Public Health Research Involving Aboriginal Peoples: Research Ethics Board Stakeholders' Reflections on Ethics Principles and Research Processes

Sarah Flicker, PhD,¹ Catherine A. Worthington, PhD²

ABSTRACT

Objectives: The second edition (2010) of the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2) prescribes a set of principles and provisions for engagement with Aboriginal communities. The objective of this study was to explore research ethics board (REB) stakeholder perspectives on the principles and processes of reviewing and conducting public health research with Aboriginal populations and communities.

Method: Twenty-four semi-structured qualitative interviews were conducted with REB staff, chairs, members (academic, community and student), and ethics policy key informants with knowledge of the ethics review process, including four Aboriginal participants. Interviews were professionally transcribed verbatim and thematically analyzed using NVivo 8 qualitative data management software.

Results: Three dominant themes emerged specific to ethical research practices with Aboriginal communities: 1) the importance of understanding Aboriginal research as a distinct form of research; 2) the unique nature and complexity of negotiating community consent; and 3) the importance of trust and relationship-building in the research process.

Conclusion: Thematic results highlight the most prominent issues that REB participants encountered in reviewing research involving Aboriginal peoples. Continued attention needs to be paid to acknowledging and respecting issues of diversity in research involving diverse First Nations, Inuit and Métis peoples. While specific to Aboriginal peoples, the TCPS2 guidelines also illustrate processes and practices that may assist in the development of respectful, collaborative public health research relationships with other historically marginalized populations.

Key words: Ethics, research; ethical review; community-based participatory research; Aboriginal research

La traduction du résumé se trouve à la fin de l'article.

Can J Public Health 2012;103(1):19-22.

Over the past 20 years, ethics principles and practices for research involving Aboriginal peoples in Canada (including First Nations, Métis and Inuit peoples) have developed in response to criticisms from Aboriginal peoples over a historical sense of betrayal by researchers.^{1,2} Within Aboriginal and non-Aboriginal health research communities, there has been considerable recent discussion of the principles and best practices for respectful research in collaboration with Aboriginal peoples that acknowledges their rights and cultural values.³⁻⁵ In the development of these principles, community partnership and direction, empowerment, co-learning, mutual respect, and the need for community benefit from research have been prioritized.^{1,6-9}

Key national research ethics documents developed out of collaborative processes led by Aboriginal peoples include the National Aboriginal Health Organization (NAHO)'s *OCAP (Ownership, Control, Access, Possession) Principles* document, and the Canadian Institutes of Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal People*.^{6,7} In December 2010, the new edition of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)* was released. It includes a revised chapter specifically on research involving Aboriginal peoples that incorporates principles from these previous documents.⁶ As TCPS2 governs research involving humans that is funded by the Tri-Council (CIHR, the Social Sciences and Humanities Research Council of Canada (SSHRC), and the Natural Sciences and Engineering Research Council of Canada (NSERC)), TCPS2 provides a foundation for much of the public health research conducted with Aboriginal peoples in

Canada. Among its articles, TCPS2 requires meaningful community engagement in Aboriginal research and recognition of diverse interests within communities; respect for Aboriginal governing authorities (including ethics authorities) and acknowledgement of the formal and customary authority structures; engagement with communities/organizations of relevance to the research; respect for community customs and codes of practice; community and researcher benefits from research; commitment to community research capacity-building; and opportunity to participate in data interpretation and review of research findings before finalizing publications.⁶

With new research practices come new challenges. The tension between the guiding ethics principle of individual autonomy and collective community rights from an indigenous worldview points

Author Affiliations

1. Faculty of Environmental Studies, York University, Toronto, ON

2. School of Public Health and Social Policy, University of Victoria, Victoria, BC

Correspondence: Catherine Worthington, School of Public Health and Social Policy, University of Victoria, PO Box 1700 STN CSC, Victoria, BC V8W 2Y2, Tel: 250-472-4709, Fax: 250-472-4109, E-mail: worthing@uvic.ca

Acknowledgements: Research funding was provided by the Canadian Institutes of Health Research (CIHR) [grant FRN 87363]. We thank: members of the Improving the Accessibility of Research Ethics Boards for Community-Based Research in Canada research team, including Robb Travers, Jacqueline Gahagan, Patricia O'Campo, Stephanie Nixon, Claudia Mitchell, Louise Binder, Mike Wilson, Sarah Fielden and Adrian Guta; the talented team of research assistants who contributed to this phase of the study, including Lauren Munro and Gillian Kolla; and our community partner, the Ontario HIV Treatment Network, for in-kind contributions. We are especially grateful to the participants who made this work possible by sharing their time and rich insights with us, and to an Aboriginal scholar who reviewed the manuscript, but who wishes to remain anonymous.

Conflict of interest: None to declare.

to a difference in cultural values.¹⁰ Previous work suggests that equitable participation may mean that Aboriginal community partners exert more control than academic partners in decision making, which may create challenges for study implementation. There are also challenges in communicating research results that protect indigenous knowledge and communities.¹¹⁻¹³ As researchers and research ethics boards (REBs) engage with the TCPS2 principles, dialogue on these challenges is useful to develop research practices. The objective of this study was to explore REB stakeholder perspectives on the principles and practices of reviewing and conducting public health research with Aboriginal populations.

METHODS

This analysis emerged from a larger study examining barriers to effective ethics review for community-based research (CBR).¹⁴ Ethics approval for the study was received from seven universities.* In order to gather information on issues that are emerging in REB CBR review, a qualitative approach was chosen. In qualitative interviews with REB staff, members, and those engaged in ethics policy work, issues specific to research with Aboriginal peoples was a prominent focus of discussion, as for many participants CBR was most associated with research involving Aboriginal communities. Thus, the authors (2 non-Aboriginal researchers who have engaged in CBR with Aboriginal communities) conducted analysis on REB stakeholder perspectives on this issue.

Study sample

For the larger study, a sampling frame of Canadian REBs reviewing research involving human subjects was developed. We were interested in speaking with REB staff persons in administrative functions who managed protocols, Board Chairs (current or past) and Board members (academic, student and community members) from diverse (in terms of region, size and location (university/hospital/community)) institutions. We targeted institutions for maximum variation, and participants were recruited via REB and personal e-mail. We also contacted individuals engaged in ethics policy development. In total, 24 interviews were conducted with key informants from across Canada (see Table 1 for description of our sample), 4 of whom were Aboriginal. It should be noted that because the study examined broader issues related to CBR, while we included Aboriginal ethics bodies and participants, we did not seek to exhaustively sample Aboriginal perspectives.

Interviews

Interviews were semi-structured and lasted 45-120 minutes. Interview questions were drawn from the CBR literature and team members' experiences, and covered REB structures, processes and review issues. (For questions relevant to this analysis, see Appendix 1.) Due to the geographic distribution of participants, most interviews were conducted by telephone. Participants were asked to speak generally, and not about details of specific reviews. Participants were offered a \$25 book gift certificate.

Data analysis

Interviews were professionally transcribed verbatim and imported into NVivo 8 qualitative data management software.¹⁵ A key theme

Table 1. Interview Participant Characteristics

	Total (n=24)	%*
Location		
Atlantic Canada	2	8
Quebec	2	8
Ontario	9	38
Alberta/Prairies	6	25
BC	3	13
Northern territories	1	4
National	1	4
Role		
REB Chair (current/past)	4	17
REB/Ethics Staff	9	38
REB Board Member	4	17
REB Community Member	4	17
Ethics Policy	3	13

* Percentages may not total 100% due to rounding.

that resulted from the initial coding framework (including 16 major codes and 128 subcodes) was research ethics processes in research involving Aboriginal communities.¹⁶⁻¹⁸ The co-authors undertook a more extensive thematic analysis of the node on ethics and Aboriginal research, as well as a node/subnodes on innovative practices, which contained examples of research ethics practices with Aboriginal communities. The first author did the initial analysis; the second author provided colleague review; and consensus on the core themes was reached through discussion.

RESULTS

Three dominant themes emerged: 1) the importance of understanding Aboriginal research as a distinct form of research; 2) the unique nature and complexity of negotiating community consent; and 3) the importance of trust and relationship-building.†

Aboriginal research as a distinct form of research

When asked about CBR review practices, most participants suggested that their REBs rarely engaged in CBR reviews, except in the case of research involving Aboriginal peoples:

"We see very, very few of these where there is community involvement and collaboration with people in the community for the purposes of research . . . We almost never see that except for First Nations."[nA]

Thus, research with Aboriginal communities generally was seen as a distinct form of research by participants. Many participants were well versed in historical contexts that made research involving Aboriginal peoples distinctive. Several told stories of past researchers abusing their power (including desecrating grave sites and collecting human samples without informed consent), and of rarely returning results to communities under study. One participant indicated this has created a situation where, "Our communities are really hesitant to do that kind of research anymore . . . because we've been burned in the past."[A] Nevertheless, it was recognized by some that despite this distrust, "We need research and we need all this data to help improve the lives of people in [region] and the health of people in [region]."[A]

One stakeholder described that Aboriginal community-based research, ". . . is a form of research whereby Aboriginal community collaboration, direction, participation and commitment are essential. The goal is to develop culturally appropriate and methodologically sound research analysis and dissemination of strategy that are

* York University, Wilfred Laurier University, St. Michael's Hospital, University of Toronto, McGill University, University of Calgary and Dalhousie University.

† Although our sample was too small to conduct comparison between Aboriginal (4) and non-Aboriginal (20) participants, to allow readers to distinguish between speakers, Aboriginal participants are identified by "A" in brackets after quotes; non-Aboriginal participants are designated with "nA".

beneficial and empowering for the participating communities and other stakeholders.”[A] As one participant poetically articulated, western and indigenous worldviews on ethics can be understood as a dialogue between two different cultures. He used the metaphor of “two canoes going in a river . . . we’re traveling down the same river together . . . but we’re travelling it in our own ways, and we are next to each other, and you can even switch boats every now and again, but we are definitely side by side in our own cultures.”[nA]

In terms of the implementation of guidelines and the ethics review process, participants suggested that reviewing Aboriginal protocols was similar to the process of reviewing others in that “we do cover some of the . . . same things, so you know, we ask about risks and benefits for participants in communities, we look at, you know, informed consent, privacy and confidentiality,” but that they also look for other factors, such as “community involvement in the project . . . we actually do look for ownership, we do look at OCAP.”[A] One participant noted that because of historical legacies, REBs needed to be cautious about the implementation of guidelines for research involving Aboriginal peoples to ensure that the principles are followed. However, some participants felt confused about how to implement these principles in practice. For instance, one participant asked, “If a randomized control trial recruited a single Aboriginal participant, did the RCT have to conform to OCAP principles?”[nA]

The unique nature and complexity of negotiating community consent

One area that participants saw as distinctive in Aboriginal research was the nature and complexity of negotiating community consent. Participants felt that while this requirement was an important one, it was often challenging to implement and monitor. Many highlighted how important the dual process of REB and community consent was:

“I guess the important thing about our ethics review is that it’s really up to the communities to decide whether or not they want a research proposal to go through a [community] ethics review . . . Once we do the ethics review and we’re like, ‘Yeah, it seems fine,’ um, it’s still up to the communities to decide whether or not they’re going to participate.”[nA]

One participant said, “Any time where there’s been any minor disagreement between which path to take . . . [our REB] has always deferred to the community.”[nA] Another participant emphasized the importance of community “buy-in.” She shared an anecdote whereby a band council had vetoed a research protocol and was later voted out of office by a community that felt the issues were important: “In the next election . . . they put three new people in, gave me a call, and said, ‘We got our approval, can we join?’”[A]

A key challenge highlighted by these comments was, “Who speaks for the community?” For example, “If you need permission from the Band Council and they’re the problem, how do you get permission from the community?”[nA] This challenge of community consent was magnified in an urban context when there is no one group that has permission to speak for the community. As one participant said, “To put it in simple form, do you treat them as individuals, or do you treat them as a member of the community? And this particularly comes up when people are, for example, registered as First Nations persons, but not even living on the reserve . . .”[nA] In addition, participants talked about how the process for getting communal consent among Métis, Inuit or First Nations people in

diverse urban contexts was less straightforward than in First Nation reserve contexts where there was more likely to be institutions (e.g., bands and Council) that one could approach. One participant talked about challenges with regard to the meaning of autonomy:

“That’s the real tension. And so, can autonomy even be read in a collective way? So, if you think of First Nations Aboriginal research they would say, ‘Yeah absolutely, autonomy is [a First] Nation’s autonomous government’. You know? So it’s about the interpretation of something like that, how broad can they choose to go?”[nA]

Many REBs have worked to find ways of supporting researchers to engage with communities. As one participant indicated, researchers are developing a range of engagement techniques: “Sometimes they come in as a terms of reference . . . Some of those are quite complex, and other times . . . a director will say, ‘Okay, we will do this’ . . .”[nA]

The importance of trust and relationship-building

Among study participants, there was acknowledgement of the importance of trust and relationship-building between researchers and communities in order to conduct collaborative research. Many stakeholders felt that relationship-building required a significant investment of human resources. Several participants talked about the REB’s role in encouraging researchers to build foundational relationships with the communities that they hoped to study: “There *must* be a period of time set aside specifically for relationship building . . . You need to do the capacity-building and build a trusting relationship with community before that research ever begins.”[A]

Many acknowledged that, rather than “all or nothing,” there was a wide range in the depth of the relationships that researchers built with communities. For instance, in some cases, communities may actually prefer a less participatory research approach: “I think research ethics boards have to have an appreciation for the fact that . . . some Aboriginal communities . . . really don’t want to be in the driver’s seat – ‘Please will you drive, you know, here’s the keys, go with it, I am happy to be a passenger.’”[nA] In other cases, communities are seeking researchers “. . . who are making an effort to do collaborative research . . . who are really working with communities . . . We’re very picky about the people who come in and say, ‘I’m doing this research study here, I’d like to do an Aboriginal group.’”[A]

Participants argued that this time spent establishing trust and developing collaborative protocols often leads to better ethics review submissions and quicker reviews:

“Most of our researchers are . . . not new at this, so they have worked with the Aboriginal communities to help establish . . . what is ethical and right in doing research . . . So things . . . come to us reflecting those considerations.”[nA]

CONCLUSION

The three themes that emerged from our analysis – Aboriginal research as a distinct form of research, negotiating community consent, and trust and relationship-building – highlight the most prominent concerns that our REB participants encountered. These are also themes illustrated in previous research.⁸⁻¹³ Thus, while our findings are exploratory as they are based on a small, qualitative analysis with a non-representative sample, and should not be taken as representative of Aboriginal researcher, REB staff, chair or member perspectives, the results do suggest areas for further research, dialogue and education among researchers, REBs and Aboriginal communities.

It is of note that within the key themes and issues presented by participants, the diversity of Aboriginal cultures, language and traditions in our Canadian context was acknowledged. Continued attention needs to be paid to issues of diversity in research involving diverse First Nations, Inuit and Métis peoples. For instance, protocols that may work in a west coast First Nation context may be highly inappropriate in a northern Inuk context. Similarly, issues of language and cultural diversity may result in markedly different worldviews and ethical frameworks.

Nevertheless, a shared history of colonialism has created a context whereby the research community has agreed to engage in more respectful research processes with Aboriginal communities. Despite the challenges associated with their implementation, our data suggest that some REB stakeholders in Canada have been sensitized to the issues of respecting research involving Aboriginal peoples as a distinct form of research. While specific to Aboriginal peoples, our participants suggested that the TCPS2 guidelines model processes and practices for respectful, collaborative public health research relationships with other populations. As one participant noted, "If we fine-tune it enough to speak to the complexity of Aboriginal people and research with them, then I think the entire country benefits from that kind of vigilance, so that we don't lower the expectations for non-Aboriginal people." [A]

REFERENCES

1. Brant Castellano M. Ethics of Aboriginal research. *J Aboriginal Health* 2004;1(1):98-114.
2. Poff DC. The importance of story-telling: Research protocols in Aboriginal communities. *J Empir Res Hum Res* 2006;1(3):27-28.
3. Ball J, Janyst P. Enacting research ethics in partnerships with Indigenous communities in Canada: Do it in a good way. *J Empir Res Hum Res* 2008;3(2):33-51.
4. Bull JR. Research with Aboriginal Peoples: Authentic relationships as a precursor to ethical research. *J Empir Res Hum Res* 2010;5(4):13-22.
5. Schinke R, Enosse L, Peltier D, Watson J, Lightfoot N. Cultural missteps and ethical considerations with Indigenous populations: Preliminary reflections from Northeastern Ontario, Canada. *J Academic Ethics* 2010;8(4):233-42.
6. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2). Ottawa, ON: Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010.
7. First Nations Centre. OCAP: Ownership, Control, Access and Possession. Ottawa, ON: National Aboriginal Health Organization, 2007.
8. Jacklin K, Kinoshameg P. Developing a participatory Aboriginal health research project: "Only if it's going to mean something". *J Empir Res Hum Res* 2008;3(2):53-67.
9. Quigley D. A review of improved ethical practices in environmental and public health research: Case examples from Native communities. *Health Educ Behav* 2006;33(2):130-47.
10. Glass KC, Kaufert J. Research ethics review and Aboriginal community values: Can the two be reconciled? *J Empir Res Hum Res* 2007;2(2):25-40.
11. Cargo M, Delormier T, Lavesque L, Horn-Miller K, McComber A, Macaulay AC. Can the democratic ideal of participatory research be achieved? An inside look at an academic-indigenous community partnership. *Health Educ Res* 2008;23(5):904-14.
12. Cochran PAL, Marshall CA, Garcia-Downing C, Kendall E, Cook D, McCubin L, et al. Indigenous ways of knowing: Implications for participatory research and community. *Am J Public Health* 2008;98(1):22-27.
13. Couzos S, Lea T, Murray R, Culbong M. 'We are not just participants - We are in charge': The NACCHO ear trial and the process for Aboriginal community-controlled health research. *Ethnic Health* 2005;10(2):91-111.
14. Israel B, Shulz A, Parker E, Becker A. Review of community based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health* 1998;19:173-202.
15. QSR International Pty Ltd., NVivo qualitative data analysis software, version 8. 2008.
16. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *Int J Qual Meth* 2006;5(1):67-79.
17. Boyatzis RE. *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage Publications Ltd., 1998.

Appendix 1. Semi-Structured Interview – Guiding Questions

1. General ethical issues in Community-Based Research (CBR) and participant experiences

How do you feel about involving communities/community members in the design and implementation of research?

Do you believe this presents any ethical issues (probe: for whom, why/why not)?

 - Is this different from traditional forms of research (how)?

Does CBR present unique challenges during formal ethics review (probe about roles/responsibilities of staff/Board/researchers)?

Should communities/community representatives be involved in the ethics process (more/less)?

In their current form, are REBs well suited to review CBR?
2. Probes to follow up on issues that emerge in relation to CBR protocols

Are there common questions/issues that come up regarding CBR protocols (ex, is the level of community involvement ever an issue)?

 - Are these discussions different than for traditional forms of research (how)?
 - Are there notable differences over CBR protocols (consider differences between staff and board members, and between board members (clash of disciplinary cultures)?

What are your impressions of the CBR protocols you have reviewed? Are they well written (compared to others) and are community ethical issues effectively addressed?

 - How could these be improved?

Do you believe your REB is able to effectively review CBR protocols? What could improve current capacities to review/submit CBR ethics protocols (staff, Board, researchers at your institution)?

Would your REB benefit from external guidance (e.g., a CBR ethics review board, or a community advisory committee)? What would this look like?

18. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol* 2006;3(2):77-101.

Received: June 17, 2011

Accepted: September 17, 2011

RÉSUMÉ

Objectifs : Dans la deuxième édition (2010) de l'Énoncé de politique des trois Conseils : Éthique de la recherche avec des êtres humains (EPTC 2), on prescrit un ensemble de principes et de dispositions pour traiter avec les communautés autochtones. Nous avons voulu étudier les perspectives des membres des comités d'éthique de la recherche (CÉR) sur les principes et les processus d'examen et de conduite de la recherche en santé publique auprès des populations et des communautés autochtones.

Méthode : Vingt-quatre entretiens qualitatifs semi-directifs ont été menés avec le personnel, les présidents et les membres (universitaires, grand public et étudiants) de CÉR et avec des spécialistes des politiques en matière d'éthique pouvant nous informer sur le processus d'examen de l'éthique, dont quatre participants autochtones. Les entretiens ont été professionnellement transcrits, mot à mot, et analysés par thème à l'aide du logiciel de gestion de données qualitatives NVivo 8.

Résultats : Trois grands thèmes se sont dégagés en ce qui a trait aux pratiques éthiques dans la recherche avec les communautés autochtones : 1) l'importance de considérer la recherche autochtone comme une forme de recherche distincte; 2) la singularité et la complexité de la tâche de négocier le consentement communautaire; et 3) l'importance d'établir la confiance et de tisser des relations au cours du processus de recherche.

Conclusion : Les résultats par thème font ressortir les principales difficultés rencontrées par les participants des CÉR lors des examens d'études de recherche auprès des Autochtones. Il faut poursuivre nos efforts pour reconnaître et respecter l'enjeu de la diversité dans la recherche impliquant diverses populations inuites, métisses et des Premières Nations. Bien qu'elles soient axées sur les Autochtones, les lignes directrices de l'EPTC 2 illustrent un processus et des pratiques qui peuvent aider à tisser des relations respectueuses et collaboratives lorsqu'on fait de la recherche en santé publique avec d'autres populations longtemps marginalisées.

Mots clés : éthique de la recherche; évaluation en éthique; recherche participative communautaire; recherche autochtone