



Ethics in First Nations Research

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Introduction

Ethical research is based, fundamentally, on respect for the individuals who participate in the research project. Contrary to this, research that is conducted with First Nations has a historical and ongoing legacy of poor practice. There are fundamental flaws in research conducted to date with First Nations. Solutions to these flaws include a well designed, ethically conducted research which include protocols and codes of ethics. First Nations need to play an active role in the design of the research project in order to achieve fundamental key principles to ethical research, i.e., obtaining prior informed consent, protection of privacy, confidentiality and intellectual property. First Nations participation can also help to answer important questions for First Nations and can provide direction for dealing with key challenges facing communities. Good research can help to build capacity within First Nations communities and their governing bodies. It is essential for current and potential researchers, and research ethics policy makers, to understand that “the gathering of information and its subsequent use are inherently political”¹ and to develop strategies that support an ethical approach to research that furthers First Nations’ sovereignty and self-determination.

Key principles that will be discussed throughout this paper include approaches to conducting ethical research, highlighting fundamental flaws in research conducted to date, and offering possible solutions to these flaws. The last section of the paper discusses research protocols and codes of ethics, providing some insight into the range of possible content and the role researchers and First Nations communities can play to support ethical research. The discussion of research that is contained within this paper refers to research conducted both by ‘outsiders’ to First Nations communities and by ‘insiders’ who identify as members of the community or Nation in which they are conducting research.

¹ Royal Commission on Aboriginal Peoples in Schnarch, Brian. (January 2004). “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research.” *Journal of Aboriginal Health*. Volume 1, Issue 1: 80-95, 81.



PART I - Challenges in Conducting Ethical Research

It is essential to understand the flaws of research practices that have been utilized thus far with First Nations in order to avoid repeating these mistakes. In the past, First Nations have often been used as research “subjects”. Research has not been grounded in respectful relationships and has failed to incorporate culturally appropriate ethical standards. Further exacerbating this situation, research has demonstrated a lack of understanding of and respect for communities’ cultural beliefs and has tended to misappropriate traditional knowledge. As author Menzies points out, “to deny the colonial legacy by not adapting our research projects to accommodate Aboriginal concerns is to participate in the colonial project itself”.² Research questions and projects have often been developed and implemented by outside researchers who have failed to account for community perspectives and needs with respect to what needs researching. The Royal Commission on Aboriginal Peoples captures the problematic situation quite succinctly, stating that:

*Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.*³

This has resulted in a widespread distrust of research and outside researchers in many First Nations communities. It is essential for outsider researchers who are considering a research project to have a clear understanding of this historical relationship and the problems inherent within it in order to overcome these challenges to work effectively with First Nations as research collaborators and co-investigators in all projects that are conducted in First Nations communities.

² In Brown, Micaela. (Winter 2005). “Research, Respect and Responsibility: A Critical Review of the Tri-Council Policy Statement in Aboriginal Community-Based Research” in *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*. Volume 3, No. 2: 80.

³ In Schnarch, Brian, January 2004: 81-82.



While it may not first appear to the outside observer that sovereignty, self-determination and research practices are linked, the three are fundamentally interconnected. Research has been used in the past as “an instrument of oppression, imperialism and colonialism”.⁴ It has been based on disrespectful relationships, misinterpreted cultural ceremonies, and inaccurate, stereotypical portrayals of First Nations peoples. Researchers have mined both physical and intellectual property, using practices ranging from disturbance of sacred burial grounds to appropriation of ceremonial practices to theft of knowledge and ideas.

This is the context for the current research terrain and the research protocols and frameworks that have emerged for conducting ethical research with First Nations. In spite of the above missteps and being continually subjected to the outside researcher’s lens, First Nations communities have continued to assert their own autonomy, demanding that outsiders recognize their rights to sovereignty and self-determination. First Nations are requiring outside researchers to better account for community research needs and priorities when conceptualizing research projects that involve them. They are also asserting themselves as partners in the research process and requiring outside researchers to acknowledge that “all research is implicitly political”.⁵

Starting by acknowledging the historic debt to First Nations that is created by the unjust research practices that have been inflicted upon them, the research community can consider a path forward by designing mechanisms that strive to prevent further harm and to expand upon the benefits of good research. Indigenous methodologies will play an important role in starting the process of mending the relationships between indigenous and western thought.⁶ By grounding research in a solid understanding of the historic relationship into which it plays, current and future research projects can apply a more respectful methodology and be internally strengthened in the process.

⁴ Durst in First Nations Centre. (2007a). *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization: 3.

⁵ O’Neil et al. 1993 in Brown, 2005: 80.

⁶ Martin-Hill, Dr. Dawn and Danielle Soucy. (yr unknown). *Ganono’sen e yo’gwilode’ Ethical Guidelines for Aboriginal Research Elders and Healers Roundtable*. Supported by: Indigenous Health Research Development Program, Indigenous Studies Programme, and McMaster University: 21.





Sharing Power

The existing balance of control within research relationships must be fundamentally changed in order to achieve a more ethical research terrain. Many of the unethical research practices that First Nations have identified in historic and ongoing research projects are endemic to the research process itself. Western epistemologies were created by and for non-indigenous peoples living in Canada. These epistemologies and related research approaches reinforce existing paternalistic relationships and do little to aid in the goal of self-determination. Further, they continue to place indigenous epistemologies and knowledge in an external box as irrelevant and ‘other’, reinforcing the framework which enables unethical research projects to be generated and inflicted.

It is important to note that much of the writing on this topic is approached through a Western framework. In order to make a true shift toward so-called “ethical” research, the research itself must be conceived from within an Indigenous paradigm that is reflective of the worldview and principles held by the First Nation where the research will occur. Application of Indigenous knowledge, experience and methodology to research projects helps First Nations communities to ensure self-determination and to move beyond mere survival. Increasingly, Indigenous academics are articulating their methodologies so that western academics can understand the paradigm in which the research is grounded. Indigenous methodologies do not represent a new approach to research and knowledge production, rather, their increasing prominence reflects a willingness on the part of Indigenous researchers to provide a textual construction of their knowledge systems so that western academics and researchers can begin to understand and value this knowledge.⁷

There are inherent power imbalances whenever an outside researcher is considering entering a First Nations community to conduct a research project. “Where power, knowledge and authority are clearly unequal, ethical guidelines seek to place limits on the exercise of power

⁷ Lui-Chivizhe and Sherwood in Martin-Hill and Soucy, 18.



by the powerful – chiefly by moral suasion”.⁸ For all research projects, whether conducted by insiders or outsiders to the community, it is essential that community protocols are embraced and put fully into practice. Specific protocols and principles that have emerged to guide ethical research practices will be discussed in more depth in Part II of this report. In order for research to be most effective, it is also important for potential researchers to work with the community to consider their research needs and to strive to work with community knowledge-holders to build upon their existing knowledge and development trajectory. In many cases, this will include initiating a research agenda where First Nations are the intellectual investigators and contributors within a given research project.

Another important challenge lies in funding distribution. In many cases, communities have been locked out of accessing research monies. Furthermore, even in cases where money is meant to be directed toward First Nations communities, the decision about which projects receive funding usually lies outside of the community or regional decision-making jurisdiction offered by chief and council, tribal councils and provincial-territorial organizations. In these cases, while the funding itself may be offered with good intent, the projects that emerge may not end up assisting with broader regional development for First Nations if they don't fit into the plans and programs that are being implemented at a regional level. As in any community development work, it is essential that research monies directed toward First Nations communities are flowed into the communities through regional organizations who understand local protocols and are familiar with existing plans and programs. This practice will help to reinforce self-determination and self-government for First Nations.

⁸ Inuit Tapirisat in Schnarch, Brian, January 2004: 83.



Informed Consent & Voluntary Participation

When working with human participants, researchers are required to obtain their consent prior to their participation. This participation must be free and voluntary, and consent must be provided based on first being “informed” about the research activities that will follow.

The method used to obtain “consent” is central to the legality and appropriateness of that consent. The legal language of most contract-type legal consent or waiver forms is alienating to individuals who are not versed in legal language. Indeed, any consent form will be deemed invalid if it is determined that it was signed under “duress”. Gathering participants in a room and providing a consent form or waiver for signing just prior to the activity commencing would fall into this category of “duress”. Potential participants require time to consider any potential risks of participation that may be communicated by the researcher. They should have the opportunity to decline in participating. If they have accumulated personal expense in order to arrive at the research location and reimbursement of this expense is withheld without participation then this, too, is inappropriate.

Researchers who are seeking written consent from individuals must ensure that they provide a readable and easy to understand document, in the participant’s language of choice, and that this document is thoroughly explained. Details such as: what the research is for, what will be required of participants, duration of the study and who will be conducting the research (including their organizational affiliation) should be provided. Potential participants should be informed of any risks associated with being involved in the research, how their information will be protected and how the results of the study will be used. The information communicated during the informed consent process is usually laid out quite clearly to the researcher during the ethics review process and will vary depending on the scope and nature of the study. There may be unique confidentiality requirements for the researcher to address. These will be discussed in the next section, entitled *Privacy and Confidentiality*.



Researchers should also be aware of local protocols and customs for establishing a consensual research process. These may include the exchange of gifts or offering of tobacco. For many First Nations this will be the most important step. It is the researcher's responsibility to ensure that any and all legal implications of signing forms are thoroughly explained and comprehended prior to gathering of signatures.



Privacy & Confidentiality

Privacy and confidentiality are recognized as important issues in all research that involves human subjects. Within the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*, “dignity and autonomy of human subjects is the ethical basis of respect for the privacy of research subjects...hence, the access, control and dissemination of personal information are essential to ethical research”.⁹ This statement implies that protection of personal and community privacy is grounded in a fundamental recognition of and respect for human dignity.

There are privacy and confidentiality issues for research involving First Nations that are not addressed by national frameworks. For example, the Pan-Canadian Health Information Privacy and Confidentiality Framework has been established to provide a set of protocols for the collection, use, disclosure and protection of personal health information for all Canadians. This framework was developed to respond to the privacy and confidentiality requirements of the average Canadian. Most health data collected on the Canadian population is held in various locations, including offices of private insurers, pharmacies, hospitals, doctors and public health establishments. In contrast, storage of First Nations’ health information is highly centralized. The vast majority of the data (and control of that data) lies with the Federal government. While personal information held by the Federal government is protected under the *Privacy Act*, aggregate community-level collections of this information can be requested by any Canadian through an “access to information” request. At the same time, for First Nations themselves, it may be logistically difficult (and in some cases not possible) to access and use their own information that is being held by the federal government.¹⁰

⁹ Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, 1998 (with 2000, 2002, 2005 amendments). pp i.5.

¹⁰ An extreme version of this difficulty is demonstrated in *Information Commissioner of Canada v. Minister of Industry*. In this case, The Chief Statistician refused to release certain census records to Algonquin Bands who were requesting their own census information. For details, please see: <http://www.infosource.gc.ca/bulletin/2008/bulletin16-eng.asp>, April 7, 2009.



Small community population sizes create another privacy challenge for First Nations. In the case above, where personal records are held by the Federal government, release of aggregate level data to the public without the community's permission can result in inadvertent stigmatizing of that community based on the content of the information released. In addition, the risk of re-identification of individuals is much higher in such communities with smaller aggregate collections of data. For example, in grouped interpretations of data where there are only a few (or one) possible members of a group, it may be possible to identify individuals to whom specific data are linked. In cases such as these, it may necessary to change data groupings to ensure that the aggregate data cannot be disarticulated to the individual level.¹¹

Successful response to First Nations' privacy and confidentiality concerns depends upon physical possession of data and information. This allows First Nations themselves to prevent possible breaches in privacy and confidentiality by fully asserting and practicing the principles of ownership, control, access and possession.¹² For example, community level data and statistics should not be released without the explicit permission of community authorities. First Nations regional and national authorities will make decisions about the release of regional and national-level statistics. For example, The First Nations Information Governance Committee makes decisions about the release of nationally aggregated information.¹³

In addition to solutions already developed, First Nations require additional support to respond to new information challenges that are emerging. For example, information sharing and access to information online create a whole new suite of privacy and confidentiality challenges. These are only just coming to light for the general Canadian population, and additional research is required to ascertain how First Nations' online privacy challenges will converge with and diverge from the average Canadian's. Community privacy officers and legal advisors can provide ongoing input into how to address new and unique privacy

¹¹ See the example described by the Assembly of First Nations at: <http://www.afn.ca/article.asp?id=1671>

¹² Assembly of First Nations. (2005). *First Nations Health Research and Information Action Plan*. Ottawa: AFN. [online: www.afn.ca/cmslib/general/HRI2005711152443.pdf, March 19, 2009]

¹³ Schnarch, Brian, 92.



challenges as they arise. It has been recommended that a First Nations Privacy Commissioner could act as an ombudsperson for the protection and communication of First Nations collective and individual rights to privacy. This individual could identify key issues and prioritize response measures in order to ensure that First Nations' privacy and confidentiality are protected and upheld. Individual First Nations can also establish their own Band Council Resolutions or laws, data-sharing agreements and privacy codes to ensure that information that they do own and possess is properly protected.



Intellectual Property Rights

Much of the discussion thus far has alluded to a key underlying issue – that of First Nations’ intellectual property and devising ways for First Nations to protect that property in perpetuity. Protection of First Nations intellectual property is central to establishing ethical research practices, as it is often this very property that researchers are striving to obtain through the course of their project.

According to the World Intellectual Property Organization (WIPO), “intellectual property refers to creations of the mind: inventions, literary and artistic works, and symbols, names, images, and designs used in commerce”.¹⁴ The Universal Declaration of Human Rights (UDHR), adopted in 1948, recognizes intellectual property as a fundamental human right for all peoples. Article 27 of the Declaration states:

- 1. Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.*
- 2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.*¹⁵

At the international level, protection of intellectual property is achieved through mechanisms such as patents, trademarks and copyrights. The intellectual property rights that are enshrined within these mechanisms are the legal protections given to a person over their so-called “creative endeavors”. These protections usually give the creator an exclusive right over the use of his/her “creation” or “discovery” for a certain period of time. International treaties set standards and guidelines for business, trade, intellectual property, human rights, access and benefit-sharing, conservation and management of biological resources.

¹⁴ World Intellectual Property Organization. (2009). “What is Intellectual Property?” [Online: <http://www.wipo.int/about-ip/en/>, April 14, 2009.]

¹⁵ Available online at: www.un.org/Overview/rights.html#a27, March 30, 2009.



Existing international and domestic protections for traditional knowledge and intellectual property do not recognize or respect the customary laws and cultural protections that First Nations already have and use. Furthermore, these current protections fail to recognize the fact that traditional knowledge, and the people who hold it, are evolving and adapting to the world and context in which they exist. To further confound the situation, the existing intellectual property legal regime involves commodifying and revealing traditional knowledge in order to have it ‘protected’. This means that, in order to receive so-called ‘protection’, traditional knowledge must be shared with outsiders who may misuse or appropriate that knowledge. Cultural property has been taken from First Nations without their consent and without compensation for over 500 years. The meager intellectual property regime that does exist provides very little protection and requires a dramatic overhaul if First Nations and other Indigenous Peoples are to benefit from it.

As the above illustrates, problems with the existing intellectual property regime are multiple. For example, requirements relating to ‘authorship’ and individual ‘ownership’ run contrary to First Nations governance structures. Much traditional knowledge was ‘authored’ by ancestors; under domestic legislation, copyright protections will be assigned to a known author / artist for their lifetime plus 50 – 70 years while unknown authorities receive copyright for a period of 50 years.

Furthermore, in order to qualify for protection, intellectual property must be “new, original, innovative or distinctive”. These requirements complicate the process of even obtaining intellectual property protection. The emphasis on individual ownership rights within the western intellectual property rights regime does not address collective ownership and the collective nature of a lot of traditional knowledge.¹⁶ Indeed, the mechanisms that exist to protect knowledge and inventions have been developed within the western knowledge system. Having to adhere to them in order to have their knowledge protected creates a dynamic wherein First Nations have to adapt their traditional systems of governance and knowledge keeping to those imposed by a Western system. Failure to sufficiently adapt will

¹⁶ Simeone, Tonina. (2004). *Indigenous Traditional Knowledge and Intellectual Property Rights*. Ottawa: Library of Parliament.



only result in theft of that knowledge. The inconsistencies between international intellectual property regimes and First Nations' traditional and customary laws are captured below:

“When we think of ownership we have to go back to traditional laws and the way we used to do things. The words copyright and patent are foreign concepts. Our communities across this land, we all had protocols and ceremonies to distinguish who owned what knowledge and we shouldn't stray from that. With my family I have knowledge that is strictly known to my family and we own it. It was given to me from my grandfather and I will give it to my grandchildren and so on. How do we respect the clan, individual house or family knowledge? We are all organized in different ways, have different protocols and culture that give expression of ownership to medicines, songs, dances, locations and masks. That should be kept in mind for any framework and patents of our knowledge. We should remember the traditional laws and respect the laws of nations across the land.”¹⁷

These matters are being addressed to some extent by the World Intellectual Property Organization (WIPO). A 1999 WIPO report identifies five major areas of concern with respect to protection of traditional knowledge, practice and cultural expression. These are: Unauthorized copying of works by Aboriginal groups and communities; Infringement of copyright of individual artists; Appropriation of Aboriginal themes and images; culturally inappropriate use of Aboriginal images and styles by non-Aboriginal creators; and expropriation of traditional knowledge without compensation.¹⁸

The WIPO is currently hosting international negotiations on traditional cultural expressions (TCEs). The goal of these negotiations is to create an international treaty or standards to regulate the use and granting of intellectual property rights for TCEs. WIPO standards and treaties for TCEs must reflect the following principles: TCEs are the common property of the Indigenous nation or community where the TCE originated; Intellectual property rights must be awarded in perpetuity to the Indigenous nation; there should be a prohibition on

¹⁷ Quote from Chris Lewis in *National Environmental Directors Meeting Proceedings*. Assembly of First Nations Environmental Stewardship Unit. Prepared by: Raincoast Ventures Ltd, B.C.

¹⁸ World Intellectual Property Organization. (1999). *Roundtable on Intellectual Property and Traditional Knowledge*. WIPO/IPTK/RT/99/3. Geneva. Prepared by: Michael Blakeney: pg 4.



outsiders accessing, copyrighting or reproducing TCEs, and criminal and civil sanctions should be imposed on violators.

Solutions to the challenge of properly protecting First Nations' intellectual property may lie in demonstrating how application of customary and traditional laws allows for preservation and protection of traditional knowledge and intellectual property. At the national and international levels, it will be necessary for a separate intellectual property regime to be established. Such separate regimes would assign rights in perpetuity to Indigenous Peoples. This means that Indigenous Peoples would always have to be paid royalties on their rights. To date, Canada does not yet have legislation in place to protect First Nations' traditional knowledge and traditional cultural expressions. First Nations communities have successfully used Canadian law to protect their intellectual property. However, they have been required to do this at their own cost and as a means to defend their own knowledge.

Defensive protection of traditional knowledge will continue to be necessary until acceptable national and international intellectual property regimes emerge. Prior establishment of traditional knowledge databases is receiving attention as one possible method for protecting this knowledge and defeating patent claims to that knowledge by external groups. In an examination of the usefulness of this tool, the WIPO found that these databases may be quite costly to establish, and that access and use of the database may not ensure adequate protection of the contents.¹⁹ Indeed, in many cases, a database of traditional knowledge may provide a one-stop repository for knowledge piracy. Additional research and practice are required to ascertain whether database applications can provide a useful tool for protecting intellectual property.

In terms of research, it is important for potential researchers to thoroughly acquaint themselves with the above concerns prior to engaging in any research activities that focus on collecting, analyzing or otherwise using intellectual property, including: traditional knowledge, traditional cultural expressions, plant and animal materials and the like. It is important for outsider-researchers to recognize the potential role that they may play in 'piracy' even if their research is well-intentioned and knowledge or resources are not

¹⁹ World Intellectual Property Organization, 2002 in Simeone, 2004.



purposefully appropriated. Any corporation, researcher, or government who is taking any element of First Nations' intellectual property must provide due compensation and protection for that property.

The principles of ownership, control, access and possession provide a good starting place for establishing a First Nations-owned and controlled intellectual property regime, but much more work is still required in this area. A First Nation-owned intellectual property protocol would draw on traditional laws and provide a framework for outsiders to follow when working with that Nation. Individual First Nations will have to develop their own positions on whether or not to share any of their knowledge with outsiders and what mechanisms they would like to establish to ensure the protection of all intellectual property in perpetuity.



PART II - Tools for Enabling Ethical Research

Research Ethics Boards

Research ethics boards are groups that review research proposals prior to the start of a proposed research project to ensure that it meets ethical standards. Research ethics boards have been established in response to the broad consensus that exists among researchers that any research involving human participants should be reviewed to ensure researcher accountability with respect to: proper research design; effective protection of potential participants' privacy; and minimization of potential risks in participating; and ensuring that participants benefit from involvement. These boards also assess the proposed method of obtaining informed consent from potential participants and any risks to participants that may be posed through their participation in a project.

Organizations that do a lot of research will often establish their own ethics review board to assess all potential projects. A widely accepted policy statement applying to most funded academic research in Canada is the *Tri-council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans*, developed by the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC). Any research that is funded by one of these major funding bodies must first be vetted through their review process.

The Tri-Council policy statement establishes itself as the governing standard for “all research that involves living human subjects” in Canada. It is essential for this statement to create space for First Nations' ownership and control of their own ethical policies and procedures. The first edition of the statement, in effect since 2003, includes a section entitled “Research Involving Aboriginal Peoples” which offers a list of “Good Practices”. The authors of the statement noted that at the time of its writing, much more extensive consultation with Aboriginal Peoples would have been required for the section to provide a more



comprehensive framework including specific policies for pursuing research with First Nations.²⁰

The lack of prescriptive direction in this first edition of the Tri-Council statement has created space for development of First Nations' protocols and agreements to govern First Nations' research. Many First Nations entities have developed their own research protocols to fill this role. These protocols have been developed at the Nation, region and community levels in order to ensure that research is done in an ethical fashion. This enables expression of regional and cultural differences in research approaches. In practice, for any research that will involve First Nations, the ethics board reviewing the proposal should have at least one First Nations expert or community member present on the board (First Nations Centre, 2003).²¹

The Second draft version of the Tri-Council statement²² provides a more comprehensive chapter on "Research Involving Aboriginal Peoples". This chapter does include specific policies for pursuing research with First Nations. It is important to note that the chapter makes specific reference to respect for, adherence to and use of First Nations' own codes of ethics and research protocols. As long as First Nations-governed policies, protocols, frameworks and codes of conduct continue to create the ethical standards for research involving First Nations, and this is clearly communicated in the Tri-council statement on research with Aboriginal Peoples, then the statement can play the important role of ensuring that researchers who are interested in working with First Nations will be aware of the principles that must be followed through the course of the research.

²⁰ Schnarch, 2004: 83.

²¹ First Nations Centre. (2003). *Ethics Tool Kit*. National Aboriginal Health Organization: Ottawa.

²² This draft of the 2nd version of the statement is available online at: <http://pre.ethics.gc.ca/eng/policy-politique/tcps-eptc/readtcps-lireeptc/>, March 30, 2009.



Ownership, Control, Access and Possession (OCAP)

In 1994, there were three Canadian longitudinal studies conducted on general health, child development/wellness and the economic well-being of the Canadian population. These surveys did not include First Nations people. The result was that the Assembly of First Nations Chiefs Committee on Health (CCOH) decided to establish a First Nations Information Governance Committee (FNIGC) to oversee development and implementation of a longitudinal health survey that would be conceptualized, owned and controlled by First Nations.²³ The FNIGC established the First Nations Regional Longitudinal Health Survey (RHS), the only national research initiative under complete First Nations control.²⁴ It was through this health survey that the principles of ownership, control, access and possession (OCAP) of information and data were first developed and expressed.²⁵ These principles now apply to all research, data and information initiatives (whether they are primary research, data collecting or other) that involve First Nations and help to ensure self-determination over all research concerning First Nations.

The principles of ownership, control, access and possession (OCAP) have been developed as an accepted, standalone framework for researchers to follow with respect to data and information management prior to, during and after a project has been completed. They are usually embedded within individual communities' research and data protocols, and have been applied in a range of different scenarios. This framework establishes principles and provides mechanisms for ensuring First Nations' governance over First Nations research, data and information. For example, they provide a means to decide: what research will be approved; how collected information and data will be used; where information will be stored; and who will be able to access that information.

²³ First Nations Health Council. (2008). *Regional Health Survey – Background*. [Online: http://www.fnhc.ca/index.php/initiatives/research_and_data/regional_health_survey, March 30, 2009].

²⁴ First Nations Centre, 2007a: 2.

²⁵ *Ibid.*



The First Nations Information Governance Committee (FNIGC) works to ensure that the integrity of all four of the OCAP principles is maintained. This includes ensuring that “the products that came from the work of the people are attributed rightfully back to the people, in a manner that is recognizable and attached to its initial formulation”.²⁶ Since their inception, the FNIGC has found it necessary to trade-mark the OCAP principles in order to maintain their integrity and to stop misuse of these principles by non-First Nations entities who at times have misleadingly stated that they are using these principles without properly applying them.

Much time and energy has gone into defining each of the four principles and their applications. Thus, a more thorough review of these principles is beyond the scope of this paper, as plenty of literature has already been produced on this topic. For more information on OCAP principles, their definitions and their application, please see: Assembly of First Nations, 2007;²⁷ First Nations Centre, 2007;²⁸ Brian Schnarch, 2004;²⁹ and the First Nations Regional Longitudinal Health Survey (RHS).³⁰

²⁶ First Nations Centre, 2007a: 1.

²⁷ Assembly of First Nations (2007). *OCAP: Ownership, Control, Access and Possession. First Nations Inherent Right to Govern First Nations data*, Ottawa. [online: <http://www.afn.ca/misc/ocap.pdf>].

²⁸ First Nations Centre. (2007a). *OCAP: Ownership, Control, Access and Possession*, Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization [Online: http://www.naho.ca/firstnations/english/documents/toolkits/FNC_OCAPInformationResource.pdf, March 30, 2009]

²⁹ Schnarch, Brian. (January 2004). “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research.” *Journal of Aboriginal Health*. Volume 1, Issue 1: 80-95 [online: http://www.naho.ca/english/pdf/journal_p80-95.pdf, March 30, 2009].

³⁰ Available online at: <http://www.rhs-ers.ca/english/>, March 30, 2009.



Research Protocols and Agreements

In many cases, First Nations have developed their own research protocols and codes of ethics to govern any research that involves them. These are implemented at the community, regional and national levels. While these frameworks vary in content, there are some general principles that are usually present, such as the OCAP principles, which are embedded in most First Nations-produced guidelines for conducting research. Each community and/or region will have a different set of guidelines which must be respected and applied. This section identifies some key themes, but is by no means a comprehensive rendition of all possible clauses that might be contained in a research protocol. Researchers must become familiar with the specific protocols, codes of conduct and agreement requirements that have been established by the First Nations with whom they would like to work. If a study involves multiple communities, there may be a different set of requirements for each community that potential researchers will have to follow.

Throughout the discussion that follows, it is important to note that form should not be mistaken for function. While research protocols and ethics guidelines can provide useful lists of ‘rules’ for researchers to follow, they must be applied with a degree of integrity that is based upon an understanding of the intent behind each rule or protocol. There will be no single rendition of an ethical practice, and the success of the research will depend in the end on the relationships that are developed through the research and the degree of moral integrity with which the principles are applied. While research protocols and codes of ethics do provide an essential framework within which to conduct research, it is equally important that principles be applied so as to fulfill the purpose which they were drafted to support.

Research Protocols

The purpose of a Research Protocol is to ensure that research conducted within First Nations communities will be of benefit to the community(s) and to indigenous peoples in general. In addition, protocols help to promote well-designed, First Nation-controlled



research. Research protocols assert cultural self-determination and community safety and well-being through the production of research. In the end, a community should be strengthened by any research project with which it is affiliated. By explaining parameters for conducting research in the language of the potential non-First Nations researcher, the community takes jurisdiction to make decisions about what research will occur and what standards that research must meet.

It is necessary for prospective researchers to consult individual research protocols in order to ascertain the specific ethical framework that will shape their research. A research protocol will have a number of components. The First Nations Centre suggests the use of tools such as: a *Code of Ethics*, a *Research Agreement* and a *Data-sharing Protocol* for First Nations to establish guidelines to be followed for any research that involves them.³¹

Code of Ethics

A *Code of Ethics* provides the policies and procedures to be applied in establishing and carrying out a research project. A *Code of Ethics* will generally apply to all research activities, regardless of whether that research is completed by a member of the First Nation, outside researchers or some combined partnership. A *Code of Ethics* may open with a policy statement that captures the overarching goals enshrined in the *Code*. It will likely then lay out a suite of guiding principles for all research that occurs. Many First Nations communities will choose to include the OCAP (ownership, control, access and possession) principles within their *Code of Ethics*. The *Code of Ethics* will also lay out the operational procedures for conducting research, including the obligations that must be fulfilled by the different research partners through the course of the research, what will happen to collected data, how and what information will be communicated and in what format. Finally, it may also provide a framework for evaluating applications to do

³¹ First Nations Centre. (2007b). *Considerations and Templates for Ethical Research Practices*. Ottawa: National Aboriginal Health Organization [online: www.naho.ca/firstnations/english/documents/toolkits/FNC_ConsiderationsandTemplatesInformationResource.pdf, Feb 3, 2009].



research that are received from external applicants. The evaluation criteria provide a baseline for considering the merits of a potential research project. The *Code of Ethics* establishes rules and procedures for new research projects. For examples of Codes of Ethics, see: Mi'kmaw Ethics Watch, 2000;³² and First Nations Regional Longitudinal Health Survey (RHS), 2007.³³

Research Agreements & Data-sharing Protocols

A *Research Agreement* will generally accompany a *Code of Ethics*, providing a formal, binding contract between researcher(s) and the community that details how the elements of the *Code of Ethics* will be upheld.³⁴ The *Research Agreement* “ensures that the research process is transparent, that interests are appropriately balanced, and that all parties understand and agree on a range of issues”.³⁵ For example, a *Research Agreement* may identify the projected research outcomes, as well as possible risks and benefits of a project for the researcher(s) and for the community. In so doing, there will also be room in the Agreement for explanation of how the potential risks will be mitigated. In signing the *Research Agreement*, researcher(s) will agree to fulfill certain obligations to the community and to follow an agreed-upon set of steps in collecting, sharing, disseminating and storing data. The *Research Agreement* will also identify research funding sources. This creates space within the agreement for researcher(s) to identify upfront whether there are any criteria for disclosure of information, dissemination of findings and other external responsibilities that will affect the researcher(s)' ability to fulfill their obligations and responsibilities, as laid out in the *Code of Ethics* and *Research Agreement*. A well-crafted research agreement will be produced in the language(s) most relevant to the First Nation.

³² Mi'kmaw Ethics Watch, *Research Principles and Protocols*, Mi'kmaq College Institute, Cape Breton University. [online: <http://mrc.uccb.ns.ca/prinpro.html>, March 17, 2009].

³³ *First Nations Regional Longitudinal Health Survey – Code of Research Ethics*. Online: www.rhs-ers.ca/english/pdf/rhs-code-of-research-ethics-2007.pdf, March 2009, revised version, adopted by the First Nations Information Governance Committee (FNIGC).

³⁴ First Nations Centre, 2007b.

³⁵ *Ibid*, 5.



A *Data-sharing Protocol* is a formalized agreement that addresses use and sharing of data and information in cases where a First Nation already has ownership, control and possession of a data set.³⁶ The intent and principles of data ownership, sharing, storage and confidentiality will likely be quite similar to a First Nation-produced *Research Agreement*, but it will address the specific case where there is an outside request for data and information to be shared. Again, the First Nation establishes the rules of conduct for sharing its information. The *Data Sharing Protocol* is a binding agreement of principles and obligations that researcher(s) must use throughout the research project and upon its completion. Establishing rules for collection, use, storage, disclosure and analysis of data prior to the project commencing provides a tool “for protecting individual and community interests, information and privacy”.³⁷

All of the above tools are helping to establish appropriate standards of practice for researchers working with First Nations. By putting binding expectations in writing, they help to eliminate the possibility of misunderstandings and gross misconduct by researchers. A good *Code of Research Ethics* and set of formalized agreements (whether they are called *Research Agreement*, *Data-sharing Protocol* or other) helps to lay out a set of principles to be followed whenever research is conducted with a First Nation and also helps govern how partners are collecting, using, storing, and disclosing data and information. For examples of research protocols, see: Inter Tribal Health Authority, 2005,³⁸ and Six Nations Council Ethics Committee Protocol.³⁹

The remainder of this section provides some guiding questions and guiding principles that are often incorporated into community research protocols and agreements. Potential researchers can use these descriptions to better understand why certain elements might be included in a research protocol. Many of the included principles were identified and described by elders and healers during a roundtable on ethical guidelines for conducting Aboriginal research.

³⁶ *Ibid*, 6.

³⁷ *Ibid*, 6.

³⁸ Van Bibber, Marilyn and Anne George. (2005) Inter Tribal Health Authority *Research Protocol, DRAFT*. [online: www.turtleisland.org/healing/itharesearch.pdf, Feb. 20, 2009].

³⁹ Available online: www.sixnations.ca/admEthicsProtocolandGuidelines.pdf, Feb. 20, 2009.



Using a Research Protocol – Guiding Principles for Potential Researchers

It is important for potential researchers to take time to reflect upon their research project and to consider its potential impacts (both negative and positive) on participants including First Nations. In doing so, the basic design of the research can begin to account for potential ethical challenges. Dealing with these issues upfront, and as they arise throughout the project, creates the opportunity for a well conceived research plan that holds ethical principles as its central guiding priority. Potential questions that a researcher may consider during the course of articulating her/his research project include: How does cultural protocol shape the research project? What is the overarching goal of the research project and who will it most benefit? How will the research project benefit the community where the research occurs? What are the potential risks facing research participants and how can these be minimized?

As discussed above, some First Nations communities and First Nations organizations have their own research protocols that provide specific instructions on research requirements for potential researchers while others have yet to produce their own protocols. In all cases, it is useful for researchers to understand the underlying goals that research protocols are designed to achieve, and the background to why these goals are central to completing sound, ethical research. A discussion of these research protocol guiding principles is below:

Community Engagement:

Approval by Community

Potential researchers must gain community approval prior to commencing their research projects. This is required, regardless of whether the potential researcher is an “insider” or an “outsider” in the community where the research will occur. The research relationship, and approval of a proposed research project, **is not a given**. This approval must be negotiated and agreed to through a written agreement or



contract that is acceptable to all parties, but most importantly, to the **researched** individuals.⁴⁰

In most cases, permission or a letter of support from Chief and Council represents community “approval”. Approval may also include establishing an advisory committee of elders and other community members. During this phase of the research, the researcher will begin to establish relationships with community members. The researcher will work with the chosen advisors to design the research project.

It is essential that the community be involved from the stage of research conception through to dissemination and storage of information and data.⁴¹ The researcher must be prepared to renegotiate research design with the advisory committee and to be accountable to those representatives. In some cases, a researcher may be asked by their advisory committee to redraft a report or provide information in more accessible formats or venues to ensure that it is properly communicated with the community. The ethical challenges associated with a given project may change as the project progresses. As a result, the advisory committee may require a researcher to incorporate a more flexible ethical review process that is integrated into all stages of the project, rather than simply completing this review one time, prior to starting the research.⁴²

Research Paradigm Vetted by Community

It is important for outsider researchers to understand that their research must fit into an Indigenous knowledge paradigm, recognizing and accepting “the validity of indigenous knowledge in its own right”.⁴³ This means starting from a place of respect

⁴⁰ Schnarch, 2004: 84.

⁴¹ Martin-Hill & Soucy, 62.

⁴² Maritime Centre of Excellence for Women’s Health. (2000). “Community-Based Research Ethics” *Moving Towards Women’s Health*. No. 5: 1.

⁴³ Martin-Hill & Soucy, 62.



and being open to an entire overhaul of the research project during the community approval process.

Ensuring cultural safety and respect are top priorities in planning any research project. Research must value the diverse knowledge of health and environmental issues as well as unique world views and value systems. The benefits are mutual, and there is reciprocity between Indigenous and western research approaches that must be understood and applied so that the research makes the greatest possible contribution to knowledge production within Indigenous and western knowledge paradigms. It is important for researchers to understand that some things cannot be researched - according to an Elder's statement on environmental issues: "genetic engineering is not acceptable. Sacred sites, artifacts, and lands must be honoured, protected and restored. Benefits derived from natural resources must be shared equally with Indigenous peoples".⁴⁴

In a lot of 'forward thinking' research, funding bodies and outside academics have begun to acknowledge that local and traditional knowledge should be incorporated into a given research project. It is important that this collecting, interpretation and use of indigenous and traditional knowledge is carried out within a framework that is acceptable to the community members sharing that information. OCAP principles provide a useful important framework for approaching this process and for ensuring that all knowledge remains in the ownership, control, access and possession of its holders only and they these knowledge holders get to determine who has access to all data and knowledge. Researchers must understand that incorporating traditional and local knowledge into research projects is not an invitation for researcher(s) to mine knowledge from a community. It is up to each First Nation to determine how much information should be shared, how it should be shared and how it should be stewarded.

The protection and stewardship of First Nations' traditional knowledge (intellectual property) has become increasingly complex as a result of the development of

⁴⁴ *Ibid*, 57.



national and international intellectual property regimes. As discussed in the preceding section on *Intellectual Property*, it has become necessary for First Nations to defend their intellectual property from within these regimes. This creates a significant challenge, as much of the philosophy upon which these regimes are based runs contrary to First Nations worldviews. Despite these challenges, First Nations and Indigenous Peoples will continue to assert their rights from within intellectual property regimes in order to ensure that they are recognized, upheld and protected.

Transparent Process

The entire research process must be characterized by transparency. This includes providing a comprehensive research plan from the start that explains why the research is being conducted and why the identified principal investigator is qualified to do the job. This plan should also provide means for the community to hold the researcher(s) accountable for work completed and for providing the collected data and information back to the community in the agreed upon way. Finally, the research plan should explain how the research will enhance existing knowledge and projects that are ongoing in the community and that relate to the topic of research being pursued. All of this information should be laid out beforehand, in a clear and accessible format of the community's choosing, so that community members can assess the costs and benefits of the proposed research and determine whether they want to participate and/or change any aspect of the research project prior to it commencing.⁴⁵

Respect for Local Protocols and Adherence to Research Protocols

In preparing to conduct research, and in completing the research project itself, it is up to the researcher to put elders' and community members' needs first. In the case of elders, this means traveling to elders' preferred location for meeting and reimbursing elders at consultant rates for providing their time and expertise. It also means accounting for language differences, and ensuring that sufficient translation is

⁴⁵ *Ibid.* 52.



provided to people wishing to speak in a language that the researcher does not understand.

In the process of establishing relationships with community members prior to commencing research, the researcher will become acquainted with local protocols for holding meetings, engaging community members and conducting research. These customs will not necessarily be captured in entirety in a community's research protocol. In cases where no formal research protocol exists, the research cannot go forward until a protocol has been developed and approved by the community and its leadership.

Proper Time Commitment

In many cases, it takes more time and money to conduct research ethically. For researchers attempting to conduct themselves in an ethical fashion, it will be necessary to withstand pressure to complete projects according to rigid funding timelines and external expectations for publication.

Research within Indigenous communities involves establishing personal relationships and committing to involvement over a long period of time. Any researcher entering a community must understand this time commitment and understand that it is inappropriate to enter a community, gather data and then disappear, leaving the community wondering what is next. The researcher remains accountable, and must follow up with the community where the research occurred, providing the results in an accessible format, answering questions and being available to assist with ongoing research based on new questions that emerge as the project unfolds. All publication and dissemination of findings must be completed according to the community's terms and conditions.

Research Outcomes:



Partnerships

Properly laid research plans will result in strong partnerships and equitable outcomes for participants and researchers. All information should be shared in a way that recognizes indigenous concerns about knowledge ownership and knowledge transfer.

Foster Indigenous Employment

Ensuring indigenous employment as part of any research project is essential. Under the existing academic research system, researchers who receive money generally use this money to fund their own graduate students. This approach privileges youth from outside of the community who happen to be at a certain university, instead of prioritizing involvement of youth from within a community. Research in First Nations communities should privilege those youth who are dedicated to their language, culture and Elders.

In many cases, funding guidelines for First Nations-based research will stipulate that capacity development must be achieved. It is important to unpack this statement, and to consider what types of capacity development are required and desired within a given community. First Nations governments will establish their own priorities for where additional capacity is required. In many cases, 'capacity' is merely a word used to replace 'funding' – often the skilled person is already present, but consistent and regular funding to pay that person is not. This may not at first seem to be an ethical issue, but it is important to establish individual research projects within a continuum of knowledge gathering and community development. Identifying what types of skills workers will need to help build a stronger social network is central to successful community development. This, in turn, will help communities to identify which areas require research and which areas simply require additional funds for ongoing project implementation. This attention to capacity needs is a way of contextualizing potential research projects so that they fall within broader plans for community and regional development initiatives.



In addition to fostering employment, any revenue that is generated through research publications that come from a project should be shared with the community or the individuals who were directly involved. This provides a means of acknowledging that the research could not have unfolded without the capacity assistance and expertise offered by members of that community who participated in the research.

A Closer Look at Community Research Protocols – Areas of Divergence

There are many areas of possible divergence among research protocols, as has been alluded to through out the preceding discussion and its emphasis on the need to consult individual research protocols for their guidance prior to proceeding with a research project.

Considering the question: *Who has authority in the area of Traditional Knowledge?*, provides insight into the complexity of issues that research protocols address, and the reason that individual research protocols end up differing from one and other.

In the case of traditional knowledge, Elders are generally recognized as the holders of this knowledge. Therefore, some First Nations may not provide their political leadership with the authority to give permission to researchers to gather traditional knowledge when these leaders are not the knowledge holders. Communities may identify alternate governing body(s) with the authority to grant permission to collect traditional knowledge.

In other cases, communities have decided that Chief and Council do have the authority to give permission to researchers to establish a research project. In these cases, researchers still may be required to work with an ethics board or committee that is external to Chief and Council that acts as a gatekeeper for researchers to work with through the course of their project.

Individual communities will determine: who will be the knowledge holder / carrier / keeper for the community; what criteria will be in place for selecting this knowledge holder; who will choose which Elders sit in an ethics board. For the potential researcher, it is essential to



understand that there will not be a single ‘correct’ way to approach all First Nation communities, and that individual First Nations will provide guidance to prospective researchers on how to proceed and what approval is required prior to doing so.



Conclusions

This paper has highlighted and discussed a range of challenges facing potential researchers and First Nations in conducting ethical research projects. The progress made in First Nations' agency and self-determination through development and application of the OCAP principles is encouraging, and provides a model for moving forward in the field of ethical research as a whole. The next major challenge facing First Nations is to ensure that their intellectual property rights are protected, respected and upheld in domestic and international intellectual property regimes. Solutions to this challenge will unfold within the broader terrain of working toward a fundamental shift of the balance of power and strengthening of First Nations' rights to self-determination and sovereignty.

Ongoing and future research involving First Nations is helping to provide important information and knowledge development within communities in support of sustainable development at the Nation, region and community level. Working with a deep understanding of the inherently political nature of research, researchers can significantly strengthen their research by accounting for ethical concerns and allowing these concerns to shape the direction and content of their research. Research that is based on the principle of respect for all participants within a research project will help to establish healthy research projects involving First Nations that can, in turn, gather important information in support of particular First Nations' research, development and community sustainability goals.



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