’être en mesure d’isoler cette population (lorsque pertinent) et d’étudier ces particularités dans son contexte culturel.

Section D. When do articles in this chapter apply and when is ethics not needed? Pg. #96 point #6 – research in the natural sciences is taking place on Aboriginal landscapes and the communities should be involved. The nation should have an authority to allow or disallow research on their land. All research, not just community based research involving human participants needs to be governed by ethics, not just at the proposal stage but the implications of the findings (e.g. counting polar bears, counting caribou). An example would be a geological survey where minerals are found. Does the nation where the resources reside want to make it public at this point in time? Those implications are not addressed in this chapter. Ethics for natural scientists should be recognized and addressed. Page 108 - To suggest that the interface between environment and Indigenous people doesn’t require review when no individual humans are involved would not fit the Indigenous world views that members of the Board are familiar with. Community harms need to be considered not just individual human harms. Indigenous communities are
extremely sensitive because of the past history of bad researchers and abuses of power.

**Section D.**

There is conflict created by Indigenous researchers’ multiple roles with the community when doing university research. (e.g., The PIs might be related to the band leader and the potential participants). How does the individual researcher negotiate this with respect to territory especially when political, cultural issues are at stake? What do REBs do regarding conflict of interests with the aboriginal community? (e.g., University aboriginal students doing research in their own community). There are increasing numbers of Aboriginal university researchers conducting research within their own communities. The complexities need to be addressed in the Chapter. There are research ethics applications where the Aboriginal researcher states that he/she doesn’t need to consult or talk with anyone from his/her own Aboriginal community or nation before conducting a study because he/she is from that territory and know the issues. There is no guidance on these related situations in the chapter for Aboriginal researchers and REBs. Providing examples of the above situations would also be helpful.

**Section D. 4. Capacity to Participate in Research**

In the academy, there appears to be a hypersensitivity that arises whenever Aboriginal research is proposed. An operative assumption that all Aboriginal groups presently constitute a vulnerable group population at risk is problematic. While some populations of Aboriginal peoples may indeed be considered vulnerable, many Aboriginal communities have very well developed protocols for dealing with research. This is well articulated in Chapter 9 (Article 9.1) 9.1 Communities vary widely in the level of human and material resources they have available to collaborate with research initiatives. First Nation communities have gone furthest in developing bodies to provide ethics oversight. Inuit land claims organizations have the authority to oversee research but have limited personnel available to fill the technical and professional roles in research implementation. Small, remote communities and urban populations have the most limited organizational resources to advise or collaborate in research. The least organizationally developed communities are the most vulnerable to exploitation and should be supported in expanding their capacity to participate rather than suffering dilution of ethical safeguards. Where Aboriginal groups have established procedures for dealing with researchers and universities (i.e. as defined in a land claim agreement) researchers and REB may find themselves in a conflict between two or more sets of guidelines and required procedures. While the Policy Statement alludes to the importance of recognizing other guidelines or protocols, it is implied that the REB would have the "last word." Such an assumption of authority on the part of the REB may be perceived as a challenge to the authority and self-determination of the Aboriginal organization/community and can potentially put the researcher or a collaboration at risk.

**Section D.**

Lines 73-76: Omission

What about community engagement particularly in community based health research? I suggest insisting on the establishment of a research project steering committee for any project where community /stakeholder oversight is relevant, from the choice of hypothesis through the dissemination of findings and the archival of data.

**General**

Chapter 9 – Where is the justification for providing Aboriginal Peoples with privileges not available to other groups (e.g., cohesive immigrant communities, other civil society organizations, etc.)? Article 9.1 could apply equally to these groups.

**General**

Ce qui me déplaît dans cette 2e édition:

Dans le chapitre 9:
- le PCAP: ce processus de contrôle total est en contradiction avec ce qui est dit plus haut dans le texte sur la liberté individuelle des gens (valeur très importante
chez les autochtones, qui ont toujours été traités comme des collectivités par le fédéral, ce qui nie leur autonomie individuelle), avec le respect du chercheur et avec les principes de recherche qualitative que vous énoncez au chapitre 10. En gros, au chapitre 10, c'est permis de faire de la recherche à l'insu des gens, mais pas, à lire le chapitre 9, s'il s'agit d'autochtones. Ce qui est inconsistent.

- l'impossibilité implicite d'exercer un esprit critique sur les pratiques ou systèmes de pensée des autochtones, ce que je trouve très paternaliste.

- la grande difficulté à faire agréer un sujet qui ne vient pas directement d'une demande des autochtones mais des collègues à moi en ont eu et ont carrément décidé de ne plus faire de terrain.

À mon avis, vous allez trop loin dans la volonté de protéger les communautés autochtones (protection qui frise le paternalisme), alors que vous négligez la liberté académique, ce qui a pour conséquences négatives de saper les bénéfices pour les participants et pour les chercheurs de conduire des recherches.

<table>
<thead>
<tr>
<th>General</th>
<th>Aboriginal and Western World views</th>
</tr>
</thead>
<tbody>
<tr>
<td>How successful are we in making the values and assumption that should guide the process? The terrain between Aboriginal and Western worldviews can be pretty murky. Littlebear speaks of jagged colonialism, where neither the colonizer nor the colonized have a pure world view, and end up having to reinvent everything they do when they encounter new situations. Perhaps we need to pay greater attention to writers such a John Ralston Saul, who suggest the after 400 years of rubbing shoulders, Canada has become a Metis country. Perhaps we need to recognize this reality and create a new process that is congruent with who we are rather than basing everything on a scientific paradigm that does not really apply to the “hard” sciences, let alone ‘human’ sciences.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General</th>
<th>Research subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.2 Ethical review continues to use terminology such as research subjects. When conducting research in Aboriginal communities, they are not usually subjects, but if we are doing it right, they are the drivers of the process.</td>
<td></td>
</tr>
</tbody>
</table>

| General | This chapter raises aspects of community engagement, but that engagement now only explicitly deals with the Aboriginal community. There are other communities or ethnic groups in Canada and elsewhere that need to be considered in terms of community engagement. This should be reflected in other chapters as relevant, for example Chapter 5 on privacy and confidentiality. |

| General | Face to Face meetings should be the norm for proper consultation process for the Draft TCPS approval, as well. This was not the case for Saskatchewan nor for the North, both of which have many vulnerable people, including Aboriginal people, in remote and/or northern locations. The consultation process cannot be considered legitimate without ample opportunity for people in Saskatchewan and in the North to be heard in face to face consultations. They are being targeted for large-scale, intrusive research and their voices need to be heard in the consultation process. Furthermore, many members of the community would not feel comfortable in a video-conferencing session, even if they were able to attend the one such session provided in Saskatchewan. None at all were scheduled in the North. I respectfully request that in the next round of consultation for the revised draft TCPS, numerous face to face consultation sessions at different dates, times and locations be scheduled in both Saskatchewan and the North, to ensure that people in these areas of Canada are accorded proper access to the consultation process. If there is no next round of full consultations, I strongly recommend that face to face consultations be held at least in Saskatchewan and in the North. |
either as an addendum to the first round of consultations, or as a version of a follow-up round dealing with the revised draft TCPS created as a result of the first round, even if the follow-up is not scheduled in other areas of Canada that were included in the first round of face to face consultations.

**General**

**General comment** Quebec as a nation

The general pluralism of Canadian society is not emphasized (in additional to aboriginal peoples). Les “Québécois” have been recognized by the Canadian Parliament as a distinct nation and nothing of this comes out in the Policy. Similar issues also concern the multiple ethic groups in Canada. An international reader of this Policy would barely come to grips with this Canadian reality.

Recommendation: Emphasize the various forms of pluralism (e.g., national, cultural, ethnic, and religious, etc.) in Canadian society that should be given full consideration to respect persons, especially for researchers not familiar with pluralism.

**General**

Also, there is a statement that refers to draft policy recommendations (page 3, point 5). Is this meant to apply to the policies governing ethical practices in research involving Aboriginal subjects? I would hope so.

**General**

To respectfully respond to this chapter, invited experts in Aboriginal research and research ethics to review the chapter and provide their comments. The substantive comments are below and more specific ones (line by line) can be found in Appendix 3.

There is a general sense that Chapter 9 is a welcome addition to the TCPS. The chapter provides guidance, direction, and information about Aboriginal communities and what is acceptable in working in these communities; it also makes clear that there is not a single set of ‘rules’ that one can impose as there is variety within and across communities.

At the same time there were a number of areas identified where language could be clarified and material could be added. Perhaps the strongest theme running through the comments is that the document is written very much from an academic perspective, and does not take into account the type of language typically used in Aboriginal research, nor the notion of embedding research within stories and ceremonies that is so important in Aboriginal research, nor the embedding in local ethical and cultural traditions that may not be available in any kind of formal way.

The group felt that there needs to be a stronger emphasis on the notion of relationship, using the language of reciprocity and respect. The notion of responsibility needs closer and careful attention.

There were areas that the group felt could use further discussion and clarification. These include:

- The discussion of context and competing interests is welcome and important. However, there is sometimes a lack of clarity about how to proceed; as one person put it, ‘the advice to attempt to engage competing groups to find common ground is utopian. A researcher may wade into conflicts that are generations old. The likelihood that a settlement will be reached just for the project is not that great. What if choices have to be made to privilege one
group over another?"

- Payment of honoraria is discussed under benefits of research: community experts are experts and should be recompensed as such.

There are areas that are not addressed. These include the following:

- Urban research. This is an evolving area, and research ethics will evolve as the area develops.
- Research on one's own family. This is very common, but often raises issues with respect to informed consent. These need to be thought about carefully, with the strengths (and weaknesses) of doing research in a community where one is well known being weighed.
- Principle of transparency.
- Follow up by REBs. It is not clear that there is any follow up on whether the researchers met their responsibilities, followed the protocols developed, and so on.

There are some major gaps that were identified as well. These are listed in no particular order.

First, when one thinks of Aboriginal communities, stories come immediately to mind. Stories bring things to life, and locate them. Stories, and particularly voices of Elders, would help to breathe some life into a document that is very academic in nature.

Second, this chapter is designed to be about research involving Aboriginal peoples. The group asked about research involving Aboriginal people doing research.

Third, there were questions raised around protection of Indigenous knowledge and the absence of discussion of traditional laws that protect intellectual property.

Fourth, there were also concerns raised about what has now become a common concept, the notion of ‘giving back’ or returning something to the community. This raises many issues including the nature of the community and just what it means to give back, with a general feeling that the presentation of a thesis or an academic book is not an example of this. A list of examples of what is considered to be ‘giving back’ would help researchers identify the many ways in which this might take place.

Fifth, there was discussion of the within-community researchers who work with the academic researchers, and the kinds of recognition that the community people should receive for their role in the academic work: benefits need to be equal on both sides.

Sixth, there was discussion about protocols and the role of protocols. When Indigenous ethics protocols and practices are in operation in a community, those practices take precedence over other ethical guidelines. REBs must acknowledge and accommodate Indigenous ethical protocols, practices and theoretical frameworks when they are in use by or with Aboriginal researchers and/or Aboriginal communities. Researchers should work closely with key Aboriginal...
community members (Elders, Band Council, traditional leaders, organizational heads) to determine if and how Aboriginal research practices, theoretical frameworks and ethics might apply to a specific research undertaking.

General
The issue here is not with the inclusion of the section dealing specifically with Aboriginal People, but why other groups are not also given special consideration in their own chapters. The more obvious ones are (a) sexual orientation, (b) women, especially in medical research, and (c) minorities. Many of the same issues that are raised in Chapter 9 would apply to each of these groups – being identifiable; community and/or individual participation; derogatory interpretations of behaviors, beliefs, or artifacts; and so on. Perhaps this could be subsumed in Chapter 4 Inclusion in Research where research involving women (4c), vulnerable people and groups, (4d) and those who lack capacity to consent for themselves (4e) are discussed.

General
Le chapitre sur les peuples autochtones / Ce chapitre devrait inclure toute la question des communautés culturelles qui fait l’objet de plus en plus de recherches au Canada.

General
De façon générale, dans les sections A, B et C du chapitre 9 (lignes 3736-3899) l’étendue des considérations qui devraient intervenir dans l’évaluation de la recherche avec les peuples autochtones sont présentées trop longuement et avec une lourdeur inutile. Le texte est peu accessible à des personnes qui ne sont pas juristes et semble rendre les dispositions prévues dans ce chapitre excessivement contraignantes. S’il va de soi que les exigences éthiques relatives à la recherche avec les peuples autochtones imposent des contraintes particulières dont les chercheurs doivent être conscients, les préambules pourraient néanmoins être sensiblement allégés, sans que soit réduite la portée des arguments. Des indications, telles que celles qui sont énumérées à l’article 9.1 (lignes 3913-3931), pourraient être ajoutées afin, par exemple, de préciser les aspects susceptibles d’être touchés par un projet de recherche et qui concernent suffisamment les intérêts des peuples autochtones pour que les CÉR doivent s’en préoccuper dans leur évaluation. Il pourrait aussi être pertinent de fournir en annexe, ou parfois directement dans les articles, des exemples d’instances, d’organismes et de sites Internet afin de faciliter à la fois le travail des chercheurs et celui des CÉR.

General
• This much anticipated chapter outlines very well the major ethical issues associated with research involving Aboriginal Peoples in Canada. It articulates the main policy directives, particularly the requirement to demonstrate community engagement and, to a lesser extent, to help build capacity for communities to engage in their own research. In doing so, it also provides good contextual and interpretive information to familiarize researchers and REB members with the reasons why special protections are necessary in the Aboriginal context.

• However, the extensive interpretive advice in the chapter can be redundant and often detracts from the essential articles of the policy.

• The authors of the chapter have gone to great lengths to articulate the diversity in Aboriginal contexts and engagement with research. Neither proscriptive nor prescriptive, the chapter adopts a principled approach that simply alerts researchers and REBs to the particular issues of research involving Aboriginal Peoples and demonstrates how the core tenets of the policy should be respected in the Aboriginal context. As such, the chapter provides general guidance on the issues, but the practicalities of application and compliance are left to individual REBs. Without the benefit of any standard process or protocol, REBs will need to inform themselves sufficiently on each case in order to be satisfied that the requirement for “community engagement” is met in a way that is appropriate to the communities and commensurate with the proposed research. This will be a significant and challenging new responsibility for the REBs.

• The opportunity to show how the TCPS will harmonise with any existing policies of individual agencies has been missed. CIHR’s Guidelines for Health
Research Involving Aboriginal People is now in force. While the TCPS and CIHR documents correspond in principle, CIHR has the additional requirement of a Research Agreement, where this is desirable from the community’s perspective. For the benefit of researchers, communities and REBs, the document should clearly state that it articulates the minimum standard, and that agencies and communities may impose additional requirements.

- Given Chapter 9 does not require Research Agreements, their absence will probably make REB work very difficult. They are important documents especially as they outline expectations from Aboriginal communities and researchers, clarify the role of each and deal with sensitive issues. How will REBs be satisfied that such discussions have taken place? Operationalization of the new chapter 9 may be difficult to achieve without such Research Agreements.

<table>
<thead>
<tr>
<th>General</th>
<th>Language in Chapter 9 may not be accessible to Aboriginal communities and could be simplified.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>General</th>
<th>COMMENTAIRES GÉNÉRAUX SUR LE CHAPITRE 9</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nous félicitons le travail fait. Nous trouvons le cadre éthique au niveau des autochtones beaucoup plus inclusif, plus précis et détaillé que celui du chapitre précédent. Nous croyons que l’éthique de la recherche chez les autochtones est continuellement en évolution. Nous croyons que le chapitre 9 est un document vivant et qu’il devrait être réévalué sur une base régulière afin de s’assurer qu’il répond aux besoins de la communauté scientifique, aux besoins des Premières Nations et des Comités éthiques de la recherche. Nous croyons par contre, que le prochain exercice de révision de ce chapitre devrait être conduit différemment. Nous suggérons que chacun des sous-groupes qui composent les peuples autochtones du Canada soit traité et consulté distinctivement. Par le fait même, le chapitre 9 devrait être élaboré de manière à inclure une section à chacun de ces groupes. Dans le même ordre d'idées, nous recommandons de définir chacun des groupes inclus dans les peuples autochtones du Canada afin d’éviter les interprétations divergentes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General</th>
<th>OVERLAP OF REB REQUIREMENTS AND TRI-COUNCIL FUNDING</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>It is important that the recommendations of the Tri-Council Policy are taken into consideration in developing criteria for funding research engaging Aboriginal participants and communities. Inability to acquire sufficient funds or time to comply with the highest standards for community engagement may result in reluctance to engage in important research, narrow construction of ethical obligations, unintentional harm, and unequal relationships – many of the dangers the Policy is intended to avoid. For this reason I raise below areas I feel are implicated by the Tri-Council Policy and that must be taken into consideration beyond the realm of research ethics. The importance of engaging with the community prior to the actual research activities through community events (e.g. feasts, celebrations, informal meetings) and planning meetings can not be overstated in terms of relationship building; clarity of the research program including goals, outcomes, and conduct of the research; and conflict resolution and avoidance. As this process is integral to the research it is crucial that this be taken into consideration in setting amounts for funding, eligible expenses, and duration of grants. Not all institutions are able to fund the pre-application phases necessary to support truly collaborative research. Ongoing communication is fundamental for the successful community engagement in collaborative research. Such communication is rarely effective using only electronic means, such as the internet, or the telephone. Follow up letters, calls, and visits are required throughout the research program as collaborative research is</td>
</tr>
</tbody>
</table>

69
time consuming and the end product often issues many years after the research is initiated. Such communication is necessary for the meaningful engagement called for by the Tri-Council Policy. This needs to be taken into consideration in allocation of funds, eligible expenses (e.g. administration costs for aboriginal organizations engaged in research) and time lines. Of particular concern is the proposed elimination of research stipends and the impact this could have on effective engagement.

Research ethics that give meaningful interpretation to respecting the integrity of indigenous knowledge systems and protection of cultural heritage extends beyond procedure to communication of ideas and application of standards for academic rigor. Meaningful community engagement means providing a mechanism for community input at all stages including interpretation of results. This raises complicated and lengthy process of review and challenges both academic institutions and researchers to re-examine what we mean by academic rigor and negotiating space for difference of opinion.

There is a danger that the policies here will be applied outside the context of research involving human participants and result in the denial of funding. For example, it is possible an assessor will consider these criteria any time issues of Aboriginal identity or community are invoked, despite the absence of human participation in the research. Not all research concerning Aboriginal peoples involves human participants nor, in the writer’s view, should this be required. In the writer’s opinion, encouraging a diversity of approaches to research and opinions is fundamental for the benefit and advancement of knowledge within and outside of Aboriginal communities. It is important to acknowledge that there are also power imbalances within communities and the ability to conduct research independent of internal mechanisms of authority remains important.

General RESEARCH INVOLVING ABORIGINAL PEOPLES Chapter 9 is a detailed discussion of the issues related to the contributions to a study of aboriginal participants and involves specific recommendations for REBs. The whole discussion and the specific recommendations for policy and practice are grounded in five basic ideas: That Aboriginal communities play an important role in protecting the collective interests that also serve individual well-being – therefore the focus of ethics policy must, in the case of Aboriginal people, be broadened out from the individual to the collectivity. Nonetheless, that this fact must be balanced with respect for the autonomy of individual members and with an awareness that all Aboriginal peoples are not represented by a formal Aboriginal governance structure. That the potential for misunderstanding is great when researchers do not share the social, cultural or linguistic characteristics of the Aboriginal people they are studying – therefore that community engagement will be crucial to ensure ethical practice, promoting mutual trust and communication, establishing mutually-beneficial research goals, ensuring respectful conduct during research both towards individuals and towards the community, and that the definitions of all the above are understood by both the researcher and the community. That Aboriginal people have been harmed by research in the past where uneven relationships of power were not acknowledged or addressed and therefore that the affirmation of Aboriginal rights and respect for community ethics codes and protocols must be expressed in order to ensure better balance and mutual benefit. That Aboriginal communities are diverse and complex. The draft changes makes note that Aboriginal organizations have become active in defining their role with external researchers and sponsoring institutions. Their initiatives have emerged from a recognition of inherent Aboriginal rights, a belief that protective measures should go beyond doing no harm but should include the protection of cultural heritage, the authentic reflection of knowledge systems and understandings of the world and to ensure equitable distribution of benefits between researchers and participant communities. The specific recommendations for REBs include: Determining when the new policy must be adapted in cases of research involving
Aboriginal people in order “to demonstrate respect for Aboriginal rights and cultural heritage, the integrity of indigenous knowledge systems and the diversity among and within Aboriginal communities.” Must review the provisions of researchers to engage the community in approving, advising on or managing the project – taking into consideration the nature and extent of governance within the community and the intensity of Aboriginal involvement in the research and including these factors: When research is to be conducted on a territory over which a First Nation, Metis or Inuit body has authority or claim settlement, researchers are required to consult with formal leaders except in cases where other bodies of authority within the community have a stake or jurisdiction or where such consultation would make critical inquiry impossible. Individual consent is still required and is not superseded by community or protocols. Must consider and take into account any existing community ethics code or protocol – clarification of mutual expectations is necessary in case of divergence (or overlap) between codes and this policy. Should encourage researchers to enter into research agreements with Aboriginal communities who have adopted ethics codes or protocols in order to clarify expectations and commitments between researchers and communities. REBs will need to respect the jurisdiction of traditional leadership structures, sacred societies etc when reviewing consent process and procedures for research, especially involving the cultural property of same. REBs will need to tread carefully in cases where people vulnerable within Aboriginal communities are part of research; will need to explore alternate avenues for participation and of research review (i.e. where leadership may be in conflict with the needs of vulnerable people in their communities (e.g. survivors of domestic violence, youth)) and may refer to “trustworthy persons who have moral authority” within the community or disallow the research when “the risks outweigh the benefits derived from proceeding with the research.” REBs may need to be find other ways to ensure cultural appropriateness and research integrity in cases where the critical nature of the research makes approval from political leadership of the community either unlikely or inappropriate (i.e. Sisters in Spirit Project has received ethical guidance and approval from the NWAC) REBs will need to consider at the outset appropriate protocols for data custody and confidentiality considering particularly the needs of small communities but respecting the rights of communities to have access to the data generated. REBs are charged with ensuring the recognition and protection of Indigenous or local knowledge both in the conduct of research and in the dissemination of findings with a specific intent of preventing the misuse or misappropriation of tangible or intangible cultural property. REBs must review all research involving the secondary use of data that is identifiable by community or segment of community and may seek culturally informed advice about the protection of cultural property – in particular, the original restrictions should be noted, the original people involved should be contacted where possible and where this is not possible, organizations who might be able to represent their views should be consulted. REBs must include in their membership, individuals with relevant expertise (either academic or community-based), either on a permanent or an ad hoc basis or through collaboration with community ethics review bodies. REBs will not impose their own standards or processes of community ethics boards, should find common ground, anticipate differences and resolve conflicts that might interfere with the ethical protection of participants and the achievement of research goals, nor should it impose definitions of conflict of interest on communities of limited membership and expertise. For example, a project manager may also sit on the community ethics board and research that is beyond the REB may be subject to community ethics review. Further, review by a community ethics board does not substitute for REB review.

REB Comments: There are several concerns. The fact that the only place where the possibility that research should be disallowed comes in the section following discussion of vulnerable peoples within the community and how community consent should be obtained is very troubling. While the REB agrees that communities as well as individuals should not, in a general way, be harmed by research, in some cases, particularly in cases where the community suppresses the rights of
individuals, some harm may be necessary in order for long-term benefit to both individuals and communities. Research needs to be cognizant of community division but should not be held captive by it. There needs to be a clear definition of secondary data and its use. For example: Does a researcher need to go to communities for advise on how to use records generated about Wendat people by Jesuits in the 16th century? When records are generated at the interface of multiple communities, how will this be handled? How will this policy be meshed with current archival access policies and under the provision of FOI-POP and current copyright law? How will the REB interpret and enforce “Researchers should afford the community an opportunity to react and respond to findings before the completion of the final report, in the final report or even in all relevant publications”? Who will define community in cases where it is vulnerable members that have been involved or when the study has been in the form of critical inquiry? How will the REB/researchers manage confidentiality in the various phases of reporting to the community? There should be a comprehensive re-examination of how these provisions are compatible with the fundamental concept of science as a methodology for discovery and an understanding of how social and physical systems are organized and function.

| General | This section needs considerable redrafting in more accessible and clearer language to eliminate repetition and vagueness, and to shorten the chapter. |
| General | Clarification regarding contradictions between what is generally accepted in the rest of this Policy and what is recommended in Chapter 9 would be useful. |
| General | Cross indexing will increase the effectiveness of Chapter 9’s message and better integrate it into the rest of the Policy. |
| General | Terminology in Chapter 9 that would be useful to include in the Policy’s glossary includes: welfare, well-being, engagement, protocol, Community (in urban and rural and reserve contexts), operative protocol (3499), First Nation, Inuit, Aboriginal, Métis, Aboriginal rights (esp. 3167, 3176-82, 3194), research product, and cultural knowledge, to name a few. |
| General | There was considerable consultation in the development of these guidelines. Have those involved in those consultations been asked to comment on the draft and will they be consulted about any changes? |
| General | This chapter needs to make explicit that communities exist at many different levels and that it is the researcher’s obligation to do sufficient preliminary research to identify what those communities are and how to approach them respectfully. |
| General | The text contains offensive language (e.g., diminishing expertise of Aboriginal knowledge) and is too vague. |
| General | Some contradictions were noted between chapters. If someone conducts qualitative research, he/she can do “trial” studies which address the consulting aspects in Chapters 9 and 10. But if someone is a quantitative researcher, he/she would presumably have to get approval first. They’ve created two standards. Maybe this draft chapter needs to be more exact about qualitative and quantitative research and Aboriginal research and that they are not so distinct but overlapping categories. There needs to be guidance in how the chapters ought to be read in relation to one another. It would be helpful to know when and how these Chapter 9 guidelines apply and when are there differences that REBs should consider. |
| General | As noted earlier, there is a poor fit between the three core principles and research involving Aboriginal peoples due to a focus on individual autonomy and lack of a sense of understanding regarding community expectations for collective consent. There is still a biomedical model underlying the new framework of the Draft. In this regard, the rationale from moving from the principles of the current TCPS (1998) to the new Draft is not well-developed. |
General | In general, the introductory sections (A, B and C) for Chapter 9 are well developed but the Articles are not. The Articles do not translate the broad concerns and issues into clear guidance, moreover the Article are generally weak given the use of “may” rather than “ought” or “should.”

General | In a number of instances (tabulated below), the term “rights” appears. In general, rights should be linked with “responsibilities” (i.e., rights and responsibilities) to be consistent with Aboriginal worldviews.

General | As we raised in our letter of , it remains unclear as to what has been the consultation strategy involving Aboriginal communities on the Draft, particularly Chapter 9. We hope this point will be clarified in due time and that proper and sufficient consultation has taken place during the extended consultation period.

General | • The option of a participatory approach, as in CIHR Guidelines Article 3: “Communities should be given the option of a participatory-research approach:

  The CIHR Guidelines are grounded in community and researcher partnerships that require communications and meaningful consultations with community compared with the Draft TCPS Articles that specify consultations as a requirement only when Aboriginal government has authority or jurisdiction. The Draft provides little guidance on when community engagement is necessary and how to decide on what is an appropriate level of community engagement

General | THE CONFERENCE OF THE PARTIES TO THE ANNUAL MEETING OF THE HELD IN

UNDERTAKES the following on behalf of the who AGREE that further consultation and additional resources are needed in order to finalize and implement the provisions contained in Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS) and RECOMMENDS to the Interagency Advisory Panel on Research Ethics (PRE) that:

a) PRE fulfill its duty to properly consult First Nations, Inuit, and Métis communities and take into consideration their input

b) PRE accepts the CIHR-IAPH guidelines as the health ethics reference for Chapter 9 until such time as proper consultation of Aboriginal communities are conducted

c) PRE consults with the and their community partners on future drafts of Chapter 9

d) PRE provides funding to support the participation of Aboriginal communities and organizations in the process of consultation on TCPS

e) PRE works with the and their community partners to develop infrastructure to support the ongoing participation of Aboriginal communities and organizations in the initial implementation and application of the provisions of the new TCPS.
This resolution is not intended to be exhaustive, but instructive in addressing the concerns of the parties.

General

7. We are pleased that culturally sensitive approaches in research with Aboriginal communities have been adopted in Chapter 9. These issues and communities are well and importantly served by this separate chapter. But we think it would be good to follow it with a second, shorter chapter, on other groups and communities per our point 8 below.

8. **Recommend** adding a separate chapter on other groups and communities: Like Aboriginal communities, other groups will raise similar (but not “the same”) issues of cultural sensitivity, and some of them will have community structures that add complexity to the consent process. Yet others will involve geographic contexts such as towns where not only individuals in towns, but the towns themselves may be affected by the results of the research. See our comments beginning on page 7.

General

1. **Extend consultation time**

More consultation time on chapter 9 than the previous six months is required, unless the consortium of Aboriginal groups at the Panel has been heavily involved in drafting. The nature of research involving Aboriginal peoples requires extensive consultation with Aboriginal communities in development of ethical guidelines. Many of these communities have been waiting for a chapter in the TCPS since the original edition. Many have also been engaged in research with universities for several years, and thus have extensive experience to draw upon. Additionally, the Panel's approach to consultation – a tour of Canadian universities and online submissions – is inadequate for meaningful engagement with Aboriginal communities. More efforts must be made to take a community-based approach and actively reach out to communities with experience in research for input. CIHR's “Guidelines for Health Research involving Aboriginal People” had a fifteen month consultation period involving a pre-existing and comprehensive network of community-based researchers and Aboriginal communities. We propose that the Panel adopt this model and, as per the CIHR Guidelines, use the NEAHR network (formerly the ACADRE network) and other projects funded through SSHRC and NSERC.

However, if a consortium of Aboriginal groups has already been involved, we would like to know much more about its’ functioning in order to allay some of our concerns about meaningful Aboriginal consultation. We would chiefly be concerned about the opaqueness and lack of transparency with which this mechanism has operated. It would be important to know about the experience these groups have with research. Moreover, we do feel that input from the community level and especially from the elders (v. national organization level) is essential to creating a robust document that responds to needs at that level.

The Panel should also consider including or making reference to the model research agreement appended to the CIHR guidelines.

General

II. **Add a subsection on research with other communities**

The principles set out in chapter 9 are equally applicable to research with other communities where a power imbalance exists between researchers and the community. We recognize and support the special status that Aboriginal peoples have in Canadian culture, history and law. However, many other traditionally marginalized communities have been subjected to unethical research practices in the past as well. These other communities may be ones of culture, ethnicity,
These communities should be afforded the same protections as Aboriginal communities outlined in chapter 9. Principally, they should be offered the opportunity to partner at all stages of the research project, whether or not they choose to do so. Forming research partnerships, especially with vulnerable communities, supports the principles of Concern for Welfare & Respect for the Vulnerable, Balancing Benefits & Harm, and Proportionality Justice at a community level in addition to an individual level. Community members are then not dependent on researchers’ decisions but can themselves decide on issues of welfare and respect, discuss potential harms in addition to potential benefits and decide on proportionality of justice.

For a more thorough discussion, see: C. Weijer and E. J. Emmanuel, “Protecting Communities in Biomedical Research”, Science (Aug 18, 2000) 289: 1142.

To recognize this, we propose two options: one, to add a subsection to the chapter entitled: “Guidance for other Partnerships”; a second, to note in the introduction of the chapter, that while these guidelines are principally intended for research involving Aboriginal peoples, they may serve as best practices for research partnerships with other communities. In both instances, references to key analogous and emergent ethics policies or relevant review articles from the literature could support the point. A good starting place is the work of Barbara Israel (http://www.sph.umich.edu/urc/about/).

There are also now many funding opportunities for researchers to partner with health organisations and policy makers. These research projects also need to respect guidelines of partnership, and agreement needs to be reached for the added responsibilities of ‘protection’ of the partner in addition to protection of any individuals in the research process.

<table>
<thead>
<tr>
<th>General</th>
<th>IV. Address funding realities of the three councils</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The requirements set out in chapter 9 may be unrealistic given the present funding structures of CIHR, SSHRC and NSERC. The chapter includes the general requirement to collaborate with communities. Funding is necessary to back up these requirements. It must take into account the considerable time involved in collaborative research, especially for protocol development and post-study dissemination and discussion.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General</th>
<th>V. Simplify and standardize language</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Many of the articles of chapter are long (some more than one sentence) and hence should be simplified to make interpretation and application easier. These articles, perhaps more than those in other chapters, will be used by community-based REBs. Many of their members may not have had the opportunity to pursue a background in research, ethics or law. A more lay, user-friendly, non-complicated language would help facilitate community review of research projects. We note that most of articles of the CIHR guidelines mentioned above are quite short and succinct. We propose that this approach be taken to drafting the chapter 9 articles.</td>
</tr>
</tbody>
</table>

One term for Aboriginal involvement in research should be used and defined at the beginning. Throughout the chapter, “engagement”, “consultation” and “collaboration” are all used interchangeably. None of these terms are defined, and their non-standardized use can cause confusion about the nature of the relationship between researchers and Aboriginal communities. For clarity's sake, we propose the umbrella term “partnership” to frame all research involving Aboriginal peoples. Partnership encapsulates the key point that researchers should enter into a relational and ongoing consultation process with the community with which they work. Relational in the sense that the research takes place in complex webs between researcher and community. Ongoing in the sense that
consultation is not a one-time event; rather it extends for the duration of the project.

Partnership captures the notion that research should be done “with” Aboriginal communities and not “on”. It means that the community should always be given the opportunity to equitably participate in all stages of the research project – from finalisation of study design, data collection, analysis and interpretation, and results dissemination – whether or not it chooses to do so. Partnership also recognizes that both researchers and community are experts in their own right. Nevertheless, we recognize that partnerships operate on a continuum ranging from researcher control to community control. A medium should be found that respects both the researchers' and community's contexts.

General

1. What is Ethical?

Ethics is a socio-cultural concept which has taken on certain meanings within the context of scholarly research and institutions. It may and does have other meanings in other institutions. The document provides some general principles on what is "ethical," however, it may be more appropriate to be explicit about the specific cultural and legal interests of the Tri Council and related institutions. The university cannot assume to have jurisdiction over all issues of ethical concern. Some of us take the position that the risk management concerns of the corporate university have been confused with ethical conduct. In other words, are there tensions between a process to ensure the ethical treatment of research participants with legalistic priorities? The ethical issues and situations concerning a biomedical research approach have been conflated with the diverse approaches of social science research, and in our view, the bio-medical model still dominates. To illustrate, anonymity is necessary for research on disease and individuals, (as well as certain modes of social science inquiry), however, in the case of oral history or participatory research, often individuals, (i.e. Elders) expect the recognition that comes with identification. In other words, by not naming the participant in published versions of the research, a certain unintended appropriation of Aboriginal knowledge can occur. Often anonymity serves to strip information from context and authority. It has proven difficult to explain this aspect of Tri-Council Ethics policies to community research partners. Our experience with REBs is that a strong case has to be made in order to obtain an exception for what is largely a procedure that is most appropriate to bio-medical research. In effect, the assumption is that all information obtained by researchers from individuals should be confidential. Exceptions are made on a case by case basis.

Overall, there seems to be a tendency to follow deductive thought processes, whereas, inferential approaches and even serendipity can generate important discoveries. The habits of highly structured research processes carry into assessments of ethics review. A more open-ended data collection process may be antithetical to the demands of ethics review processes. The guidelines do allude to the importance of inductive research or emergent design.

2.7 Because research involves advancing the frontiers of knowledge, its undertaking often involves uncertainty about the precise magnitude and kind of harms that attend proposed research. Certain accepted research paradigms bring inherent limitations to the prior identification of risk. For example, when research in the social sciences employs emergent design, the manner in which the study will proceed and any associated risks will be known only as the study unfolds. Despite this reference, the emphasis in the Policy Statement and the University ethics processes in general is that researchers can anticipate the outcomes of their research. This is not always the case, particularly in research with Elders or Aboriginal communities. The inference in the Policy Statement, however, is that a more open-ended data collection process may be antithetical to the demands of Ethics Review processes.
<table>
<thead>
<tr>
<th>General</th>
<th>2. Individual versus Socio-Political Ethics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>It should be appreciated that the concept of privacy (respect for autonomy) reflects a particular cultural premise based on individualism. With respect to ethics review, does the privacy of individuals necessarily trump group interests? Thus, the discussion concerning safeguarding information emphasizes privacy and security (Article 5.3), whereas, there should also be an emphasis on the preservation of information provided by research participants (human subjects). It would seem that safeguarding and preserving data, often obtained by public expense, is an academic responsibility with ethical implications. However, the capacity to properly steward data is a cost issue. The interpretative application that &quot;REBs should not automatically impose a requirement that researchers destroy the research data&quot; is welcomed. Again, a case has to made for data preservation, and the default is data destruction. For a number of reasons, data destruction has an inherently anti-intellectually character.</td>
</tr>
</tbody>
</table>

The document (Chapter 9) recognizes the cultural biases that may be introduced by assuming consent at the individual level. The Policy Statement makes some important and poignant statements in regard to the need to balance individual and collective interests: Chapter 9 A: This Policy acknowledges the important role of Aboriginal communities, particularly those that exercise local or regional governing authority, in promoting collective interests that also serve individual well-being. The Policy also directs attention to ethical protections for the autonomy of individual members within communities and to the interests of urban and other Aboriginal populations who may not have formal representation in an Aboriginal governance structure ... Communities are particularly concerned that research should enhance their capacity to maintain their cultures, languages and identities as distinct peoples and to facilitate their full participation in Canadian society. The interpretation of welfare and the balance between concern for individual well-being and broader concerns for collective welfare may therefore differ significantly in an Aboriginal context, as compared with more individualistic social situations. Despite this recognition, the emphasis in the document is on the individual in procedures related to "informed consent." Procedures for collaboration with a group or political organization are conversely not emphasized nor required. While there is recognition of the benefits of collaborating for the researcher, benefits of collaborating for potential participants and populations at risk are not emphasized. In some cases, the suggestion is made that collaboration with a organization or political body creates further risks for participants. |

3.6 Consent is not required from an organization in order to conduct research on that organization. While critical inquiry is an important methodological approach and fundamental to (human subjects). It would seem that safeguarding and preserving data, often obtained by public expense, is an academic freedom, it is not appropriate in all cases. By requiring only individual consent (as opposed to the consent of organization) the Policy Statement implies that it is only individuals who are vulnerable and not organizations. Further, the focus on the individual to the exclusion of the organization implies that the researcher and the REB are able to represent or take responsibility for the broader socio-cultural and political and ethical implications of the research. Given the emphasis in the document on individual scale ethics issues and the emphasis in the university research on academic freedom and individual scholarly pursuit, it is likely that these important points made in the introduction to Chapter 9 will be little considered or addressed in practice by the REB. The onus will continue to be on the Aboriginal organization and or the researcher to provide evidence or prove that the collaboration does not create undue risk for participants or impinge upon academic freedom. As such, research with Aboriginal peoples may continue to be a pursuit of scholarly interest only with little benefit to those being researched. |

| General | 6. Rights of the Researchers |
The Policy Statement is somewhat unclear with respect to the rights and interests of researchers including students in the process. Ideally, REBs will operate with a balanced perspective on managing the risks of potential research participants with the rights and interests of researchers. In some extreme cases, however, researchers may be unfairly disadvantaged due to the political and competitive nature of the academic institution. This Policy Statement may, however, need to be clearer on how the rights of the researcher is protected including the following:

* Intellectual Property Rights of the Researcher (PI) in respect of research design, methods, data instrument. It is unclear from the Policy Statement whether there are constraints on the REBs with respect to the kind of information to be disclosed.
* Bureaucratic Slippage/ Institutional Intransigence: Guidelines and stipulations on the efficiency of the REB process are unclear. In some cases, REBs may unduly delay a decision on an application to the dis-benefit of the researcher. This may for example, lead to the loss of a field season and or introduce new or additional costs to researchers.
* Disincentive to Innovation: The ethics review may in fact limit innovation in research. Research that is standard in focus and methods for example, is more likely to be expedited and or reviewed more quickly than those which introduce new approaches or methods. As such there is a structural disincentive to adapting procedures for data gathering to meet the needs or interests of a particular research group, and or to introducing alternative methods.

Chapter 6 does provide some guidance on addressing these concerns, however, there is much that could be left up to the interpretation on an REB. The reference in Article 6.18: "Researchers have the right to request, and research ethics boards have an obligation to provide, reconsideration of decisions affecting a research project .... REBs are to follow principles of natural and procedural justice in their decision-making" is not clear. For example, the term "natural" is problematic and ambiguous in reference to justice.

<table>
<thead>
<tr>
<th>General</th>
<th>The two most pressing issues that require resolution are</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1) further development of Chapter 9 so as to operationalize an ethics review process that is appropriate for both the academy and Aboriginal interests; and</td>
</tr>
<tr>
<td></td>
<td>2) define the mandate of REBs and provide a focus of ethics review so as to preclude irrelevant discussions of design/methods.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General</th>
<th>Deux projets éthiques</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nous pensons que les multiples difficultés d'application posées par l'intégration des groupes à la recherche proviennent du fait que l'ÉPTC défend deux projets éthiques, qui bien qu'étant reliés à certains égards, sont pourtant bien distincts. D'une part, il s'agit de prévenir les effets négatifs que pourrait avoir la diffusion de certains résultats de la recherche sur une population donnée. L'ÉPTC est relativement claire à ce sujet. La diffusion de certaines données pourrait avoir comme conséquence la stigmatisation de certains groupes, accentuant ainsi leur vulnérabilité, voire leur exclusion. Il est donc important que le chercheur prenne connaissance de ces risques et travaille à les éviter. La consultation des groupes devient ainsi un moyen d'aller chercher de l'information, (et non une fin). Mais, dans ce cas spécifique, les CÉR pourraient simplement exiger du chercheur qu'il démontre les moyens qu'il a mis en œuvre pour s'informer des risques et pour les éviter autant que possible, et non exiger de lui qu'il ait pris en compte le point de vue des groupes concernés. La consultation d'experts ou d'articles scientifiques nous apparaissent comme des moyens tout aussi légitimes de documenter cet aspect de la recherche.</td>
</tr>
</tbody>
</table>
Mais à ce souci de protéger une population des risques de stigmatisation et d'exclusion liés à une recherche se greffe une autre préoccupation, un second projet éthique qui consiste à donner une voix aux groupes ou aux communautés et à reconnaître dans cette voix exprimée l'exercice d'une autonomie. Cette position, qui s'inscrit dans une vision à la fois « communautariste » et « constructiviste » des réalités sociales, n'est pourtant pas énoncée de façon explicite dans l'ÉPTC, bien qu'elle serve, selon nous, de toile de fond à bien des considérations relatives à l'intégration des groupes à la recherche.

Nous pensons que les diverses considérations relatives à la prise en compte de ces groupes trouvent leur fondement soit dans l'un, soit dans l'autre de ces deux projets éthiques, et que ce double objectif contribue à un sentiment de confusion et d'indécision. Il nous semblerait abusif de laisser croire, par exemple, que la prévention des risques est conditionnelle à l'expression de l'autonomie d'un groupe ou d'une communauté. Il nous semble important que le GER clarifie les principes selon lesquels la prise en compte des points de vue des groupes pourrait être assimilée à la reconnaissance du droit à l'autodétermination. Si cette assimilation concernant la recherche avec les Autochtones est plus clairement justifiée et bien encadrée par un ensemble de textes et de documents normatifs, il n'en va pas de même pour les autres communautés. À quel point le droit des communautés à l'autodétermination devra-t-il être pris en compte, dans la détermination par le CÉR des risques, des dommages possibles et de leur degré de vulnérabilité?

À la lumière de ce que nous avons écrit plus haut, nous aimerions aborder la question de l'évaluation des risques et des degrés de vulnérabilités des groupes ainsi que les difficultés théoriques et pratiques que pourraient rencontrer les CÉR lors de ce processus. Les épistémologies communautaristes et constructivistes ont ceci de commun qu'elles ont centré leur intérêts sur les groupes minoritaires et mis en évidence la question de la vulnérabilité vue comme un enjeu identitaire. Dans leur article « Regards croisés sur la vulnérabilité : le politique, le scientifique et l'identitaire », les auteurs M. Clément et N. Bolduc démontrent que dans la mesure où la notion de vulnérabilité s'est imposée comme mode de lecture sociale, elle se présente parfois « comme un construit autour duquel se déploient, pour certains groupes des enjeux de reconnaissances identitaires »2. Dans certains cas, choisir la vulnérabilité permettrait alors de « s'octroyer délibérément la possibilité de se faire entendre auprès de ceux qui ont (ou qui devrait avoir), envers nous, une responsabilité ». Mais cette notion de vulnérabilité deviendrait de plus en plus difficile à circonscrire dans la mesure où elle tendrait « à nommer et à définir de plus en plus de gens, de plus en plus de situations et de conditions variées ».4

---

En conclusion, et pour reprendre les propos de Françoise Saillant « toute définition de vulnérabilité associée à une condition qui se fait aussi identité devient potentiellement utilisable par les groupes qui cherchent leur place et surtout leur reconnaissance ».5

Nous pensons que la question de l'instrumentalisation de la condition de vulnérabilité par certains groupes à des fins politiques ou identitaires devrait être abordée dans l'ÉPTC et servir de mise en garde au CÉR appelé à s'exprimer sur cette question. Les CÉR devrait être à tout le moins invités à s'informer des possibles enjeux politiques et identitaires pouvant intervenir dans la position qu'un groupe pourrait adopter face à un projet de recherche et non seulement des caractéristiques culturelles de ce groupe.

Interprétation et violence symbolique

Une autre difficulté liée à la protection des groupes porte sur l'identification par le chercheur et le CÉR des dommages potentiels pouvant être causés à un groupe au terme d'une recherche. Nous pensons que l'ÉPTC ne fournit pas suffisamment de critères de référence à cet effet. Comment le CÉR peut-il évaluer la gravité d'un dommage lorsque cette évaluation porte sur des notions aussi abstraites que le bien-être culturel ou le respect des identités?

Dans ses expressions les plus radicales, le constructivisme aurait tendance à disqualifier des interprétations qui pourraient aller à l'encontre des identités revendiquées. Selon P-A Taguieff, l'éthique de la reconnaissance pourrait avoir comme impératif d'éviter de dévaloriser l'autoreprésentation d'un groupe et d'affecter l'estime de soi de ses membres tout comme porter atteinte à l'image social d'un groupe minoritaire.6 Comme le souligne Saillant : « Une connaissance autre, celle qui viendrait par exemple d'une mauvaise science, parce qu'elle serait trop extérieure aux groupes vulnérables, celle que l'on soupçonne de trop se rapprocher du pouvoir et d'attribuer des identités indésirables aux groupes vulnérables, est devenue douteuse ».7

Nous pensons que ce sont ces principes qui ont servi de trame à l'élaboration par le GER de sa politique de recherche avec les Autochtones. La notion de « représentation erronée » rencontrée à deux reprises en fait foi. Ainsi, il ne s'agit plus de contester un savoir qui serait erroné en raison d'un manque de rigueur théorique ou méthodologique, mais de contester un savoir qui serait erroné parce qu'il portera atteinte à l'image de la communauté et serait porteur, de ce fait d'une violence symbolique, toute interprétation externe étant vu comme l'expression d'une domination.
Bien que les revendications des Autochtones commandent le respect, nous appréhendons les conséquences de l'application de ces principes sur le travail des CÉR. Est-il à ce point souhaitable que les CÉR soient amenés à jouer un rôle dans l'affirmation des identités collectives? Est-ce là son rôle?

Nous sommes conscients de l’ampleur de la tâche du GER et très reconnaissants de la place qu’il accorde à l’ensemble de la communauté universitaire dans le processus d’évaluation de sa Politique. Nous pensons qu’il existe bien des difficultés liées à la question de la protection des groupes et de la prise en compte de leur approbation. Nous sommes heureux d’avoir pu participer à la discussion.


5\textsuperscript{1} ibid: 75

6\textsuperscript{1} ibid: 71

7\textsuperscript{1} SAILLANT, F., 2004 : « Constructivismes, identités flexibles et communautés vulnérables », in Identités, vulnérabilités, communautés, Éditions Nota bene, p. 36.

8\textsuperscript{1} TAGUIEFF, P-A.: texte présenté en tribune au Figaro, juillet 2003, p.2


### Human Genetic Research

3739-46 Bi-directional cross-referencing between Chapter 9 and Chapter 13 will be useful. Adding a comment on the historical abuse of genetic samples and the consequent need for sensitivity especially with regard to the Nuu-Chah-Nulth case in British Columbia.

### Human Genetic Research

The human genetic sub-section and Human Tissue chapter (Chapter 12) would seem to be important in relation to Aboriginal research involving tissue samples, blood work. Cross referencing should also be made with Chapter 10 if possible.

### Introduction

It should be made clear at the start that this chapter applies mainly to Aboriginal populations within Canada and only has a short section on Aboriginal populations outside Canada.

### Research Involving Indigenous Peoples in Other Countries

We are writing to express some concerns we have regarding the policy framework and guidelines for ethical review of research involving aboriginal peoples (Chapter 9) as it applies to the context of working with indigenous or aboriginal populations outside of North American (Canada and the United States). It is our feeling that, while the general principles guiding ethical research with indigenous and aboriginal groups are applicable both in the Canadian context and abroad, many of the specific guidelines and policies set out for REBs in the evaluation of research proposals are inappropriate for many international contexts. We believe that the specific guidelines being developed are formulated too specifically on the circumstances and cultures of the Aboriginal peoples of Canada and the United States.
As the document itself acknowledges, the framework presented for ethical research with aboriginal communities is strongly informed by the context of Aboriginal peoples (First Nations, Inuit, and Métis) in Canada. Although there is some acknowledgement that the circumstances of aboriginal peoples in other countries may be different (3747 ff), we feel that this is not recognized strongly enough and the tone of the document implies that the socio-political circumstances of Aboriginal peoples in Canada and the United States is the world norm. The North American circumstances, however, are far from the most common situation for indigenous groups in the rest of the world, who (unlike their Canadian counterparts) rarely enjoy official recognition as separate entities from the larger non-aboriginal society, may not have separate administrative bodies or effective community representation, and often see themselves (for better or for worse) as first and foremost members of the larger national society in which they are embedded, albeit with a history that may set them apart from the majority.

These differences can have profound effects on what constitutes ethical behaviour on the part of the researcher working with such communities. One example of this is the issue of securing “community” approval for research with an aboriginal group. This requirement for ethical approval, suggested in the draft document (3354–3360), presumes that there is an administrative or political body from which such approval can be sought, and that any such body would be representative of the interests of the aboriginal community. However, in a large number of regions in Latin America and in other parts of the world, many—if not most—aboriginal communities are not recognized as separate administrative entities, and any local political authorities (e.g., municipalities or village-level governments) are part of the larger national political systems and do not specifically represent aboriginal peoples or their group interests. In the best case scenario, such an authority would be indifferent to research with the aboriginal population in their jurisdiction and, more than likely, unwilling to express active support for a proposed research project. In the worst case, such authorities might seek to impose conditions on research from which they would derive financial or political benefit, at the expense of both the project and the disempowered aboriginal members of the community involved.

Even in areas where the majority of people in a particular political jurisdiction are indigenous, it is commonly the case that local political representatives are themselves non-aboriginal or are aboriginal but identify themselves with the non-aboriginal national society. In either case, these authorities are likely to act against any research that might empower the indigenous community or strengthen their identity by recognizing them as a distinct group, and will not make decisions about research projects based on the interests of the aboriginal community. In extreme cases, seeking approval from local political authorities can draw unwanted attention to potential consultants and members of indigenous groups. Researchers working in many areas routinely carry out risk assessments before undertaking field work at particular sites and relocate projects when these are deemed to carry any sort of potential for negative consequences for consultants. Drawing unnecessary attention from potentially unfriendly authorities only increases the risks for all parties involved, and makes common solutions to such difficulties, such as removing research activities to “neutral” ground, ineffective.

Of further concern is the consistent stereotyping of all aboriginal cultures on the world stage on the model of traditional cultures in Canada (e.g., 3205–15). Even within Canada, as is acknowledged in the following paragraph (3216 ff), there is a great deal of cultural diversity amongst Aboriginal communities; on a world stage this cultural diversity is even greater, and it is our feeling that this document creates the expectation on the part of REBs that all indigenous people conform to a greater or lesser extent to this profile. This, however, is not the case. Not all indigenous or aboriginal communities have the same cultural relationship to land,
place, social network, or traditional knowledge that North American Aboriginal groups lay claim to, and these profound differences shape the ethical context for research, as well as participants’ and communities’ attitudes towards researchers. Of particular concern to us is the wording in 3439ff with respect to First Nations’ attitudes towards ownership of knowledge and rights to control of access to that knowledge. This is by no means a generalizable phenomenon on the world stage, and many researchers in fact find themselves devoting energy to creating interest in traditional knowledge in aboriginal communities, rather than securing permission to do research with it. Once again, we feel that these divergent circumstances create a very different set of ethical obligations on the part of the researcher, and that this document portrays one particular (and probably unusual) cultural context as the norm or standard which REBs will apply to ethical review.

Without going into further detail, we believe that the circumstances of aboriginal and indigenous peoples in the world at large are more varied and complex than the current document would lead REBs considering research in international settings to believe. We also believe that the situation of Aboriginal peoples in Canada and the United States—which is presented as the norm and the standard against which work with indigenous peoples in general must be measured—is, in fact, by world standards the exceptional case. As a result, we believe that the current document needs to be reformulated to reflect these realities, and to make it explicit (perhaps through re-titling the relevant chapter and sub-sections) that the policies currently outlined in Chapter 9 reflect and are aimed specifically at the circumstances of Aboriginal peoples in Canada and the United States, and should not be expected to apply in their specifics to work with indigenous and aboriginal peoples in the rest of the world.

We agree that the Tri-Council policies should explicitly state that the general principles espoused for the ethical treatment of aboriginal participants in research must be adhered to by all researchers working with indigenous and aboriginal peoples. These policies should recognize that informed consent, respect for the equal status of human beings, respect for cultural ethics and protocols, ethical distribution of benefits between researchers and community partners, ensuring accurate and informed research with indigenous communities, and protection of indigenous knowledge from unethical commercialization apply to all indigenous and aboriginal communities; however, the specific framework for meeting these goals and guidelines for ethical review presented here are inappropriate for most contexts outside the North American setting. We believe that, as the document is currently structured, there is a substantial risk that REBs will take the North American context to be the norm, and, as a result, researchers working with indigenous groups outside of Canada and the United States may be met with inappropriate or impossible requirements in order to secure ethics approval for their research.

There is no mention of cultural identity and heritage outside of the First Nations. Some of our members feel that this is missing. There is the possibility that other ethnocultural groups could raise the same demands, and ask to have the same treatment and process of ethics review and evaluation by the REB as for aboriginal groups. The implications of this are not entirely clear. wonders whether Chapter 9 will be applicable to other ethno-cultural groups, or whether the specific history of research with the First Nations should render the articles in this chapter distinctive to them and not applicable to other groups. If so, a rationale needs to be provided.

It may be that some people will not read this chapter since it is only titled Aboriginal Research and their research won’t involve this population. The
Involving Indigenous Peoples … principles addressed in this paragraph are applicable to other indigenous or collective decision-making settings. This paragraph should be mentioned in other chapters to direct people to read this chapter (or re-name this chapter).

Research Involving Indigenous Peoples … There is ambiguity about whether the guidelines apply to all research with Aboriginal individuals or only to the Canadian context. We think it would be clearer to limit the chapter initially to the Canadian context and then to discuss at the end how the guidelines apply outside Canada.

Research Involving Indigenous Peoples … It is recommended that it is premature to recommend the guidelines found in Chapter 9 be applied to research conducted with Indigenous peoples in other countries. These recommendations reflect uniquely Canadian situations and needs. An alternative is to expand the section on community based participatory research (CBPR) in Chapter 10 (§939) under General Principles and Methodological Requirements and Practices, Research Partnerships (subsection h).

Research Involving Indigenous Peoples … Research Involving Indigenous Peoples in Other Countries: The recommendation that this chapter should be applied to Indigenous peoples in other countries seems inappropriate and premature. These recommendations reflect a uniquely Canadian context and needs. A reasonable alternative is to expand the section on community based participatory research (CBPR) in chapter 10 on Qualitative Research.