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# Ethics of Biological Sampling Research with Aboriginal Communities in Canada

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## Abstract

**Background:** The objective of this paper is to identify key ethical issues associated with biological sampling in Aboriginal populations in Canada and to recommend approaches that can be taken to address these issues.

**Methods:** Our work included the review of notable biological sampling cases and issues. We examined several significant cases (Nuu-chah-nult people of British Columbia, Hagahai peoples of Papua New Guinea and the Havasupai tribe of Arizona) on the inappropriate use of biological samples and secondary research in Aboriginal populations by researchers.

**Results:** Considerations for biological sampling in Aboriginal communities with a focus on community-based participatory research involving Aboriginal communities and partners are discussed. Recommendations are provided on issues of researcher reflexivity, ethical considerations, establishing authentic research relationships, ownership of biological material and the use of community-based participatory research involving Aboriginal communities.

**Conclusions:** Despite specific guidelines for Aboriginal research, there remains a need for biological sampling protocols in Aboriginal communities. This will help protect Aboriginal communities from unethical use of their biological materials while advancing biomedical research that could improve health outcomes.

**Keywords:** bioethics, biological sampling, DNA, aboriginal peoples, Canada, community-based participatory research

## 1. Introduction

General agreement exists in the literature that Aboriginal populations are commonly targeted for health research (e.g., the Yanomamö communities in Venezuela and Brazil) suggesting that they need to protect their communal identity, social structures and rights in biomedical research (Arbour & Cook, 2006; Castellano, 2004; Weijer & Anderson, 2002; Weijer, Goldsand, & Emanuel, 1999; Williams, Chagnon, & Spielman, 2002; Wilson & Young, 2008). Despite centuries of colonialism, Aboriginal communities are becoming more self-sufficient (Aboriginal Affairs Northern Development Canada, 2014); they are moving towards self-determination but may need specific research ethics guidelines that protect their communities, their peoples and their genetic material. The term 'Aboriginal' is defined in Section 35 of the Canadian Constitution and refers to people who are legally recognized as Indian, Inuit, or Métis (Indian and Northern Affairs Canada, 2004). Other terms used interchangeably in the literature are First Nations, American Indians, or Indigenous.

In 2011, the Aboriginal population in Canada was 1,400,685 and accounted for 4.3% of the Canadian population (Statistics Canada, 2013). The Aboriginal population has increased by 20.1% since 2006 while the non-Aboriginal population has increased by only 5.2% (Statistics Canada, 2013). This growth in population could have implications for health outcomes, health policy, and health service delivery. Aboriginal peoples suffer

disproportionately from diseases as compared to non-Aboriginal peoples partly due to the social determinants of health and distinctive genetic differences (Waldram, Herring, & Young, 2006). Research has shown that Aboriginal peoples tend to experience disparities in health status and have unequal access to health services when compared to non-Aboriginal populations (Frohlich, Ross, & Richmond, 2006). In addition, research has found that Aboriginal populations tend to have shorter life expectancies, higher rates of mortality from accidents or injuries and higher rates of chronic health conditions (Castellano, 2004; Macmillan, Macmillan, Offord, & Dingle, 2000; Waldram et al., 2006; Wilson & Young, 2008). The continued growth of the Aboriginal population in conjunction with the above mentioned health disparities supports the need to continue health research with Aboriginal populations and to better understand how to improve health outcomes. McCormick (1998) states, "To not conduct research with [Aboriginal] populations would be considered unethical. (pp. 291-292)" Since then, health research has expanded in Canada, however, negative experiences with government and academic researchers has resulted in Aboriginal peoples feeling apprehensive about participating in research (Castellano, 2004; Poff, 2006). Smith (1999) articulates the reaction many Aboriginal peoples have when confronted with the word research:

The word itself 'research', is probably one of the dirtiest words in the indigenous world's vocabulary. When mentioned in many indigenous contexts, it stirs up silence, it conjures up bad memories, and it raises a smile that is knowing and distrustful. The ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the world's colonized peoples (p. 1)

Historically, Aboriginal peoples have been deceived and mistreated as research participants (Castellano, 2004; Poff, 2006; Dodson & Williamson, 1999; Weijer, Goldsand, & Emanuel, 1999). In addition, research has often been misguided and harmful towards Aboriginal peoples, and there is a fear of losing funding for essential services if research requests are denied (Castellano, 2004). Concerns lie with the motives of the researchers, misuse and exploitation of data, and unrelated secondary research that was not originally agreed upon (Weijer & Anderson, 2002).

Researchers should strive for a balance between research benefits for Aboriginal populations while mitigating the risks to Aboriginal participants (Castellano, 2004). Aboriginal peoples have been politically active for decades and have fought for their rights in a number of different areas. Research is one area where Aboriginal peoples have been taking greater control, particularly in the area of research ethics (National Aboriginal Health Organization, 2005). In response to unethical research practices, some Aboriginal communities such as Akwesasne, Kahnawake and Manitoulin Island have developed their own research ethics guidelines (Manitoulin Anishinaabek Research Review Committee, 2003). These communities used elders, sharing circles and community forums to identify important community needs regarding research in order to develop their frameworks. Biomedical research can be beneficial if it advances the techniques for managing diseases that affect the Aboriginal population (Jacobs, Roffenbender, Collmann, & Cherry, 2010) but there is a need to do so in a manner that is culturally relevant and ethical.

The objective of this paper is to identify key ethical issues associated with biological sampling in Aboriginal populations in Canada and to recommend approaches that can be taken to address these issues.

## **2. Methods**

The data were collected using PubMed and Google Scholar databases as well as through searching reports related to biological sampling with Aboriginal populations and through the use of the snowball technique (e.g., reviewing references of collected articles for additional references in peer review, government and grey literature).

To be considered relevant and included in the study, the paper had to meet the following criteria: 1) evaluated or discussed research involving biological samples in the Aboriginal context; 2) findings were limited to English; and 3) evaluated and discussed research that is relevant and applicable to the Canadian context. Articles pertaining to health research were included, while articles focused on culture and environment were excluded. The intent was to review research ethics guidelines developed by Aboriginal communities and to identify issues surrounding biological sampling. This review was conducted at the request of an Aboriginal community based research ethics committee located on Manitoulin Island in northeastern Ontario. The community based research ethics committee is seeking guidance in dealing with research projects that have a biological sampling component.

## **3. Results**

### *3.1 A Review of Notable Biological Sampling Cases and Issues*

Our review comprises two key areas: a review of notable biological sampling cases and issues; and

considerations for biological sampling in Aboriginal communities with a focus on community-based participatory research involving Aboriginal communities and partners.

Social and biomedical research that has taken place in Aboriginal communities has been widely criticized by Aboriginal peoples (Castellano, 2004). The main reasons for these criticisms is that “the purposes and meaning associated with [research on Aboriginal communities] by academics and government agents were usually alien to the Aboriginal people themselves and the outcomes were, as often as not, misguided and harmful” (Castellano, 2004, p. 98). Therefore, research has historically been a source of unease and distress in Aboriginal populations (Arbour & Cook, 2006; Castellano, 2004; Cochran et al., 2008). Some of the criticisms include “lack of involvement of the community in the planning of the project, insensitivity to cultural beliefs, ... potential stigma of research results, lack of feedback to the community once a project is completed, commercial ownership of DNA and overall impressions of exploitation of the communities” (Arbour & Cook, 2006). Furthermore, there are concerns about insensitivity to cultural beliefs around the human body and human tissue samples.

There are several public cases about the inappropriate use of biological samples and secondary research in Aboriginal populations by researchers. In one Canadian case, blood samples collected from a First Nation community in British Columbia (800 people of Nuuchahnulth origin) that were supposed to be used to study rheumatic disease but were instead used to establish ancestry lines (Arbour & Cook, 2006; Atkins et al., 1988). This case raised awareness of the mistreatment of Aboriginal populations in research studies. The importance of building a solid partnership allows researchers to adapt to the study environment and earn the trust of the Aboriginal population, which in turns, signifies the recognition of their rights of self-determination. Moreover, there’s an emphasis on “community respect,” as opposed to just individuals, in order to address concerns regarding to the community as a whole keeping Aboriginal heritage out of harm (Weijer & Anderson, 2002).

Similarly, in 2003, Havasupai tribe members in the United States discovered that their DNA samples, collected for genetic studies on Type II diabetes, had been used for studies on schizophrenia, migration, and inbreeding without their consent (Drabiak-Syed, 2010; Garrison & Cho, 2013). The lawsuit launched by the Havasupai tribe resulted in a settlement in April 2010 in which tribal members received monetary compensation and the return of their DNA samples (Garrison & Cho, 2013). It may also be an ethical issue if a researcher did not disclose the intentions of the study or obtain consent from the participants who provided the biological samples. Furthermore, the researchers might not share ownership with participants.

Another example of inappropriate use of biological samples was when the Hagahai of Papua New Guinea had sought outside assistance from the Institute of Medical Research (IMR) in the U.S., in collaboration with the National Institutes of Health (NIH), to deal with a disease (Taubes, 1995). The researchers discovered that the Hagahai peoples carried a gene that protected them from developing leukemia and the researchers made this the focus of another study without disclosure. While it was discovered that the Hagahai peoples suffered from an epidemic from a lack of adaptation and immunity as a result of social isolation, other research took place with their biological samples without consent (Jenkins, Dimitrakalds, Cook, Sanders, & Stallman, 1988). A nonprofit organization publicly accused IMR, the lead researcher, and collaborators from NIH of seeking a patent for this gene without obtaining consent from either the donor or the Hagahai community. In fact, the researchers did not seek a patent for a gene. Rather, they sought a patent for a cell line containing the benign variant of leukemia that was obtained from Hagahai blood samples.

The principal investigator stated that she obtained consent from participants, who were given half the royalties. However, the accusation was released publicly and excluded these details. The fact that many people believed this story illustrates the negative reputation of academic researchers among many Aboriginal peoples. These cases, and others like it, have been brought to public attention and have prompted some Aboriginal communities to become extremely cautious about research and for some to develop their own research guidelines (Arbour & Cook, 2006; Cochran et al., 2008).

Many Aboriginal peoples are rightly concerned about research involving biological sampling and genetic studies. Moreover, the current body of literature on Aboriginal health has been criticized for its lack of breadth and operationalized protocols on biological sampling with Aboriginal communities (Sanson-Fisher, Campbell, Perkins, Blunden, & Davis, 2006; Smylie & Anderson, 2006; Wilson & Young, 2008; Young, 2003).

There is national and international support for the protection of Aboriginal peoples and their biological materials. In 2007, the Canadian Institutes for Health Research published Guidelines for Health Research Involving Aboriginal People which addressed the use, proprietary interest, and storage and transfer of data and biological samples. The Guidelines are to be considered a resource document and research involving First Nations, Inuit and Metis peoples in Canada is now governed by provisions in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) released in 2014. Chapter 9 of the TCPS2 deals specifically

with research involving the First Nations, Inuit and Metis peoples of Canada. In addition, Chapters 12 and 13 address human biological materials and human genetic research. At the international level, article 31 of the United Nations Declaration on the Rights of Indigenous Peoples states that Indigenous peoples have the right “to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources...” (United Nations Declaration on the Rights of Indigenous Peoples, 2007).

However, TCPS2 must be developed further in order for Aboriginal peoples to be effectively autonomous in the research process (Stiegman & Castleden, 2015). While Aboriginal peoples have jurisdiction in approving a research proposal that has been submitted to a university Research Ethics Board (REB), there is no protocol for resolving conflicts between the two different groups. When a researcher wishes to carry out a study with Aboriginal peoples, the researcher must seek approval from the REB and the Indigenous ethics board (if one exists) and the community. If guidance from one group contradicts the other and the researcher follows the guidance of the Indigenous ethics board, the REB act as a gatekeeper for academic research and the researcher is compelled to follow what has been labeled as ‘procedural ethics’ (Guillemin & Gillam, 2004). Such an approach is immersed in a positivist epistemology of controlled laboratory settings that adhere to a linear scientific positivist methodology (Stiegman & Castleden, 2015).

Although the TCPS2 provides the minimum standard of protection for Aboriginal peoples in research, particularly biological sampling, it does not allow Aboriginal peoples much autonomy in how a study is carried out. Stiegman and Castleden (2015) relate an experience in which they submitted a research proposal to the university based REB. The proposal was revised several times and ultimately, the approved method was inflexible to potential changes throughout the research process as advised by the Indigenous ethics board. These authors state that they were able to carry out CBPR despite, and not because of, the TCPS2. While the TCPS2 progresses towards protecting Aboriginal peoples in biomedical research, it requires further development to decolonize Aboriginal research.

In Canada, Aboriginal community groups such as the Akwesasne Task Force Environment (ATFE), the Cree Board of Health and Social Services of James Bay Research, Kahnawake School Diabetes Program Code of Research Ethics (KSDP), Six Nations and the Manitoulin Anishinaabek Research Review Committee have developed their own codes of ethics based on principles of equity, empowerment, ownership, collaboration and respect. While none of these codes deal explicitly with the handling of biological samples, all of them stipulate that the use of data (including collection of samples) must be by permission of the community. The lack of community specific guidelines on biological sampling leaves a gap in the literature and in research practice. The importance of creating specific guidelines for research with Aboriginal peoples that addresses biological sampling will help protect communities and provide guidance to researchers.

#### **4. Discussion**

##### *4.1 Considerations for Biological Sampling with Aboriginal Populations*

Research that requires biological samples leaves genetic material vulnerable to patenting and Aboriginal peoples are extremely cautious about this type of research. Researchers must understand that working with Aboriginal peoples requires an understanding of the unique nature and complexity of negotiating community consent and the importance of trust and relationship-building (Flicker & Worthington, 2012). Researchers must also build a trusting relationship with Aboriginal peoples (Fletcher, 2003). In order to conduct research with Aboriginal communities, a balance between meeting the goals of the research while protecting participants should be met (George et al., 2007). Moreover, improving the health of Aboriginal communities’ warrants researchers to collaborate with the community and identify research priorities and determine benefits. Outcomes will reflect a common interest of both researcher and the community (Smylie & Anderson, 2006).

Researchers must negotiate ownership of the biological samples, identify who will have access to the samples, where the samples will be stored, the limits on how the samples can be used and what will be done with the samples once the study is complete. These stipulations should be made prior to the collection of any samples and documented in a research agreement. In addition, the research agreement should outline the obligations of both the researcher and the participating community (National Aboriginal Health Organization, 2007)

Arbour and Cook (2006) suggest that DNA be considered ‘on loan’ to researchers for the duration of a research project. This way, the community and the participants retain the ability to determine the future handling and use of the biological samples. The researcher should not have the authority to use the samples for any other purpose unless the community and individual participants provide free, prior and informed consent. If genetic research is a priority, issues for consideration should include: the use of genetic information, privacy and confidentiality, psychological impact, reproductive issues, and the control and impact of commercialization (e.g., Human

Genome Project). Researchers wanting to ‘borrow’ biological samples from Aboriginal peoples should develop a research plan in collaboration with the community (CIHR). Researchers must obtain free, informed and prior consent for the secondary use of biological samples originating from Aboriginal populations and individual participants must re-consent (Tri-Council Policy Statement, 2015).

Research with Aboriginal populations may be subject to approval by both an institutional Research Ethics Board and an Aboriginal community research ethics board (REB) (Table 2). Ethics review processes are intended to protect participants and communities from risks that research can pose. In situations where an institutional REB’s policies are not consistent with an Aboriginal community’s policies or guidelines, the REB should defer to the community’s priorities, needs, values and knowledge systems (Weijer & Anderson, 2002; Weijer et al., 1999).

Table 1. Biological sampling issues and ethical consideration with aboriginal population

Title	Purpose	Method	Results	Conclusion	Research Significance
<i>DNA on loan: issues to consider when carrying out genetic research with Aboriginal families and communities-(Arbour &amp; Cook, 2006).</i>	The paper aims to explore practical ways of maintaining a respectful research relationship when genetics research with Aboriginal peoples is being conducted.	Examined Canadian guidelines that defined ethical research in Aboriginal communities. Included insight from numerous Aboriginal community research studies to evaluate the current respect for Aboriginal communities and identified how it can be improved.	Various methods are used to respect Aboriginal communities. Community-based participatory research (CBPR) focuses on research that reflects the needs of the community and respects the Aboriginal culture and values. Biological samples are considered to hold traditional and spiritual significance. Therefore, all blood and tissue accepted for research in Aboriginal communities is considered to be ‘on loan’ to the researcher.	When research requires a genetic component, there are several issues that must be addressed. Respect for accepted method of CPBR and the biological sample ‘on loan’ is required for success of the project.	A raised awareness of the mistreatment of Aboriginal populations in research studies has been noted. The importance building a solid partnership allows researchers to adapt to the study environment and earn the trust of the Aboriginal population, which in turns, signifies the recognition of their rights of self-determination.
<i>Scientists Attacked for ‘Patenting’ Pacific Tribe (Taubes, 1995)</i>	The paper examines the case of medical anthropologist Carol Jenkins and the accusation that she and her employer Papua New Guinea Institute of Medical	The researchers had patented a virus-infected cell line form Hagahai blood.	Demonstrates the widespread distrust among indigenous populations and the scientific community regarding	The National Institutes of Health in the U.S. sought patent protection for a cell line developed from the DNA of a Hagahai donor and ultimately to the development of a vaccine and other therapeutic interventions.	Research with indigenous communities including the Hagahai should be conducted with prior, free, and explicit informed consent

<p><i>Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignity Harms as Legitimate Risks Warranting Integration into Research Practice (Drabiak-Syed, 2010)</i></p>	<p>Research and the National Institutes of Health stole Hagahai genes.</p> <p>The paper describes the Arizona State University's research efforts in Havasupai community, the process of blood sample collection, the scope of the Havasupai tribes consent, and the problems with the project's overall research design.</p>	<p>The author suggests that investigators, academic and research centers may still fail to recognize how research involving Native American tribal blood samples can harm individual participants and the tribes because of the spiritual and cultural significance of these materials</p>	<p>Provided an overview of the Havasupai Tribe v. Arizona State University, its legal and cultural implications and recommendations. Demonstrates the importance of developing trusting, long-lasting meaningful relationships in working with Native American tribes.</p>	<p>Recommendations on how procedures and protocol can adhere to standards that protect the rights and welfare of Native American participants. These recommends offer a re-aligned of research standards from the viewpoint of the participants.</p>	<p>Genetic research using the biological materials from an individual within a Native American group involves the rest of the tribe. Therefore, the individual shares the genes with the rest of the tribe, information that the research exposes about the individual also reveals the characteristics of the group</p>
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Table 2. Selected Aboriginal community/organization research protocols

Name of Community/Organization	Ethics protocol or guidelines currently implemented	Characteristics of protocol
<p>Mohawk Council of Akwesasne (Mohawk Council of Akwesasne, 1996)</p>	<p>Akwesasne Task Force on the Environment Research Advisory Committee Protocol for Review of Environmental and Scientific Research Proposals</p>	<p>The basis of the Akwesasne Good Mind Research Protocol is the principals of peace, good mind, strength, respect, equity and empowerment. The purpose of this research protocol is to protect the community, to empower the community, to control the research process and to protect their data. Another aim of this research protocol is to develop good working relationships between the community and the researcher.</p>
<p>The Cree Board of Health and Social Services of James Bay (Cree Board of Health and Social Services of James Bay, 2009)</p>	<p>Code of Ethics (Guide for Interveners and Users of the Pathways to 'Miyupimaatisiun)</p>	<p>The Code of Ethics is a guiding instrument concerning the actions and interactions of all stakeholders involve in the course of service delivery to people. Moreover, it is based on a vision statement and its expressed values are the foundation of the Code of Ethics. It recognizes each individual's right to receive appropriate, adequate, and continuous health and social services. The Code of Ethics is one of the guidelines used to evaluating research propoals.</p>
<p>Mohawk Council of Kahnawake (Mohawk Council of Kahnawake, 2007)</p>	<p>Kahnawake Schools Diabetes Prevention Program Research Code of Research Ethics</p>	<p>This Code of Research Ethics establishes a set of principles and procedures that will guide the research partners to achieve the goals and objectives of the Kahnawake Schools Diabetes Prevention Project</p>



		(KSDPP).
Six Nations (Martin-Hill & Soucy, ND)	Ganono'se'n e yo'gwilode' One Who is Full of Our Traditional Knowledge - Ethical Guidelines for Aboriginal Research Elders and Healers Roundtable	The Six Nations Ethics Committee developed specific guidelines for accessing biomedical knowledge consisting of ten protocols. These guidelines govern researchers who wish to conduct research in Six Nations.
Yukon Research Centre, Yukon College (Yukon Research Centre, 2013)	Protocols and Principles for Conducting Research with Yukon First Nations	An institutional protocol for researchers associated with Yukon College who wish to conduct research with First Nations in the Yukon. The approach to this protocol is consistent with Yukon First Nations self-determination and encourages researchers to honor the principles of partnerships, protection, and participation.
Manitoulin Anishinaabek Research Review Committee (Manitoulin Anishinaabek Research Review Committee, 2003)	Guidelines for Ethical Aboriginal Research (GEAR)	The guidelines were developed by seven First Nation communities and are based on the seven grandfather teachings of respect, wisdom, love, honesty, humility, bravery and truth.
Mi'kmaw Ethics Watch (Mi'kmaw Ethics Watch, 2014)	Mi'kmaq Ecological Knowledge Study Protocol 2nd Edition	The Mi'kmaq Ecological Knowledge Study Protocol (MEKS) provides guidelines and standards on practices and procedures relevant to the planning, design, development, implementation and reporting stages of a research project.
Royal Commission on Aboriginal Peoples (RCAP) research ethics (Royal Commission on Aboriginal Peoples 1996)	Ethical Guidelines for Research.	These guidelines were developed to ensure that in all research sponsored by the RCAP, appropriate respect is given to the cultures, languages, knowledge and values of Aboriginal peoples. The guidelines include considerations of Aboriginal knowledge, using collaborative research approaches, promoting community benefit.
Inuit Tapirisat of Canada - Negotiating Research Relationships: A Guide for Communities (Inuit Tapirisat of Canada)	Negotiating Research Relationships: A Guide for Communities (Inuit Tapiriit Kanatami) Negotiating Research Relationships with Inuit Communities: A Guide for Researchers	Researchers: The guide provides practical advice to assist researchers who plan to work with Canadian Inuit communities. It presents some core universal themes in communication and relationship-building that apply to researchers working in the Canadian North.  Communities: A guide to assist Inuit to set priorities for research and to influence how research is conducted in their communities. The document provides information about research relationships, legal rights and offers ways for collaboration and partnerships in research activities.

Researchers can establish an “authentic research relationship” throughout a project in an effort to practice community-based participation (Bull, 2010). In Labrador, Canada, Bull (2010) carried a study to look at the effect of practicing “authenticity” on Aboriginal individuals’ experience in participating in research. This is a process in which a project is developed and guided by both the researcher and the community. In this way, the researcher learns about the environment (physical, social etc.) in which they are carrying out their study in the context and perspective of Aboriginal culture. Stiegman and Castleden (2015) stated that the guidelines of the university REB were sometimes not in agreement with those of the Indigenous ethics boards. Furthermore, the guidelines of the REB took precedence in these cases. One way in which this can be resolved is to practice authenticity. Authenticity can be practiced by obtaining consent (which includes building a relationship with the community from the beginning of the project and establishing a mutual agreement between both researchers and participants), ensuring that participants are well-informed and that the researcher’s project is reviewed upon any concerns stated by the participants, ensuring that the participants play a role in the project by providing them

with the results and conducting research that is initiated by the Aboriginal people themselves, as well as research that is beneficial to the community (Kovach, 2009).

In addition, researchers can practice “reflexivity” to develop skills in “ethics in practice”. Guilleman and Gillam (2004) propose that researchers should be as concerned with the well-being of their research participants as they are with conducting their study. In this way, the participant plays a role in how the study is carried out. In the context of Aboriginal peoples, this technique can be used in the effort to decolonize academic research. Reflexivity is a possible technique by which researchers can become aware of potential ethical issues that arise when they conduct a study, and develop skills in how to respond in these situations.

Community-Based Participatory Research (CBPR) is an approach that may be suited to assisting Aboriginal communities in dealing with biological sampling because it focuses on social and structural inequities and aims to empower Aboriginal populations (Jacobs et al., 2010). CBPR requires an equal partnership between researchers and Aboriginal communities throughout the entire research process in order to understand and address health concerns amongst Aboriginal populations (Israel, Schulz, Parker, & Becker, 2001). An important aspect of this approach is the recognition of Aboriginal peoples’ sovereignty. Furthermore, benefits for the Aboriginal population are prioritized. The exploration in the attempts and successes of the use of CBPR provide recommendation for future research studies. Efforts in CBPR studies emphasize the inclusion of community members and the social construction of knowledge (Fisher & Ball, 2003). Research engaging community members as active participants should specify the processes in which they are involved. A considerably amount of time is put into earning the trust of communities stipulating that communities retain ultimate control over data putting restrictions on researchers right to publish.

Community-based participatory research is beneficial for researchers by guiding them towards valid results and for Indigenous populations to address their research priorities (Ball & Janyst, 2008). LaVeaux and Christopher identify eight principles of CBPR including: respect for community identity, building on strengths and resources of the community, facilitating collaborative partnerships throughout the whole research process, integration of knowledge and action for mutual benefits, promoting co-learning, an iterative process ensuring post-research feedback is discussed with the community, addressing health from both positive and ecological perspectives, and disseminating findings to all partners (LaVeaux & Christopher, 2009). Although CBPR is very time-consuming and requires a long-term commitment with communities (Holkup, Tripp-Reimer, Salois, & Weinert, 2004), respecting these principles is necessary to conduct relevant research (LaVeaux & Christopher, 2009).

One method that can be used to practice CBPR is a modified version of Photovoice. Photography is a value form of data in qualitative research. In participant-employed photography (PEP), the participant, instead of the researcher, takes the photographs (Castleden & Garvin, 2008). The research topic can be seen from the perspective of the participant, achieving both a better understanding of the topic and the goal of shared ownership in CBPR. However, CBPR requires a lot of patience and caution. Data can easily be misinterpreted and the directionality of the intended objective can be misguided. CBPR can immensely benefit First Nations along with the research society when it is accomplished with carefulness (Holkup et al., 2004). Such an approach may be used to establish dialogue, and develop meaningful, long-lasting trusting relationship that may lead to additional research opportunities (e.g., biological sampling).

When using a CBPR approach, the communities and researchers must come to an agreement about the ownership, control, access and possession of the data (National Aboriginal Health Organization, 2005). It is understood that whenever in disagreement that the community principles and values should always be deferred to (Flicker & Worthington, 2012). In order to support CBPR approaches, policy changes are recommended including funding research partnerships, capacity building and training for CBPR partners (Israel et al., 2001). By having Aboriginal communities as partners and collaborators, the ethics of biological sampling would be addressed during the development of the research project.

However, community-based participatory research has limitations (Leeuw, Cameron, & Greenwood, 2012). A researcher may make the effort to be ethical as he or she conducts his or her research. The researcher may characterize his- or herself as “good”. If the researcher is being insensitive to the needs of the participants (e.g. cultural or emotional), they may not perceive themselves as unethical as a result of characterizing themselves as “good”. In other words, they may be resistant to criticism and ultimately, resistant to change. An attempt to eliminate the hierarchy between the researcher and participant by making the participant an “equal partner” reinforces the existence of a difference and distance between researcher and participant, because the attempt assumes that there is a difference and distance to overcome in the first place. CBPR may replace traditional research approaches; however, CBPR may not be appropriate for every group of participants or context. For example, a participant may not be able to play a role in the study, and asking them to do so may actually be a burden. Thus, promoting CBPR may lead to its establishment as the main mode of research practice, however it

cannot be assumed CBPR is applicable in all situations. Lastly, it is difficult to reconcile the differences in opinion between the needs of the participants and the Indigenous ethics boards with university REBs. This is demonstrated by the experience of Stiegelman and Castleden (2015) when trying to gain approval by REB and practicing CBPR despite the TCPS2 in Canada. Therefore, while the CBPR approach can be carried out in an effort to overcome ethical issues in biological sampling for the purpose of health research with Aboriginal peoples, it may actually present disadvantages for these groups.

## 5. Conclusion

The need for biological sampling guidelines for research involving Aboriginal populations will likely increase as Aboriginal communities are faced with requests for biomedical research to be conducted. This undertaking presents two key areas: a review of notable biological sampling cases and issues; and considerations for biological sampling in Aboriginal communities with a focus on community-based participatory research involving Aboriginal communities and partners. A key component in conducting ethical research is actively involving Aboriginal communities throughout the entire research process (Arbour & Cook, 2006; Bull, 2010; Leeuw et al., 2012; Stiegman & Castleden, 2015). Developing a trusting relationship with Aboriginal communities and addressing the power imbalance can address the risks imposed by researchers and their history of betrayal in health research (Arbour & Cook, 2006). Collaborative research not only recognizes Aboriginal population's right of self-determination, but could have the potential to improve health measures, health tracking, health evaluations and overall health outcomes in Aboriginal communities by ensuring that the research is relevant (Castellano, 2004; Smylie & Anderson, 2006). This approach to research could also help address the health disparities that would be most relevant to affect Aboriginal communities (Wilson & Young, 2008).

## Competing Interests Statement

The authors declare that there is no conflict of interests regarding the publication of this paper.

## References

- Aboriginal Affairs Northern Development Canada. (2014). *Fact Sheet: Aboriginal self-government*. Ottawa, ON, Canada: The Government of Canada.
- Arbour, L., & Cook, D. (2006). DNA on loan: Issues to consider when carrying out genetic research with aboriginal families and communities. *Community genetics*, 9(3), 153-160. <http://dx.doi.org/10.1159/000092651>
- Atkins, C., Reuffel, L., Roddy, J., Platts, M., Robinson, H., & Ward, R. (1988). Rheumatic disease in the Nuu-Chah-Nulth native Indians of the Pacific Northwest. *The Journal of rheumatology*, 15(4), 684-690. PMID:3260954
- Ball, J., & Janyst, P. (2008). Enacting research ethics in partnerships with indigenous communities in Canada: "Do it in a good way". *Journal of Empirical Research on Human Research Ethics*, 3(2), 33-51. <http://dx.doi.org/10.1525/jer.2008.3.2.33>
- Bull, J. R. (2010). Research with aboriginal peoples: Authentic relationships as a precursor to ethical research. *Journal of Empirical Research on Human Research Ethics*, 5(4), 13-22. PMID:21133783. <http://dx.doi.org/10.1525/jer.2010.5.4.13>
- Castellano, M. B. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health*, 99.
- Castleden, H., & Garvin, T. (2008). Modifying Photovoice for community-based participatory Indigenous research. *Social science & medicine*, 66(6), 1393-1405. <http://dx.doi.org/10.1016/j.socscimed.2007.11.030>
- Cochran, P. A. L., Marshall, C. A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., & Gover, R. M. S. (2008). Indigenous ways of knowing: Implications for participatory research and community. *American Journal of Public Health*, 98(1), 22-27. <http://dx.doi.org/10.2105/AJPH.2006.093641>
- Cree Board of Health and Social Services of James Bay. (2009). *Guide for Interveners and users of the Pathways t "Miyupimaatisiun" Services*. Montreal, QC, Canada: Cree Board of Health and Social Services of James Bay.
- Drabiak-Syed, K. (2010). Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignity Harms as Legitimate Risks Warranting Integration into Research Practice. *J. Health & Biomedical L.*, 6, 175.
- Fisher, P. A., & Ball, T. J. (2003). *Tribal Participatory Research: Mechanisms of a Collaborative Model*, 32.

- Fletcher, C. (2003). Community Based Participatory Research Relationships With Aboriginal Communities In Canada: An Overview Of Context And Process. *Pimatisiwin: A Journal of Aboriginal & Indigenous Community Health*, 1(1).
- Flicker, S., & Worthington, C. A. (2012). Public health research involving aboriginal peoples: Research ethics board stakeholders' reflections on ethics principles and research processes. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 19-22.
- Frohlich, K. L., Ross, N., & Richmond, C. (2006). Health disparities in Canada today: Some evidence and a theoretical framework. *Health Policy*, 79(2), 132-143. <http://dx.doi.org/10.1016/j.healthpol.2005.12.010>
- Garrison, N. A., & Cho, M. K. (2013). Awareness and Acceptable Practices: IRB and Researcher Reflections on the Havasupai Lawsuit. *AJOB primary research*, 4(4), 55-63. <http://dx.doi.org/10.1080/21507716.2013.770104>
- George, M. A., Masotti, P., MacLeod, S., Van Bibber, M., Looch, C., Fleming, M., ... Smith, C. (2007). Bridging the research gap: aboriginal and academic collaboration in FASD prevention. The Healthy Communities, Mothers and Children Project. *Alaska medicine*, 49(2 Suppl), 139-141. PMID:17929623
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative inquiry*, 10(2), 261-280. <http://dx.doi.org/10.1177/1077800403262360>
- Holkup, P. A., Tripp-Reimer, T., Salois, E. M., & Weinert, C. (2004). Community-based participatory research: An approach to intervention research with a Native American community. *ANS. Advances in nursing science*, 27(3), 162. PMID:15455579 PMCid:PMC2774214. <http://dx.doi.org/10.1097/00012272-200407000-00002>
- Indian and Northern Affairs Canada. (2004). *Words First: An Evolving Terminology Relating to Aboriginal Peoples in Canada*. Ottawa, Ontario, Canada: Indian and Northern Affairs Canada.
- Inuit Tapirisat of Canada*. Negotiating Research Relationships: A Guide for Communities/(Inuit Tapiriit Kanatami) Negotiating Research Relationships with Inuit Communities: A Guide for Researchers Ottawa, Ontario, Canada: Inuit Tapiriit Kanatami.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for health*, 14(2), 182-197. PMID:14742017. <http://dx.doi.org/10.1080/13576280110051055>
- Jacobs, B., Roffenbender, J., Collmann, J., & Cherry, K. (2010). Bridging the divide between genomic science and indigenous peoples. *JL Med. & Ethics*, 38, 684. <http://dx.doi.org/10.1111/j.1748-720x.2010.00521.x>
- Jenkins, C., Dimitrakalds, M., Cook, I., Sanders, R., & Stallman, N. (1988). Culture change and epidemiological patterns among the Hagahai, Papua New Guinea. *Human ecology*, 17(1), 27-57. <http://dx.doi.org/10.1007/BF01047651>
- Kovach, M. E. (2009). *Indigenous methodologies: Characteristics, conversations, and contexts*. University of Toronto Press.
- LaVeaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin*, 7(1), 1. PMID:20150951 PMCid:PMC2818123
- Leeuw, S. d., Cameron, E. S., & Greenwood, M. L. (2012). Participatory and community-based research, Indigenous geographies, and the spaces of friendship: A critical engagement. *The Canadian Geographer/Le Géographe canadien*, 56(2), 180-194. <http://dx.doi.org/10.1111/j.1541-0064.2012.00434.x>
- Macmillan, H. L., Macmillan, A. B., Offord, D. R., & Dingle, J. L. (2000). *Manchette Aboiginal health*, 155(1/1), 1569-1578.
- Manitoulin Anishinaabek Research Review Committee. (2003). *Guidelines for Ethical Aboriginal Research (GEAR)*. Little Current, Ontario: Noojmowin Teg Health Centre.
- Martin-Hill, D., & Soucy, D. (n.d.). *Ethical Guidelines for Aboriginal Research Elders and Healers Roundtable: Indigenous Health Research Development Program to the Interagency Advisory Panel on Research Ethics*.
- Mi'kmaw Ethics Watch. (2014). *Mi'kmaq Ecological Knowledge Study Protocol* (2nd ed.). Truro, NS, Canada: Kwilmu'kw Maw-klusuaqn Negotiation Office.
- Mohawk Council of Akwesasne. (1996). *Akwesasne Task Force on the Environment Research Advisory Committee Protocol for Review of Environmental and Scientific Research Proposals*.

- Mohawk Council of Kahnawake. (2007). *Kahnawake Schools Diabetes Prevention Program Research Code of Research Ethics: Mohawk Council of Kahnawake*.
- National Aboriginal Health Organization. (2005). *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities*. Retrieved from [http://www.naho.ca/documents/fnc/english/FNC\\_OCAPCriticalAnalysis.pdf](http://www.naho.ca/documents/fnc/english/FNC_OCAPCriticalAnalysis.pdf)
- National Aboriginal Health Organization. (2007). *Considerations and Templates for Ethical Research Practices*. Retrieved July 27, 2015, from <http://www.naho.ca/firstnations/health-a-to-z/research-ethics-sp-new/>
- Royal Commission on Aboriginal Peoples (1996). *Ethical Guidelines for Research*. Ottawa, ON, Canada: Royal Commission on Aboriginal Peoples.
- Sanson-Fisher, R. W., Campbell, E. M., Perkins, J. J., Blunden, S. V., & Davis, B. B. (2006). Indigenous health research: A critical review of outputs over time. *Medical Journal of Australia*, 184(10), 502. PMID:16719748
- Smith, L. T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. New York, NY: Zed Books.
- Smylie, J., & Anderson, M. (2006). *Key methodological and conceptual challenges* (pp. 602-605).
- Statistics Canada. (2013). *Aboriginal Peoples in Canada: First Nations People, Métis and Inuit*. Retrieved September 22, 2014, from <http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.cfm>
- Stiegman, M. L., & Castleden, H. (2015). Leashes and lies: Navigating the colonial tensions of institutional ethics of research involving Indigenous peoples in Canada. *International Indigenous Policy Journal*, 6(3). <http://dx.doi.org/10.18584/iipj.2015.6.3.2>
- Taubes, G. (1995). Scientists attacked for 'patenting' Pacific tribe. *Science*, 270, 17. <http://dx.doi.org/10.1126/science.270.5239.1112>
- Tri-Council Policy Statement. (2015). *Human Biological Materials Including Materials Related to Human Reproduction (Article 12.4)*. Retrieved January 25, 2015, from [http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter12-chapitre12/#ch12\\_en\\_a12.4](http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter12-chapitre12/#ch12_en_a12.4)
- United Nations Declaration on the Rights of Indigenous Peoples. (2007). *United Nations Declaration on the Rights of Indigenous Peoples*. Geneva, Switzerland: United Nations Human Rights Office of the High Commissioner for Human Rights.
- WalDRAM, J. B., Herring, A., & Young, T. K. (2006). *Aboriginal health in Canada: historical, cultural, and epidemiological perspectives*. Toronto: University of Toronto Press.
- Weijer, C., & Anderson, J. A. (2002). A critical appraisal of protections for aboriginal communities in biomedical research. *Jurimetrics*, 187-198. PMID:15119332
- Weijer, C., Goldsand, G., & Emanuel, E. J. (1999). *Protecting communities in research: Current guidelines and limits of extrapolation*, 23, 275-280.
- Williams, S. R., Chagnon, N. A., & Spielman, R. S. (2002). Nuclear and mitochondrial genetic variation in the Yanomamö: A test case for ancient DNA studies of prehistoric populations. *American journal of physical anthropology*, 117(3), 246-259. <http://dx.doi.org/10.1002/ajpa.10035>
- Wilson, K., & Young, K. (2008). An overview of Aboriginal health research in the social sciences: Current trends and future directions. *International Journal of Circumpolar Health*, 67(2-3). <http://dx.doi.org/10.3402/ijch.v67i2-3.18260>
- Young, T. K. (2003). *Review of research on aboriginal populations in Canada: Relevance to their health needs*, 419-422.
- Yukon Research Centre. (2013). *Protocols and Principles for Conducting Research with Yukon First Nations*. Whitehorse, YT, Canada: Yukon Research Centre.

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