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**Proceedings of the CIHR-supported Panel on Indigenous Health Research, and the CAREB-ACCER and CIHR-supported Indigenous Research Ethics Workshop on Doing Good Research with First Nations, Inuit and Métis Peoples  
May 25, 2018, Mississauga, Ontario**

Hosted by:  
Canadian Institutes of Health Research (CIHR) Ethics Office,  
CIHR Institute of Indigenous Peoples' Health, and  
Canadian Association of Research Ethics Boards



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The views expressed herein do not necessarily reflect those of the Canadian Association of Research Ethics Boards or the Canadian Institutes of Health Research.

For more information and to obtain copies of the report, please contact [support-soutien@cihr-irsc.gc.ca](mailto:support-soutien@cihr-irsc.gc.ca).

## Acknowledgements

This report provides the proceedings for two sessions held in the context of the 2018 Indigenous Health Conference, May 24 to 26, 2018:

- Keynote Panel on Indigenous Health Research, and
- Indigenous Research Ethics Workshop on *Doing Good Research Ethics with First Nations, Inuit and Métis Peoples*.

These sessions were hosted by the Canadian Institutes of Health Research (CIHR) Ethics Office, CIHR Institute of Indigenous Peoples' Health (IIPH), and, for the workshop, in partnership with the Canadian Association of Research Ethics Boards. These three hosts entities would like to acknowledge all those who presented on the panel and who participated in the workshop for their valuable contributions, including those who assisted in the writing of this report.

## Panel Presentation Summary

Over 700 people attended the 2018 Indigenous Health Conference. At this conference, a keynote panel discussion entitled, Indigenous Health Research and Indigenous Research Ethics, took place. Members of the panel included: Dr. Carrie Bourassa, Ms. Susan Zimmerman, Dr. Dawn Martin-Hill, Dr. Fred Wien and Dr. Lynn Lavalée. The session was moderated by Dr. Earl Nowgesic.

Dr. Nowgesic (Anishinaabe, Kiashke Zaaging Anishinaabek; Assistant Scientific Director, CIHR Institute of Indigenous Peoples' Health [IIPH]; Status-only Assistant Professor, Dalla Lana School of Public Health and Adjunct Lecturer, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto) began the session by acknowledging the traditional territory of the Mississaugas of the New Credit First Nation and introduced each panel member to the conference participants, who spoke on the topic of ethics when carrying out research involving Indigenous Peoples (i.e., First Nations, Inuit and Métis).

### Dr. Carrie Bourassa

Dr. Bourassa (Métis, Riel Métis Council of Regina Inc., Local 34; Scientific Director, IIPH; and Professor, Department of Community Health and Epidemiology, College of Medicine, University of Saskatchewan) began by saying that Wisdom Water (i.e., community knowledge) is at the center of research and the Hunter Gatherer has a responsibility to act in an ethical way especially during this era of Truth and Reconciliation. Principles and concepts to adhere to in carrying out research with and in Indigenous communities are:

- reciprocity
- the collective
- building relationships

- giving back
- holism
- responsibility
- respect

Dr. Bourassa said that the seven generations before and seven generations to come must be taken into consideration when doing research with Indigenous Peoples. Relationships are developed over time and, therefore, it is extremely important to develop and maintain trust throughout the research project, because Indigenous Peoples have been greatly exploited in the past. It is important for researchers who are working with Indigenous Peoples to take leadership and assist academia in understanding that Indigenous ways of doing are different from the mainstream ways such as, for example, the provision of honoraria to Indigenous Elders who are involved in research projects.

The researcher can learn from the Indigenous community and should engage with the community in a genuine manner, Dr. Bourassa stated, and should also ensure that the community is benefitting from the research in a meaningful way. The First Nations principles of OCAP® (Ownership, Control, Access and Possession)<sup>1</sup> should be kept in mind when gathering data and establish from the outset who owns the data and where the data is to be housed. Dr. Bourassa indicated that ethical research should be in line with the concept of Indigenous self-determination.

According to Dr. Bourassa, disparities in the health status of Indigenous Peoples, who carry a disproportionate burden of ill health, are based, among other factors, on race. Racism and stigma are “killing us,” Dr. Bourassa stated, which is beginning to be addressed by the IIPH. Dr. Bourassa indicated that it is important for researchers to focus on the resiliency of Indigenous Peoples.

The following are the current IIPH Strategic Directions:

1. to propel First Nations, Inuit and Métis Peoples and communities to drive First Nations, Inuit and Métis health research and knowledge translation;
2. to transform First Nations, Inuit and Métis health using Indigenous Ways of Knowing, and the guiding principle of reciprocal learning; and
3. to advance beyond acknowledged notions of health equity and give primacy to wellness, strength and resilience of First Nations, Inuit and Métis Peoples.

Dr. Bourassa stated there is difficulty in translating knowledge into policy. There must be respect in the notion that Indigenous knowledges are science because Indigenous knowledges as praxis have a lot to offer as health interventions for Indigenous Peoples.

Dr. Bourassa spoke about the CIHR Network Environments for Indigenous Health Research (NEIHR) Program. The purpose of the NEIHR Program is to establish a national network of centres focused on capacity development, research and knowledge translation to provide supportive research environments for Indigenous health research driven by, and grounded

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<sup>1</sup> OCAP® is a registered trademark of the [First Nations Information Governance Centre \(FNIGC\)](#).

in, Indigenous communities in Canada. Dr. Bourassa concluded her presentation by saying that the NEIHR grants could be held by communities.

### Ms. Susan Zimmerman

Ms. Zimmerman (Executive Director of the Secretariat on Responsible Conduct of Research [SRCR]) began her presentation by asking if the participants had worked with Chapter 9 (i.e., Research Involving the First Nations, Inuit and Métis Peoples of Canada) of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2014*, (TCPS 2). While some did, not all conference participants were familiar with Chapter 9.

The SRCR is responsible for the implementation of the TCPS 2, which is a joint statement of the CIHR, the Social Sciences and Humanities Research Council (SSHRC), and the Natural Sciences and Engineering Research Council (NSERC). CIHR, SSHRC and NSERC are known as the Tri-Agencies.

Ms. Zimmerman stated that the Tri-Agencies chose to issue a joint ethics policy statement because ethics is a component of all research disciplines. The TCPS 2 is based on a fundamental value: respect for human dignity. This value is expressed through three core principles: Respect for Persons, Concern for Welfare, and Justice.

TCPS 2 Chapter 9 integrates best practices for research with First Nations, Inuit and Métis Peoples, which is premised on respectful relationships with communities. In developing the document, SRCR collaborated with representatives of National Indigenous Organizations as well as with a committee of researchers with experience in working with Indigenous communities. They added the principle of *Reciprocity* to the guidance principles in Chapter 9 of the TCPS 2 - an important addition and a key part of the preamble.

Ms. Zimmerman reviewed a few key elements in Chapter 9:

- the importance of community engagement
- the importance of a research agreement, which should include the expectations of the researcher and the community
- the need to consider mutual benefits of the research within the context of the principle of reciprocity. Does it meet the community's needs?
- the importance of respecting local codes of practice such as OCAP.

### Dr. Dawn Martin-Hill

Dr. Martin-Hill (Mohawk, Six Nations of the Grand River; Paul R. McPherson Indigenous Studies Chair, and Associate Professor, Department of Anthropology, McMaster University; and College Chair, CIHR College of Reviewers) stated that the experiences of Indigenous Peoples are not generally reflected in universities' teachings, programs and practices even though Indigenous Peoples had a scientific calendar and contributed to knowledge well before the settlers came to colonize Indigenous Peoples in North America. Dr. Martin-Hill

noted that Indigenous knowledges have been subjugated over time due to government policies aimed at assimilating Indigenous Peoples into the mainstream Canadian society.

A new research paradigm for Indigenous Peoples is needed because the Western model does not fit. Ethics and systems of knowledge always existed and under the spirit of reconciliation, Indigenous science is now on the main stage.

Dr. Martin-Hill stated that the following questions should be asked in doing Indigenous research:

- who benefits?
- who is the research designed for, Indigenous or non-Indigenous?
- what is the practical application of Indigenous/decolonizing methodology across disciplines?
- what role do cultural protocols play for the researcher?
- how do researchers use Indigenous knowledges and methods in quantitative and qualitative research?

Dr. Martin-Hill indicated that the practical approach to Indigenous research is to decolonize research methodologies across various disciplines.

Indigenous cultural protocols should play an important role in research. Under the Western model, there is a lack of funding to study Indigenous knowledges that is held by healers/Elders and knowledge guardians. Dr. Martin-Hill stated that it is the decision of the community to determine authenticity of who the healers/Elders are and not for institutions to determine who they are. Dr. Martin-Hill ended by saying that there is a need to see how Indigenous knowledges fit into TCPS 2 Chapter 9 and to update that chapter to remove existing barriers to Indigenous community-led research.

### Dr. Frederic Wien

Dr. Wien (Professor Emeritus, School of Social Work, Dalhousie University) spoke about his experience in working on the CIHR-funded project entitled, “The Poverty Action Research Project,” that involves a partnership of academics from across Canada, the University of Arizona, the Assembly of First Nations (AFN) and five volunteer First Nations. This multi-year research project is set out to examine poverty as an upstream health determinant.

The research model is based on a community-based participatory approach (CBR) and is consistent with Chapter 9 of the TCPS 2. Ethics applications were submitted and underwent reviews by both the university and Indigenous processes.

Dr. Wien raised the notion that a CBR approach involving Indigenous populations is ill-suited with mainstream ethics guidelines and related procedures. This tension is due to the level of detail required in advance of carrying out the research and the need for flexibility when carrying out CBR. Dr. Wien noted that once you engage with a community, you must be ready to adapt to the community’s needs.

Dr. Wien stated that an ethics application may require 100 plus pages because of the detail required such as, for example, who the participants will be, what questions will be asked and what will be posted on social media. Following this first phase, a second phase may be required necessitating an additional 50 plus pages which can take an additional two to three months to develop and to be reviewed. During this time span, many things can change at the community level such as a newly elected First Nations Chief and Council resulting in personnel changes and, in this case, an incident in the community that suggested it would be unsafe for young interviewers to go door-to-door.

Dr. Wien also raised the fact that First Nations communities often say there is little return for the time, effort and knowledge they put into research projects. Dr. Wien suggested that adding “action and policy” components to a research initiative would result in a more equal exchange with the research team. For this project, the university ethics committee requested that both the evaluation and action components be removed as these were not regarded as being research initiatives, and therefore, could not be reviewed by the committee. In disregarding these components, communities are more vulnerable to action research because of the lack of oversight by research ethics boards.

Universities and Research Granting Councils (e.g., CIHR, SSHRC, NSERC, etc.) are not well aligned with Indigenous research. The application process poses challenges in terms of language and the application process for community participants, especially in regard to Indigenous Elders in requiring their SIN (Social Insurance Number); the issuing of taxation/T-4 slips is also problematic. Obtaining reimbursements for community protocols that call for the provision of a meal, cash and door prizes for research participants is also challenging, stated Dr. Wien. University research ethics committees and financial service departments respond to these requests in an *ad hoc* manner. Dr. Wien added that universities are resistant to change and fear being audited and found to be non-compliant by the Research Granting Councils.

Dr. Wien stated that it would help if the Research Granting Councils would develop protocols and provide guidance to universities about modifying standards and procedures to accommodate the unique needs in regard to Indigenous CBR. Dr. Wien indicated that the Research Granting Councils should begin a dialogue with the research community and include Indigenous representatives on what is the most appropriate way to review action research proposals; he further stated that it is now time to re-visit Chapter 9 of the TCPS 2.

#### **Dr. Lynn Lavallee**

Dr. Lavallee (Anishinaabe, Registered with the Métis Nation of Ontario; Vice-Provost, Indigenous Engagement, and Associate Professor, Faculty of Kinesiology and Recreation Management, University of Manitoba) began her presentation by providing personal information about her Indigenous ancestry and linkages based on her traditional customs. This is also done intentionally to challenge the cultural fraud that is apparent in the academy. She stated that we need to identify our families and communities in an effort to be

transparent about our identity, particularly when we are checking the 'Indigenous box' that affords us opportunity.

Dr. Lavalée stated that the inclusion of Chapter 9 of the TCPS 2, following the revision of the TCPS in 2010, provided a framework or tool that helped to validate and carry out research in Indigenous communities. Dr. Lavalée expressed her pleasure in the revision but cautioned that the TCPS 2 can be manipulated to make it appear like researchers are working according to this framework when they, in fact, may not be. Dr. Lavalée indicated that researchers must abide to 'moral' ethics and should take into consideration the following questions prior to carrying out research with Indigenous Peoples:

- why are you interested in the research topic and population? Have funding envelopes influenced your interest in researching Indigenous Peoples?
- what assumptions do you have about the topic to be researched and population you are exploring? How might you challenge your assumptions? Will you allow them to be challenged by others?
- what privileges do you carry as a researcher?
- for Indigenous researchers, what oppressions do you carry and how do these oppressions intersect and impact the research and participants?

Dr. Lavalée stated that having and maintaining personal integrity is important to the research process particularly so for researchers of Indigenous ancestry because, "if relationships are damaged it impacts us personally as well as professionally". Her main priority in research is to ensure her integrity and reputation with the community and noted that we have to be prepared to walk away from research teams and individuals that compromise our relationship with the community.

Following the panel presentation, conference delegates who were eager to take part in an open dialogue with the panel presenters were invited to attend the workshop entitled *Doing Good Research Ethics with First Nations, Inuit and Métis Peoples*, held immediately after the panel discussion.

## Workshop Summary

The workshop entitled *Doing Good Research Ethics with First Nations, Inuit and Métis Peoples*, (see Appendix), was attended by 38 people. The majority of the participants were female, several of the participants were of Indigenous ancestry, and many of them affiliated with academic and/or research institutions. There were a few government representatives and some students were also in attendance.

Dr. Geneviève Dubois-Flynn (Manager of Ethics, CIHR) presented the objectives of the workshop, which were:

1. To consider research ethics from various perspectives, including the 2007 United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP); the 2015 Final



- Report of the Truth and Reconciliation Commission of Canada (TRC); and the 2017 Final Report of Canada's Fundamental Science Review;
2. To understand the TCPS 2 Chapter 9, and discuss challenges to implementing Chapter 9; and
  3. To identify best and wise practices in ethical research with Indigenous communities.

Dr. Dubois-Flynn thanked the Canadian Association of Research Ethics Boards for having accepted to co-host the workshop with CIHR. She invited participants to provide their views on what is currently working well in Indigenous research ethics; what are some of the key challenges; and what are some good and wise practices that participants can share with the group. Several persons were invited to be part of the panel and to be key resources during the discussion.

Dr. Earl Nowgesic informed the participants that a *draft* report would be developed and sent to each workshop participant for feedback prior to developing the final workshop report. The final workshop report will be made public and posted on the CIHR website.

In the workshop introductory remarks, the participants were reminded that it is mandatory for research involving Indigenous Peoples to be reviewed by a research ethics board (REB) if the researcher belongs to a research institution that receives Tri-Agency (i.e., CIHR, SSHRC, and NSERC) funding. Tri-Agencies are currently considering expanding the eligibility status so that community-based organizations can also apply for funding.

It was noted that it is important to adhere to TCPS 2 Chapter 9 when conducting research involving Indigenous Peoples but that some academic institutions, however, don't know how to make the best use of it. Further direction is needed regarding how to properly use Chapter 9 and it was suggested that this could be done by developing a webinar specific on it.

Chapter 9 defines *community* in three ways, which are by territory/region, organization and communities of interest. It is important to engage the community when doing research, and to ensure that the research benefits the community. It is also ideal when the research can be of benefit to other communities. REBs must pay more attention to whether the community has been engaged and how the community was approached when they review research protocols. Chapter 9 of the TCPS 2 outlines how this can be done. REBs should keep in mind that communities should have input into the research process. Given these issues, it is important to examine the member composition of REBs and how well-informed REB members are of Indigenous research ethics.

REBs should ensure research ethics protocols provide evidence in defining who the community is (geographical or phenomenological), as well as evidence in how the community is engaged and to what degree. In addition, evidence of reciprocity, who and how research will benefit the community and evidence that Indigenous self-determination and governance (e.g., OCAP® principles) are practiced should be verified by the REBs. Researchers must refrain from being paternalistic and should remember the principles of reciprocity and responsibility towards the community.

Some Indigenous communities have started developing their own ethics research guidelines and must adhere to both their local guidelines and Chapter 9 of the TCPS 2. A current gap is the lack of an evaluation mechanism at the community level to assess how the research is being conducted throughout the duration of the project. Institutional REBs are the only entities that would have that level of authority but they do not conduct these types of inquiries. Indigenous communities could add that function to their local REB if they have one.

A similar issue was identified by one participant. It related to the need for Indigenous communities who are research partners with academic researchers to follow university REB standards, particularly in cases when universities sub-grant research dollars to communities. This issue could be addressed by: (1) all research partners receive training in the area of Indigenous ethics; (2) provide funding to communities to hold ethics workshops; (3) provide supports to communities examining various research governance models; and (4) communities establish their own REBs.

Should research agreements be made mandatory before a research project is undertaken? It is not currently the case in TCPS 2 Chapter 9. It would put an additional burden on researchers but would be more protective of communities and supportive of the ethical engagement of Indigenous Peoples in research.

Another challenge raised by the workshop participants is who in a First Nations community is the appropriate authority to approve research on particular issues, for example on the cessation of smoking or on the prevention of domestic violence. Research institutions currently ask for a band resolution but this may not be appropriate for all types of research; other bodies / methods may need to be considered given the sensitivity of the above-noted topics. Somewhat related to these issues, a question was posed pertaining to the type of Indigenous leadership available and its implications for research under the TCPS 2. For example, there are elected First Nations Chief and Council on one hand and there are traditional First Nations leadership who are recognized by the UNDRIP and the TRC on the other hand. Both UNDRIP and TRC are not discussed in Chapter 9 of the TCPS 2. Furthermore, memoranda of understanding (MOUs) that are used to guide research are usually based upon Western pedagogies and protocols that are not consistent with traditional Indigenous methods of agreements.

Researchers in the workshop raised the issue of reimbursement of funds and indicated a current gap in Chapter 9 of the TCPS 2 in regard to claiming out-of-pocket expenses to pay for honoraria for Indigenous Elders and to pay for gifts to be used in traditional Indigenous gift-giving ceremonies. This issue is very problematic. Although this issue is not directly addressed in Chapter 9, it is addressed under the Tri-Agency Financial Administration Guide where it is noted that it is acceptable to cover such expenses. Elders should be compensated for their knowledge in much the same manner as are physician scientists and other research experts.

Regarding obtaining Indigenous community consent on a proposed research project, the community has the final say on whether the research will be undertaken or not. As gatekeepers, the First Nations Chief and Band Council will often make that decision. However, depending on the nature of the research, this is not always appropriate. Obtaining consent to carry out research in an urban community is challenging as there may be no specific authorities to consult with. In some cases, agencies can become co-researchers such as is the case in Toronto.

An MOU or a First Nations Band Council resolution may be necessary prior to doing research in a First Nations community. The same applies to research involving regional authorities.

In critically exploring the implications of involving political leadership in research, the following question was posed by one participant: “In some instances, why is Indigenous research in Canada required to subordinate to political entities when the ‘arm’s length of scientific inquiry’ from political interference is a known standard principle?” To illustrate why science should not be solely governed by political bodies, the public case in the United States was highlighted where some leadership deny that climate change exists despite the scientific findings that indicate otherwise. In the Indigenous context in Canada, a significant barrier in past research is the regular changing of First Nations political bodies who govern research where, for example, different First Nation Chiefs leaving and entering political office might have different research priorities possibly leading to already established research being jeopardized.

It was suggested that a hub of Indigenous researchers, research and research guidelines, similar to the Banff Centre, would be useful as well as the development of a resource database of healers and shamans.

In closing, the participants were advised that the *draft* workshop report would be sent to them and that they would each have the opportunity to add additional comments before the report is finalized and posted on the CIHR website.

## Appendix

University of Toronto Indigenous Health Conference  
WORKSHOP ON RESEARCH ETHICS  
May 25, 2018, 1045h to 1145h\*  
Hilton Mississauga Meadowvale Hotel, Mississauga, Ontario

### **TITLE**

Doing good research ethics with First Nations, Inuit and Métis Peoples

### **INTENDED AUDIENCE**

Indigenous (i.e., First Nations, Inuit and Métis) and non-Indigenous individuals interested in research ethics.

Health service providers, program officers, policy makers, other knowledge users and researchers interested in research involving Indigenous Peoples.

Groups and individuals involved in and/or interested in learning about and sharing their experiences working in the area of research ethics involving Indigenous Peoples.

### **OBJECTIVES**

To consider research ethics from various perspectives, including the 2007 United Nations Declaration on the Rights of Indigenous Peoples; the 2015 Final Report of the Truth and Reconciliation Commission of Canada; and the 2017 Final Report of Canada's Fundamental Science Review.

To understand the Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans (2<sup>nd</sup> edition) Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada, and discuss challenges to implementing Chapter 9.

To identify best and wise practices in ethical research with Indigenous communities.

### **WORKSHOP HOSTS**

This workshop is co-hosted by the Canadian Institutes of Health Research (CIHR) and the Canadian Association of Research Ethics Boards-L'association canadienne des comités d'éthique de la recherche (CAREB-ACCER):

Dr. Geneviève Dubois-Flynn, Manager, CIHR Ethics Office;

Dr. Earl Nowgesic, Anishinaabe, Kiashke Zaaging Anishinaabek (Gull Bay First Nation);

Assistant Scientific Director, CIHR Institute of Indigenous Peoples' Health; and Status-only

Assistant Professor, Dalla Lana School of Public Health and Adjunct Lecturer, Lawrence S.

Bloomberg Faculty of Nursing, University of Toronto; and

Ms. Catherine Paquet, President, CAREB-ACCER

### **PANEL PARTICIPANTS AND RESOURCE PEOPLE**

- Dr. Anita Benoit, Mi'kmaq, Esgenoopetitj First Nation; Assistant Professor, Dalla Lana School of Public Health, University of Toronto; and Adjunct Scientist, Women's College Research Institute, Women's College Hospital

- Ms. Julie Bull, Inuk, NunatuKavut, Labrador; Research Methods Specialist, Centre for Addiction and Mental Health; and PhD Candidate, Interdisciplinary Studies, Faculty of Graduate Studies, University of New Brunswick.
- Dr. Lynn Lavallee, Anishinaabe, Registered with the Métis Nation of Ontario; Vice-Provost, Indigenous Engagement, and Associate Professor, Faculty of Kinesiology and Recreation Management, University of Manitoba
- Dr. Dawn Martin-Hill, Mohawk, Six Nations of the Grand River; Paul R. McPherson Indigenous Studies Chair, and Associate Professor, Department of Anthropology, McMaster University; and College Chair, CIHR College of Reviewers
- Dr. Fred Wien, Professor Emeritus, School of Social Work, Dalhousie University
- Ms Susan Zimmerman, Executive Director, Secretariat on Responsible Conduct of Research

## **METHOD/APPROACH**

Workshop delegates should have some familiarity with Chapter 9 (Research Involving the First Nations, Inuit and Métis Peoples of Canada) of the Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans (2<sup>nd</sup> edition)

<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/#toc09-1>.

A report on the proceedings of this workshop will be developed for publication on the CIHR website. A draft will be sent to workshop delegates for their review before being uploaded on the CIHR website.

\*From 0930h to 1015h on May 25, 2018, there will be a plenary panel presentation involving the following people: Dr. Carrie Bourassa (Scientific Director, CIHR Institute of Indigenous Peoples' Health), Ms Susan Zimmerman, Dr. Dawn Martin-Hill, Dr. Fred Wien and Dr. Lynn Lavallee. This plenary panel presentation will be moderated by Dr. Earl Nowgesic.