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Intersections of Ethics of Indigenous Health Research and Health Research Education

by

Juan Carlos Rodriguez Camacho

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Curriculum, Teaching and Learning
Ontario Institute for Studies in Education
University of Toronto

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Juan Carlos Rodriguez Camacho

Doctor of Philosophy

Curriculum Teaching and Learning
University of Toronto

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Abstract

Health research involving Indigenous peoples is regulated by guidelines based on the ethics of Indigenous health research, which establish routes to knowledge development in order to support and improve health for Indigenous communities. Despite these guidelines, health imbalances remain and continue to negatively impact Indigenous peoples. This thesis explores some of the barriers and strengths of ethical guidelines of Indigenous health research in Canada. Using a community-based approach, this research shifts the focus away from a study of Indigenous peoples themselves, to a study of the practices that health researchers employ when conducting health research involving Indigenous peoples. An online survey was developed and distributed via email and through social networks to health researchers who work in the field of Indigenous health research. The survey consisted of 22 questions using a Likert scale (Likert, 1932) to explore perceptions of ethical guidelines in use by researchers who engage in Indigenous health research. After data quality control analysis, 228 respondents were considered valid and constituted the data set. Results suggest a general level of agreement (Somewhat Agree) with the value of the health ethical guidelines used by researchers. High agreement was found for basic items such as ethical guidelines being easy to access and the amount of information offered was appropriate. However, low agreement was found on items that rated the perceived characteristics of ethical guidelines: their clarity, and whether they reflected the current social context of

Indigenous peoples; the inclusion of Indigenous paradigms inside ethical guidelines and whether the guidelines enhanced health researchers' understanding of Indigenous worldviews. Results also describe some other characteristics of Indigenous health research, such as exploring who is researching what, when, and how with special attention to research methodologies, approaches and perceived engagement with Indigenous communities. A major implication of these results suggests the need for the inclusion of Indigenous research perspectives in health research and health research education much more broadly if they are to effectively support Indigenous healthier communities.

Acknowledgments

As a member of the Indigenous Mhuysqas families of the Condor; a relation of the Chias, Chipchas, and Choques peoples from the northeast side of the Andes; and as a visitor on First Nations, Inuit, and Métis land in Canada, I acknowledge the Great Grand Mothers' and Great Grand Fathers' knowledge, teachings, and relations who, for centuries protected and preserved the lands of Turtle Island. This research traces my learning journey as a health researcher who strives to work in good spirit with knowledge and practices that support healthier Indigenous communities.

I am grateful to have received support for this research from two scholars at the University of Toronto Dr. Suzanne Stewart and Dr. Clare Brett. This research is based on Dr. Suzanne Stewart's (2018) research project entitled, "Aboriginal Health Research Ethics: Updating Protocols and Guidelines Through Community-Based Research," which was funded by the Fraser Mustard Institute of Human Development at University of Toronto. My immense gratitude to Dr. Suzanne Stewart who not only provided me with opportunities to learn, research, connect, and work with Indigenous communities, but who also offered me guidance and mentorship. Suzanne allowed me to experience the strengths and challenges of living in-community and the infinite richness of what it meant to have supportive sisters and brothers alongside me in this journey of knowledge, ceremony, and life.

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Table of Contents

Acknowledgments.....	iv
Table of Contents.....	v
List of Tables.....	viii
List of Figures.....	ix
List of Appendices.....	x
Chapter 1: Introduction.....	1
1.1 Purpose of the study.....	1
1.2 Research question.....	4
1.3 Significance of the problem.....	4
1.4 Foundational Principles.....	6
1.5 Definitions.....	11
1.6 Research Context.....	14
1.7 Data Collection, Analysis and Findings.....	16
1.8 Outline of Thesis.....	18
Chapter 2: Literature Review.....	19
2.1 The Field of Indigenous Health Ethics.....	19
2.2. Health Knowledge Perspectives.....	29
2.3. Knowledge frameworks of health research.....	31
2.4. Indigenous Ethics Perspectives.....	37
2.4.1. Ethics Guidelines.....	37
2.4.2. The Ethics of this Study.....	41
2.4.3. Data Sources.....	43
2.4.4. De-colonialism and Indigeneity.....	46

2.4.5. Real Science and Cultural Knowledge	53
2.5. University Health Education.....	61
Chapter 3: Method	67
3.1. Method	67
3.2. Participants.....	69
3.3. Sampling Techniques.....	73
3.4. Measures	73
3.5. Instruments and Data Collection.....	74
3.6. Procedures.....	75
3.7. Data Analysis	77
Chapter 4: Results	78
4.1. Preliminary Analysis.....	78
4.2. Closed-ended Questions Analysis.....	81
4.3. Open-ended questions.....	93
Chapter 5: Discussion	98
5.1. Discussion.....	98
5.2. Lessons from the survey	106
5.3. Impacts on Health Research Education	109
5.1.1. Knowledge creation	110
5.3.1.1. Owners of Knowledge	110
5.3.1.2. Triangulation Instead of Mono-Perspectives	111
5.3.1.3. Indigenous Ethical Guidelines require a complex dynamic approach.....	111
5.3.1.4. Experiential Knowledge and Academic Knowledge	113
5.3.1.5. Course Contents	118
5.1.2. Perspectives of Power and Knowledge in Health Research Education	125
5.3.2.1. Discursive Practices and Pedagogomologies.....	128

5.3.2.2.	Rules	129
5.3.2.3.	Roles	131
5.3.2.4.	Power	132
5.3.2.5.	Knowledge	133
5.3.2.6.	Health Knowledge as a Commodity	134
5.4.	Limitations of the Study.....	137
5.5.	Recommendations for Future Research.....	139
References.....		141
Appendix A: Structure of the Survey.....		161
Appendix B: Recruitment Letter.....		167
Appendix C: Acronyms Used.....		168
Copyright Acknowledgements.....		170

List of Tables

Table 1. Reliability Analysis by Cronbach's Alpha Test	78
Table 2. Median Analysis of All Items	79
Table 3. Disciplines of Research	83
Table 4. Research in Provinces	87
Table 5. Frequencies of Use of Ethical Guidelines.....	90
Table 6. Median Guideline Perception	90
Table 7. Likert scale for questions 33-46 (frequencies and percentages).....	91
Table 8. General Agreement vs Disagreement	93

List of Figures

Figure 1. Agreement Scale for Perceptions of In-Use Guidelines.....	81
Figure 2. Dichotomous Agreement vs. Disagreement Scale.	92

List of Appendices

A. Structure of the survey	126
B. Recruitment letter	132
C. Acronyms Used	133

Chapter 1

Introduction

1 Purpose of the study

Health research involving Indigenous peoples is considered a field in need of decolonizing. Dismantling Eurocentric research practices while engaging participatory research and culturally safe and relevant methods is required. There is a need to explore research practices in which decision-making around how research is conducted, and by whom, is centered within Indigenous communities, and we need to understand how culturally relevant training can be provided for health practitioners (Smylie, Tait, Martin, Chartrand, Hogg, Tugwell & Macaulay, 2004). The previous approach to conducting health research with Indigenous populations—that is, research that is “positivist, empirical, and driven by the agenda of the Academy” (Ermine, et al, 2004)—is not relevant to Indigenous people and communities because it is not based on Indigenous culture nor ways of knowing.

Indigenous health research is characterized as research that is carried out by Indigenous self-identified researchers and non-Indigenous researchers, from:

“... any field or discipline related to health and/or wellness that is conducted by, grounded in, or engaged with, First Nations, Inuit or Métis communities, societies or individuals and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present.”
(CIHR, 2019, pp 1).

In this study, the term, “Indigenous health research” will refer to the CIHR’s definition, without specific differentiation of health researchers as Indigenous or non-Indigenous persons. Thus, researchers who involve Indigenous peoples in health research are considered “respondents” or “participants” or the population for this inquiry, independently of their Indigenous background or their epistemology, methodology, and axiology used in their health research studies. This methodological position assumes that in the field of Indigenous health research, not all health researchers involved use exclusively Indigenous epistemologies. It is likely that the field of Indigenous health research includes a range of epistemological and methodological perspectives including both Western and Indigenous views of health research and health knowledge. This

assumption builds on the emergence of Indigenous epistemologies and paradigms that are progressively more accessible (Smith, 2010, Wilson, 2008; Brant-Castellano, 2004), and the Call to Action 23 (TRC, 2015) which stresses the need for an increase to the number of Aboriginal/Indigenous professionals working in the field of health-care.

Research is not new for Indigenous peoples (Former Chief Norman Bone, 2016, Keeseekoowening First Nation contends University of Manitoba) and it is recognized that Indigenous knowledge development is considered an ancestral and ongoing Indigenous activity. After contact with Europeans, Indigenous knowledge was systematically relegated to the margins (Smith, 2000), penalized, and fragmented by the destruction of Indigenous languages. Indigenous ways of knowledge and education was “ridiculed, denounced, prohibited, suppressed and invalidated” (Battiste, 2010, p. 41) by White settlers. After contact, health research has caused knowledge exploitation, cultural assimilation, and reinforced colonial practices of exclusion and oppression. These harms—including residential school system, the Sixties Scoop, the Pass System and many examples of inadequate of health services for Indigenous people and health research on Indigenous communities—have been denounced by Indigenous scholars and Indigenous communities. (Amnesty International, 2009; Kubick, Bourassa, & Hampton, 2009).

In a movement away from the main-stream perspective of ethics towards a decolonizing process, there have been clear calls for systemic change and the need for Indigenizing the ethics of Indigenous health research, following Indigenous epistemologies and research methods, for example, applying the Two Eyed-Seeing perspective (Marshall, 2017). Indigenizing movements understand Indigenous knowledge as “a complete knowledge system with its own epistemology, philosophy, scientific and logical validity” (Battiste and Henderson, 2000). Indigenous research methods include a shifting of power relations and the incorporation of traditional knowledge (Funston, 2013; Rothe, Ozegovic, & Carroll, 2009; Walker, Fredericks, Mills, & Anderson, 2014). Complementarily, systemic change aims to disrupt the status quo sustained by scientific and positivistic methods of science. (Adelson, 2009; Duran, Duran, Yellow Horse Brave Heart, & Yellow Horse-Davis, 1998; Episkenew, 2009; Linklater, 2014; Prussing, 2014; Schwan & Lightman, 2015; Tuhiwai-Smith, 2006).

This exploratory survey research study aligns with the Indigenous decolonizing education intention also expressed by Indigenizing movements. Both routes seek to support healthier Indigenous communities by providing new knowledge that is “conducted by, grounded in, or engaged with, First Nations, Inuit or Métis communities, societies or individuals and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present” (CIHR, 2019, pp 1). The field of Indigenous ethics has developed and continues to develop as a response to the harms caused by Eurocentric health research (National Collaborating Centre for Aboriginal Health, 2013).

As the first stage of a two-phase research project, this particular study explores and provides relevant information on what is working and what needs to be adjusted when conducting Indigenous ethical health research in Canada. The study invited Canadian health researchers working in the field of Indigenous health research to respond to an online-survey on how they design, conduct, and share their research. Research data was analyzed by perceived strengths and weaknesses concerning the practices of ethical Indigenous health research in Canada. The present report only includes the first phase: an exploratory survey, and contains relevant information to inform important themes to be explored along with complementary methods in phase two of the study. Relevant topics for further exploration include the field of Indigenous health research, the perception of ethical guidelines, and implications of the findings for the design of educational interventions in the field of health research.

Data-based research is included in Indigenous methodologies: data collection is part of Indigenous knowledge production, but it is only one part. Indigenous knowledge builds on data that is collected, and engages in methods that “come from above” (Wilson, 2008) as a source of knowledge and transformation. Without data—or, evidence-based information about everyday practices and research strategies—it is difficult to adjust and design strategies to improve current ethical practices of health research. Evidence-based information is also required to provide training, information, and guidance to health researchers who are invested in advancing the field of Indigenous health research, and supporting Indigenous healthier communities.

1.1 Research question

This descriptive study is guided by the following research question: *According to researchers who engage with Indigenous health research in Canada, what are the perceived strengths and weaknesses of current Indigenous health research ethical practices?*

This question is addressed in two stages of the survey. In the first stage, a general description of the practices of researchers who engage in Indigenous health research will map out the current field of Indigenous health research in Canada and how Indigenous peoples are involved in designing, conducting, analyzing, producing, and sharing knowledge gained. The second part of the survey will gather information about health researchers' particular use of Indigenous health research ethics involving Indigenous people.

Some of the more well-known ethical frameworks available build on several Indigenous research frameworks including 1.) Utility, Self-voicing, Access, Inter-relationality -USAI- developed by the Ontario Federation of Indian Friendship Centres (OFIFC, 2012); 2.) Chapter 9 of the Policy Statement on the Ethical Conduct for Research Involving Humans (Tri-Council Policy Statement, Panel of Research Ethic, TCP 2, 2015) published 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); 3.) Ownership, Control, Access, and Possession (OCAP™) established by the First Nations Information and Governance Centre (FNIGC); 4.) Brant-Castellano's (2000) Indigenous epistemologies; and 5.) Wilson's (2008) "Research Is Ceremony" framework.

1.2 Significance of the problem

Indigenous communities in Canada experience health crises in the following areas: homelessness (Stewart & Elliott, 2014); infant mortality; maternal morbidity and mortality; infectious disease; malnutrition; life expectancy; smoking; social problems; alcohol and drug dependency; accidents; poisonings; violence; homicide; suicide; obesity; diabetes; hypertension; chronic renal disease; and diseases caused by the contamination of water, land, and air (National Collaborating Centre for Aboriginal Health -NCCAHA, 2013). Despite all research conducted involving Indigenous communities these health conditions are not changing and it is necessary to

understand why harms are being reproduced and cultural, systemic and structural barriers still present.

In the current Canadian context, Western health research and health systems can no longer be meaningfully applied to Indigenous communities. Harm has been perpetrated—historically and currently—on Indigenous people, via oppressive, colonial processes, which continue to support Western culture and health systems, while denigrating Indigenous knowledge, practices, and communities. Health research involving Indigenous peoples in Canada has primarily been carried out from a Western scientific research perspective and does not necessarily reflect ethical principles or health concerns of Indigenous communities. This is because health research is frequently designed from outside the interests and participation of Indigenous communities. When using Western approaches to health in relation to Indigenous populations, Western health researchers alienate Indigenous peoples from their own recovery processes by “prescribing” interventions that are not culturally-based or culturally supportive, transforming Indigenous peoples into “participants,” and consequently seen as passive knowledge producers who are excluded from decision-making from the beginning to the end of the health knowledge-building process. A profound change in health research then is required in Canada, in which the acknowledgement, acceptance and effective responses to the Calls for Action (Truth and Reconciliation Commission of Canada -TRC, 2015) are incorporated into health research practices and health research education. Furthermore, Indigenous communities may require a new knowledge based on Indigenous worldviews, rather than being based in Western health research methods, health research tools, knowledge translation projects, and evidence-based approaches. For example, Indigenous health education would incorporate into medical education concepts, information included in the Aboriginal Knowledge Translation Strategy (Estey, Smylie & Macaulay, 2009). In sum, recognition of rights and transformation of social and educative systems will require deep changes in the structure of how Indigenous health knowledge is created, used, shared, and stored (First Nations Centre, 2007).

The significance of this research study is grounded in processes of describing inappropriate uses, lack of comprehension, information gaps, and/or negative perceptions of the ethics of Indigenous health research by health researchers involving Indigenous communities in health research. By

disregarding Indigenous knowledges and well-being through systemic oppression and settler colonial practices and beliefs, absence of specific information about which main representations health researchers “use” in designing and conducting health research can further marginalize Indigenous populations, reproduce harms, and prevent recovery. This absence of Indigenous worldviews and collectivistic principles in Western health research are a significant source of concern to Indigenous people. Indigenous people may view health research that uses bio-causal models as an example of the kind of power and knowledge structures that continue to represent and enhance the colonial enterprise, and fail to acknowledge the cultural frame required by Indigenous peoples. This research then, seeks to offer information that would fill this gap in knowledge by providing information about the practices that are working, and those that are not. Knowledge obtained about the weakness and strengths perceived of Indigenous ethics of health research will support interventive and transformative approaches as well as future research in this field. Intervention programs will support educative initiatives that provide training opportunities for health researchers in this field.

For Indigenous persons who are conducting health research and are familiar with ethical practices of Indigenous health research, this study may mirror their own ideas and practices developed through personal, familial, and community experiences on Indigenous ethics (Brant-Castellano, 2017). For health researchers unfamiliar with Indigenous worldviews, this study may offer pathways to build knowledge throughout culturally safe training courses, self-reflexive learning, and Indigenous history learning. This study suggests there is a need for education on Indigenous health, trust building processes, and honest, transformative, respectful, and non-prescriptive approaches to the ethics of Indigenous health research.

1.3 Foundational Principles

This thesis is based on the following principles: Self-Determination Universal Right of Indigenous peoples; Two Eyed-Seeing (Marshall, 2017); the need to decolonize Western health research that involves Indigenous peoples; and the use of community-based research frameworks. These principles are elaborated in the rest of this section.

In 2008, as a result of the long struggles of Indigenous peoples to achieve the recognition of Indigenous rights, United Nations published the United Nations Declaration on the Rights of

Indigenous Peoples where, among other rights, the principle of Indigenous self-determination was recognized:

Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development. (UN, 2008, Article 3 p. 3)

The United Nations Declaration of the Rights of Indigenous peoples was ratified by Canada by the Honorable Carolyn Bennett, Minister of Indigenous and Northern Affairs:

I am here to announce on behalf of Canada, that we are now a full supporter of the Declaration, without qualification. We intend nothing less than to adopt and implement the Declaration in accordance with the Canadian Constitution (United Nations Permanent Forum on Indigenous Issues, 2016, p.3)

The principle of Indigenous self-determination interconnects with Indigenous cultural diversity. Indigenous First Nations, Inuit, and Métis are composed of many nations, languages, traditions, protocols, knowledges, and histories, creating a rich landscape where the ethics of health research cannot be reduced to a simplistic, one-dimensional set of guidelines. Additionally, Indigenous nations interact on different levels with federal, provincial, local government agencies, research institutions and centers, private companies and health researchers adding more complexity to this field.

Under the notion of Indigenous self-determination, Indigenous ethics would be controlled and administered by Indigenous peoples. Indigenous ethical guidelines do not require translation, verification, or validation from Western knowledge systems, nor should Indigenous ethics be analyzed or assigned value from outside Indigenous knowledges perspectives. From this perspective, Indigenous research that analyzes, questions, evaluates, and catalogues Indigenous ethics and health practices from Western perspectives put Indigenous communities at risk by marginalizing and exploiting their knowledge, and disrupting their knowledge development processes. This happens frequently: health research is currently, often, conceived, designed, conducted, shared, and used by non-Indigenous systems which is to the detriment Indigenous people and knowledge. This current research focuses on the importance of Indigenous practical knowledge that evolves through community expansion in response to new challenges that

modernity has imposed on Indigenous communities (Brant-Castellano, 2000). In this sense, Indigenous practical knowledge should be central as communities deal with issues such as water contamination, air pollution, land ownership, food insecurity, economic impositions, education and professional training, isolation, mental health challenges, social stigmas, health challenges, and more (Brant-Castellano, 2000).

That said, this thesis study focuses on stage one of a two-stage study on the perspectives and practices of researchers who engage in Indigenous health research. Stage one uses a Likert scale which has an epistemology that some Indigenous researchers believe is inconsistent with the view that Indigenous practice and knowledge always be central in Indigenous health research. To address this inconsistency, I turn to the idea of Two Eyed Seeing/ Etuaptmumk (Marshall, 2017) which invites two or more perspectives into play when facing any situation—health-related or otherwise—in order to maximize the best possible outcomes. Inspired by Mi'kmaq people, the Two Eyed-Seeing principle brings together Western sciences and Indigenous perspectives in mutually beneficial, intercultural, and collaborative relationships that can bring about new understandings, knowledge, and practices.

In stage one of the study, which is the focus of this thesis study, the research team (which consulted members of different Indigenous communities) has drawn on the Western Likert scale to map the current field of Indigenous health research. However, both the team and I recognize shifting and decolonizing health research for Indigenous people is a priority. One way to decolonize oppressive research practices is to dismantle Western research paradigms that assume reality and real knowledge is only reached using Western epistemologies and conceptual frameworks. In the case of health knowledge from Indigenous perspectives, this process can be carried out by “Indigenizing” health research with Indigenous practices and Indigenous knowledge systems. This requires “changing the system:” eliminating practices of Indigenous exclusion, and re-framing the historical, socio-political, economic, educative, and Westernized construction of reality that is reproduced by Western health research under the bio-medical model approach of “problem-solution.” In the bio-medical perspective, epistemic search (or, the way knowledge creation is conceived) and the ontological position (or, what is considered “real”) unfold discursive practices rooted in Western philosophy, which impose the “universal truth” on Indigenous communities (Wilson, 2008). Thus, science, health systems, and

technologies are defined by Western understandings of health, and these Western understandings of health do not correspond with Indigenous understandings of health. I anticipate a discussion of the ways ethical guidelines do and do not reflect Indigenous understandings of health will emerge in the second stage of the study.

The harms caused by the imposition of non-Indigenous health research on Indigenous communities was widely denounced by Indigenous communities, forcing government agencies to create a field to define and improve Indigenous health and healthcare. In collaboration with the Canadian Institute of Health Research, and Aboriginal Health Research (AHR), the Institute of Aboriginal Peoples' Health (IAPH, 2017), defines the field of Indigenous health research as,

any field or discipline related to health and/or wellness that is conducted by, grounded in, or engaged with, First Nations, Inuit or Métis communities, societies or individuals and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present (para. 1)

Additionally, Western approaches to health care—namely, the problem-solution framework, the exclusive use of scientific methods to obtain knowledge, and the biomedical dominant perspective of health—view health mainly as an individual condition. This concept is contrary to Indigenous perspectives of well-being. According to Indigenous perspectives, health knowledge is centered both on individual and community health dynamics, and includes multiple determinants of health such as, “colonialism, gender, culture, early childhood development, the environment, geography, Human Virus of Immunodeficiency HIV/AIDS, medicine, and policy” (Greenwood et al, 2018). Thus, health is conceived as an interrelational balance that can be interrupted and altered drastically by the exclusion of Indigenous knowledges and peoples from sociocultural and political economic systems and institutions of our current society, and by the imposition of approaches and guidelines that are contradictory to Indigenous knowledges. Thus, as Greenwood et al.'s (2018) research points out, Indigenous health circulates beyond social and biological perspectives. Put another way, health challenges are conceived by Indigenous communities as resulting from different root causes related to intersecting social, historical, political, and economic factors. These factors may include, for example, challenges in relation to

housing, employment, social services, legal status, and “a range of historical and culturally-specific factors which include aspects of colonization, assimilation, loss of language, historical conditions, and cultural identity” (Assembly of First Nations, 2018).

Social determinants of health are highly relevant to Indigenous perspectives. Yet, the concept of “social determinants of health” requires further consideration. The social determinants of health framework, which is grounded in the World Health Organization’s conceptual framework (Solar & Irwin, 2010), and translated into practices (Blas, Sommerfeld & Sivasankara-Kurup, 2011) is valuable, but it does not include historical and current Indigenous health perspectives. According to the Assembly of First Nations, “well-being” rather than “health” should include a community-centered approach—rather than an emphasis on the individual—that is attuned to the right to self-determination and self-government. From a health promotion perspective, health is understood to be a state of unity or balance across the physical, mental, social, and spiritual components of a person’s well-being, rather than merely the presence or absence of disease (Dell et al. 2011).

Furthermore, Loppie and Wien (2009) tells us, health and well-being are experienced over the life course, thus the framework should incorporate the four cycles of the lifespan allowing for variations in determinants in each stage of life. Western methodologies currently favored in health research primarily take a “cause-and-effect” or “problem-solution” approach, and deploy biological concepts of health. Health researchers often hold preconceived notions about who is an expert (i.e. the health practitioner) and who is considered in need of knowledge-solution (i.e. the patient). As the Western approach fails to resolve Indigenous health concerns, the term “health research” should be considered carefully, in the same way the Assembly of First Nations prefers the term “well-being” (Assembly of First Nations, 2013).

Finally, this research supports knowledge-building processes and research practices grounded in community-based research in all Indigenous communities, and assumes that no beliefs, knowledge, and/or practices from any community or culture are superior to any other. As such, this study follows the United Nations Declaration on the Rights of Indigenous Peoples (2007) which states, “all doctrines, policies and practices based on or advocating superiority of peoples or individuals on the basis of national origin or racial, religious, ethnic or cultural differences are

racist, scientifically false, legally invalid, morally condemnable and socially unjust.” (United Nations, 2007, p. 2).

1.4 Definitions

The National Aboriginal Health Organization (NAHO) *Journal of Aboriginal Health* (JAH, 2014) developed a guide to terminology for academic writing in Indigenous health research, that was modified by the *International Journal of Indigenous Health* (IJIH, 2017). The present section includes some important definitions recommended by the NAHO- IJIH.

Aboriginal Peoples: ‘Aboriginal Peoples’ is a collective name for all of the original peoples of Canada and their descendants. Section 35 of the Constitution Act of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups – Indian (First Nations), Inuit and Métis. The term, ‘Aboriginal Peoples’ should not be used to describe only one or two of the groups. (p. 2).

Aboriginal people – When referring to ‘Aboriginal people,’ one is referring to more than one Aboriginal person rather than the collective group of Aboriginal Peoples.

Band: A ‘band’ or an ‘Indian band’ is a governing unit of Indians in Canada instituted by the *Indian Act*, 1876. The Indian Act defines Indian band as a “body of Indians.” It is a community of Indians for whom lands have been set apart and for whom the Crown holds money. It is a body of Indians declared by the Governor-in-Council to be a band for the purposes of the Indian Act. Many bands today prefer to be called First Nations and have changed their names accordingly (e.g., the Batchewana Band is now called the Batchewana First Nation) (p. 3).

Elder: First Nations, Métis and Inuit Elders are “acknowledged by their respective communities as an ‘Elder’ through a community selection process. Gender and age are not factors in determining who is an Elder. Traditional teachers are those individuals learning under the mentorship and guidance of an Elder (Centre for Indigenous Initiatives, 2019). Elder is capitalized to indicate honor or title, and used when describing Indigenous cultural and spiritual leaders. The lowercase ‘elder’ should be used when generally referring to an Indigenous person who is a senior. Therefore, not all older Indigenous persons can be Elders, and some Elders can be relatively young. (p. 3).

First Nation: Some communities have adopted First Nation to replace the term, “band.” Many bands started to replace the word band in their name with First Nation in the 1980’s. It is a matter of preference, and writers should follow the choice expressed by individual First Nations/bands. (p. 3).

Indigenous (Indigenous person): Indigenous means “native to the area.” In this sense, Aboriginal Peoples are indeed indigenous to North America. Its meaning is similar to Aboriginal Peoples, Native Peoples or First Peoples. The term ‘Indigenous peoples’ is frequently used in international contexts. It is gaining acceptance, particularly among some Aboriginal scholars, to recognize the place of Aboriginal Peoples in Canada’s late-colonial era, and it also implies land tenure. The term is also used by the United Nations in its working groups and in the Decade of the World’s Indigenous People. As a self-declared term (rather than a government imposed one), and because of its international connotation, it was the term chosen for the title of the IJIH. (p.5).

Indigenous Health Research Field: Indigenous Health Research (IHR) can be defined by any field or discipline related to health and/or wellness that is conducted by, grounded in, or engaged with, First Nations, Inuit or Métis communities, societies or individuals and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present. Indigenous health and wellness research embrace the intellectual, physical, emotional and/or spiritual dimensions of knowledge in creative and interconnected relationships with people, places, and the natural environment. Such research is based on the right to respectful engagement and equitable opportunities. It also honors culture, language, history, and traditions. Indigenous health and wellness research, thus defined, may be implemented and adapted in research involving Indigenous peoples around the world. Whatever the methodologies or perspectives that apply in a given context, researchers who conduct Indigenous research, whether they are Indigenous or non-Indigenous themselves, commit to respectful relationships with Indigenous peoples and communities (CIHR, May 2017, para. 1-3).

Inuit: Inuit are a circumpolar people, inhabiting regions in Russia, Alaska, Canada, and Greenland, united by a common culture and language. There are approximately 55,000 Inuit living in Canada. Inuit live primarily in the Northwest Territories, Nunavut, and northern parts of Quebec and coastal Labrador. They have traditionally lived for the most part north of the tree-

line in the area bordered by the Mackenzie Delta in the west, the Labrador coast in the east, the southern point of Hudson Bay in the south, and the High Arctic islands in the north. The Indian Act does not include the Inuit. However, in 1939, the Supreme Court of Canada interpreted the federal government's power to make laws affecting "Indians, and Lands reserved for the Indians" as extending to Inuit (p. 6).

Indigenous Community: Community describes a "collectivity with shared identity or interests that has the capacity to act or express itself as a collective" (TCP2-2014, p. 111). A community can be territorial, organizational, or a community of interest. 'Territorial communities' have governing bodies exercising local or regional jurisdiction (e.g., members of a First Nations resident on reserve lands). 'Organizational communities' have explicit mandates and formal leadership (e.g., a regional Inuit association or a friendship centre serving an urban Aboriginal community). In both territorial and organizational communities, membership is defined and the community has designated leaders. 'Communities of interest' may be formed by individuals or organizations who come together for a common purpose or undertaking, such as a commitment to conserving a First Nations language (TCP2-2014, pp. 112).

Settlements: Settlements are considered temporary places to live. For example, Inuit live in communities and settlements. Inuit have never lived on reserves, therefore the terms 'on-reserve' and 'off-reserve' do not apply to Inuit, only to First Nations. When referencing all Aboriginal communities—for example, referencing people living on a reserve, off a reserve, or in urban areas—users must add the term, 'Inuit' in order to be inclusive of Inuit living in the North. There are four comprehensive Inuit land claims regions covering more than one-third of Canada: the Inuvialuit Settlement Region in the Northwest Territories, Nunavut, Nunavik in northern Quebec, and Nunatsiavut in Labrador. Nunavut has three subregions—Kitikmeot, Kivalliq and Qikiqtaaluk—which are called regions. These are not referred to as Inuit Regions or Inuit Territories. (p. 7).

Métis: The word Métis is French for "mixed blood." Section 35 of the Constitution Act of 1982 recognizes Métis as one of three Aboriginal Peoples of Canada. Historically, the term Métis applied to the offspring of 1.) French fur traders and Cree women in the Prairies; 2.) English and Scottish traders and Dene women in the North; and 3.) British and Inuit in Newfoundland and

Labrador. (p.7). Currently, Métis refers to “a person who self-identifies as Métis, is distinct from other Aboriginal peoples, is of historic Métis Nation Ancestry and who is accepted by the Métis Nation” (Metis Nation of Alberta, 2003, para 2).

Métis Nation: This term refers to “Aboriginal people descended from the Historic Métis Nation, which is now comprised of all Métis Nation peoples and is one of the “aboriginal peoples of Canada” within the meaning of s.35 of the Constitution Act 1982.”

Participant, Respondent: In this research, a “participant” or “respondent” refers to a health researcher who engages in Indigenous health research and includes Indigenous peoples in their health research.

1.5 Research Context

Tensions often exist between experienced health researchers, institutions, government, and Indigenous communities when health research projects that are based on Westernized frameworks of health are proposed to Indigenous communities. Indigenous peoples will often reject such health research projects if they are not rooted in Indigenous ethics. Health researchers are part of these tensions involving Indigenous communities who ask for transformative meaningful health research.

The Calls to Action of the TRC references these tensions and states that health researchers must not reproduce past harms by imposing a colonial model of health on Indigenous communities (TRC, 2015). Instead, open and respectful conversations on the practice of health research and health education, and flexible approaches of knowledge that recognize complex social and historical systems of relationships expressed in human health, social systems, natural environments, and relational boundaries are expected to be integrated into research.

This research is grounded in relationships of knowledge and power by questioning how health researchers create scientific knowledge and produce colonial assumptions required to maintain this knowledge as the unique source of truth. From a decolonial process of Indigenous health research aimed at increasing Indigenous community health capacity, this inquiry will explore what is being researched, as well as when, why, how, and by whom (Mignolo, 2009) such research is being conducted.

Mobilizing new health research knowledge that is guided by principles of Indigenous well-being and relationality as proposed in the ethics of Indigenous health research, is intended to rebuild trust, acknowledge and address historical harms, and promote effective reparation of healthy Indigenous communities (Wilson, 2008). In this process, from an Indigenous perspective, reality is understood as cyclical, shared, multidimensional, and co-constructed; related to nature and histories; and experienced on individual and community levels (Schroeder, 2014). This perspective guides the ontological, epistemological, and methodological decisions made in the processes of health research knowledge building. Such an approach to health research integrates the processes of building, sharing, applying, and evolving with and by Indigenous communities and peoples, and is based on the First Nations inter-relationality framework: Utility, Self-voicing, Access, and Interrelationality (OFIFC, 2012).

By asking questions about dominant bio-medical and empirical-positivist perspectives, alternative approaches to health research education require pedagogical as well as ontological and epistemological adjustments to Western health science and health knowledge, particularly in the way health and health knowledge can be defined and conceived. Approaches to Indigenous health and well-being, therefore, need to include understandings of complex historic approaches to Indigenous health, analyses of knowledge and power in relation to science and technology, and create awareness of the impact of social inequalities on Indigenous people and communities, rebalancing Indigenous communities as priorities related to Indigenous health.

In this process it is important to know how health researchers are accessing, interpreting, and applying ethical guidelines of Indigenous health research. There is little information about empirical evidence that may be compared and reproduced by other health researchers on this topic. The lack of empirical evidence generated by research on ethical protocols and guidelines of Indigenous health research in Canada, sustain this study as an exploratory approach to the problem of perception and use of the ethical standards of Indigenous health research. As a way to address this gap, the present research was planned to explore both demographics and perceptions of the ethical guidelines practiced by health researchers.

1.6 Data Collection, Analysis and Findings

It was described in the previous sections how Western-based health research causes harms and reproduces colonialisms by applying non-Indigenous perspectives and methods of knowledge development and imposing dependencies of health systems to Indigenous people. The dominant, practiced, and accepted bioethical paradigm has been denounced as intrusive and harmful for Indigenous communities. (Ermine, et al, 2004; Smylie et al, 2004, Benatar 1998; Benatar, Daibes & Thompsons, 2016). The present research addresses these challenges by producing a shift from the traditional mainstream way to understand science and the ethics towards alternative views of ethics aligned with Indigenous worldviews and epistemologies. There are different ways to face this challenge: recovering that which has been silenced and developing new Indigenous research methods (Absolon, 2011), applying Participatory Action Research (Brant-Castellano, 1993), adopting decolonizing methodologies (Mignolo, 2007), and conducting research that mobilizes community-based research perspectives (Stewart, 2008, 2011).

In the traditional approach to research, people who conduct research on or about a community who are not part of that community, are seen as an “outsider.” However, in community-based research, when the person conducting research is a part of the community with whom the research is being conducted, they are called an “insider” (Swisher, 1993). Indigenous community-based research necessarily involves the participation of a given Indigenous community in all phases of research. This collaborative approach fits into the general description of Indigenous research, which is characterized as “primarily qualitative, participatory, collaborative, and community-based (Ermine, Sinclair, & Jeffery, 2004).

Indigenous community-based research provides a space for the involvement of Indigenous peoples in research (Macauley, 1993; Macauley, Freeman, Gibson, McCabe, Robins, et al, 1999; Day, Blue, & Peake Raymond, 1998), immediate usefulness and benefit to the participating community (Benjamin, 2000; Kothari, 1997; Peacock, 1996), cultural relevance of the research project to the community (Hudson & Taylor-Henley, 2001; Weaver, 1997), and collaboration and partnership with the community (Gibson, Gibson & Macauley, 2001; Macaulay, 1993).

As this research project is a community-based research, the research team explored alternatives to data gathering and instruments of data collection. After coming to a shared agreement about

how the research would be carried out, it was decided in stage one that an online survey would be the best strategy for collecting Canada-wide data. Using a Likert Scale (Likert, 1932), quantitative data was processed using descriptive statistics and frequencies while exploring discrepancies between agreement and disagreement about assumptions related to the understanding and practical use of ethical guidelines of Indigenous health research. After collecting relevant data across Canada, a multi-level analysis perspective (Jackson & Mazzei, 2012) was included to explore the implications of the findings regarding the impact of ethics of Indigenous health research knowledge on health research education. Survey results are presented in this research study in Chapter 4, which also covers main topics in the field of Indigenous health research, as well as the major categories within perceptions of the ethics of Indigenous health research.

New health research education has been utilized to produce generational change in the way health research is designed and conducted involving Indigenous peoples in Canada. New health research education that produces knowledge of health and well-being grounded in Indigenous ethics, can protect and support Indigenous knowledge, and positions Indigenous people and communities as the main actors in the processes of knowing and knowledge construction. The education of future health researchers should involve teaching Indigenous ethics, and pedagogical processes of grounded learning and transformation in order to address systemic, structural, cultural, and socio-economic barriers that restrict Indigenous rights to self-determination.

Highlighted in this work is the richness and complexity of Indigenous health. I seek to bring into focus innovative views of and approaches to health and well-being, which aim to remove systemic barriers and encourage respectful, transformative, integrative, and individual as well as relational approaches to Indigenous health. Based on experience, knowledge, tools, and individual and community-based approaches, I present pathways to facilitating dialogue, as well as approaches to unlearning discourses, practices, and actions that act as barriers to ethical health research managed by and produced with Indigenous peoples.

Educational changes include research perspectives on how knowledge and power dynamics (Foucault, 1972) and decolonial perspectives (Mignolo, 2000) might be useful conceptual

frameworks to challenge the current orthodoxy of Western health research education. From a power and knowledge approach framework (Foucault, 1972), I conceive of health research education as a multi-level, multi-perspective process, where Indigenous health systems research approaches are rooted in self-determination, self-organization, self-preservation, and interrelationality between the individual and their Indigenous community. From this perspective health definitions and health knowledge processes may involve different ontologies (specifications of what is real and what is considered real), epistemologies (how we understand knowledge), and axiology (what value system is in place). Furthermore, principles of relationality are central to Indigenous health research ethics (Wilson, 2008). Indigenous healthcare must be grounded in Indigenous communities, and work with Indigenous practices, languages, cultural representations, knowledge, resources, and understandings of power that define and are defined by a wide range of Indigenous processes and interactions around health knowledge.

1.7 Outline of Thesis

The thesis is organized in the following way. Chapter 2 provides a literature review of Indigenous health ethics and Indigenous perspectives on ethics. Chapter 3 describes the methods used to design the online survey used in this study. Chapter 4 provides the findings of the online survey. Chapter 5 concludes the thesis with a discussion of the lessons learned from the survey.

Chapter 2:

Literature Review

2.1 The Field of Indigenous Health Ethics

The field of Indigenous health research ethics has developed and continues to develop in response to the range of health challenges currently faced by Indigenous communities. An imbalance in the levels of wellness among Indigenous people is reflected in the growing number of health concerns experienced by Indigenous peoples on and off reserves due to the consequences of colonialism (National Collaborating Centre for Aboriginal Health, 2013; Gracey & King, 2009; King, Smith, & Gracey, 2009). Statistics related to chronic disease and poor health among Indigenous peoples in Canada are far worse than the national average (Chief Public Health Officer, 2008). This gap may be even wider than the data suggests due to incomplete information and the low quality of health and mental health statistics (Wallace, 2014; Gionet & Roshanafshar, 2013; Tait, 2008). In the field of Indigenous health, the need for new health research that reflects and sustains healthy Indigenous communities is widely acknowledged. Several Indigenous scholars have identified the need to question health researchers' Westernized approaches to health (Smith, 1999; Battiste & Henderson, 2000; Wilson, 2008; Cochran, Marshall, Garcia-Downing, et al. 2008).

Indigenous communities have been demanding change for a long time. Making these demands audible has begun to have a visible impact in some areas of Indigenous health research. Although historically, researchers often incorporated Indigenous knowledge into Western health research frameworks, they frequently assumed what Indigenous health research ethics needed without much consultation and without making fundamental changes to the way knowledge and power is attached to the processes of health research. In contrast, health researchers trained in culturally safe and respectful research approaches are designing and conducting health research with and by Indigenous communities. They are questioning how knowledge is constructed, and how it relates to social justice with regards to the past and current harms inflicted on Indigenous communities.

Western health research and interventions conducted within Indigenous communities are questioned as to how effectively they can meet the health needs of Indigenous peoples. With modernity as a dominant model for living, Western health research has attempted to control the collection and dissemination of Indigenous knowledge, evincing sophisticated forms of neo-colonialism. Without a change in this Western paradigm, Indigenous health concerns cannot be addressed in a way that honours and respects Indigenous knowledge and ways of being. Western methods of thinking are based on logic, reasoning, and science. They exclude Indigenous knowledge, and as well, fail to address the pressures and concerns that Western societal values, modernity, industrialization, economics, and culture place on Indigenous people and communities.

Indigenous people may also perceive health in a unique way that does not necessarily correspond to Western definition of health. Indigenous communities understand a person's state of health as a balance of four dimensions related to their physical, emotional, mental, and spiritual well-being (Siomonn, 2013). Frequently, Indigenous health concerns are inaccurately defined and addressed. This is because data collection methods are designed with Western concepts and standards of health in mind rather than from Indigenous perspectives of health. Therefore, Indigenous health data is often incomplete. Nevertheless, Indigenous health issues include concerns that can be expressed through statistics related to infant mortality, maternal morbidity and mortality, infectious disease, malnutrition, life expectancy, smoking, social problems, alcohol and drug dependency, accidents, poisonings, violence, homicide, suicide, obesity, diabetes, hypertension, chronic renal disease, and diseases caused by the contamination of water, land and air (National Collaborating Centre for Aboriginal Health -NCCAH-, 2013). The prevalence of Human Immunodeficiency Virus (HIV), is another important health concern in Indigenous communities, and data shows that Indigenous people account for 7.5% of all persons with HIV in Canada, and 9% of all new cases diagnosed in 2005 (Public Health Agency of Canada, 2006).

Both historically and currently, Indigenous health and well-being is defined within Indigenous communities not as the absence of illness, but rather, as a holistic balance between a range of dimensions. Health imbalances are a consequence of social restrictions, stigma, and discrimination imposed on Indigenous peoples through the health services, social systems,

economic restrictions, poverty, and cultural discrimination. Further, services provided in a manner that disregards Indigenous conceptions of health and well-being are intrusive and unhelpful. Health research and services that are designed, delivered, controlled, and evaluated outside of Indigenous frameworks place Indigenous peoples at risk of being re-harmed.

Since 1989, the Canadian Government has continued to work at delegating the responsibility for health care at the community level to Indigenous communities (Health Canada, 2003), but there is a developing awareness that the complex coordination of services between federal, provincial, local, and private health service providers and a lack of adequate funding resources are significant barriers to Indigenous health improvement (Lavoie, Forget & O'Neil, 2007). There is evidence that health services and research need to adapt to realities in Indigenous communities and consider the relationships between health and socio-economic and psycho-physical conditions including access and availability of healthcare, lifestyle choices, poverty, stigma, discrimination, and environmental conditions (Siomonn, 2013).

Instead, Indigenous health is considered frequently through negative and dysfunctional lenses, and very little can be found on strengths-based approaches in relation to well-being. Despite many reports that highlight specific health issues, Indigenous health is not being fully investigated from a holistic Indigenous perspective and research focused solely on health indicators may overlook other relevant dimensions of Indigenous health. The practice of using Westernized health interventions increases negative perceptions of Indigenous communities held by health providers and perpetuates impositions of certain realities that are not Indigenous-based. Indigenous cultural diversity and beliefs remain unacknowledged when health interventions ignore Indigenous values. Overreliance on traditional health indicators should be addressed, in Northern Canada, for example, where health struggles are described using data on life expectancy, infant mortality, nutrition, and infant neglect statistics (Sisco & Stonebridge, 2010), sexually transmitted disease infections, and tuberculosis rates (McDonald, Hebert & Stanbrook, 2011). Yet these conditions are not directly understood or examined as linked to poor socio-economic conditions, ecological degradation and other pervasive systemic issues beyond community control.

The amount of research involving Indigenous communities is increasing (Panel on Research Ethics, 2015). Between 2010 and 2015, more than 300 individuals conducted health research involving Indigenous peoples in Canada, and published more than 410 peer review publications (Stewart, Rodriguez & Hyatt, 2018). According to a recent publication by the National Collaborating Centre for Aboriginal Health (NCCAH), there are 433 researchers actively conducting research related to Indigenous health, or who are involving Indigenous people in health research from medical, biological, social, and psychological disciplines (NCCAH, 2015). Unfortunately, however, information about the kind of ethical guidelines researchers follow has not been gathered in the field of health research. This is due, in part, to the complexity of rules and communication between different levels of government, and the diversity of research funders which are largely under institutional control and centered within universities and research institutes.

Additionally, Indigenous communities are not a homogenous group. Rather, they include diverse governance processes, spiritual beliefs, language, and cultural knowledge and practices. This complexity generates a variety of challenges in terms of what ethical practices might be considered adequate for Indigenous health research. There are a multiplicity of guidelines, best practices, protocols, declarations, and documents, which are frequently conflicting, outdated, and surrounded by sociopolitical, economic, and educational factors related to historical trauma, Indigenous status, on-reserve and off-reserve urban needs, determinants of health, Canadian legislation (local, provincial, federal), perspectives of scientific knowledge, private research funders, and bureaucratic practices. These are imposed on researchers mainly by universities or other institutions that initiate and conduct research (Stewart, Rodriguez, et al, 2018).

First Nations, Inuit, and Métis rights to self-determination and cultural diversity are affirmed by Indigenous organizations and research bodies who recommend health researchers consult with regional, local Indigenous authorities and communities on ethics protocols for conducting health research. To manage this complexity, Indigenous authorities and communities request that health researchers design protocols and methodologies that are not typical of conventional health research. More than fifty different connection with community strategies were mentioned by health researchers currently conducting health research in Canada. (Stewart, Rodriguez, et al, 2018).

Furthermore, if a health research project is government-funded, researchers are required to adhere to federally-recognized protocols outlined in the Tri-Council Policy Statement (2014), and to the principles of OCAP™ (2007) developed by the First Nations Information Governance Centre. Both documents contain guidelines written by Indigenous communities and/or in consultation with researchers who engage in Indigenous health research and government institutions with the aim of providing ethical guidelines based on foundational principles of Indigenous such as self-determination, ownership, control, access, and possession of research project design, data collection, data use and data “mobilization” sharing strategies.

Additionally, universities and research institutes establish committees and ethics boards that generate ethical practices that might be designed using Western perspectives, therefore, placing those guidelines outside the control of Indigenous communities. These complexities offer further challenges to this field. The process of establishing relationships between health researchers and Indigenous communities requires time, trust and ongoing efforts on the part of health researchers. Health researchers may also prioritize concerns from private or non-Indigenous parties involved in the research that are related to education, marketing, economics, and technology. As a result, researchers may be pressured to apply for funding resources that are time-consuming and thus may limit the time and resources necessary to engage and consult with Indigenous communities properly and thoroughly. This situation can therefore exclude Indigenous communities from participating in discussions, research, and interventions that concern their health. As Brant-Castellano (2004) stresses, this type of situation creates a lack of trust on the part of Indigenous communities and contributes to the misalignment between research projects and current relevant Indigenous health concerns. The continued application of Western-based research principles to Indigenous people along with misinterpretation and disregard of ethical Indigenous research protocols can lead to the ongoing replication of colonial practices (Fanon, 1963). Such practices further negate the diversity of Indigenous people and define Indigenous exclusively in relation to how they are similar or different than the dominant culture that self-positions as constituting the “model” in this case Western perspectives of health.

Western health research, which frequently bypasses Indigenous knowledges by relying on Western institutional rules and thinking, has been traditionally conducted from scientific, empirical and experimental perspectives of reality, knowledge and constructions of human-

nature interactions mediated by culture and progress. Dominant health models and psychological approaches that are based on biology and research evidence are supported using scientific “data” derived from empirical and experimental methods. As a result, health models frequently assume a view of reality based on the empirical vision of reality and health.

In contrast to these singular perspectives of reality, an ethnically diverse world (Young, 1994) would support another reality, based on different epistemologies and world views. Indigenous worldviews conceive reality and interactions between human beings and nature by different perspectives to Western-based worldviews. Failing to recognize the richness of Indigenous peoples’ perspectives can be the starting point for discrimination in research because it assumes a homogeneity of Indigenous communities and their languages (Trepanier & Creighton, 2011). Difference is a characteristic of societies composed of racialized and marginalized minorities. One of the challenges of an ethnically plural society intrinsically connected to ethics and research, is to be able to develop respectful interactions between people and ethnic communities in a way that supports full social participation. Respectful social interactions engage diversity, ethnicity and plurality while building alternative possibilities for knowledge construction, legitimization and sharing. Thus, it follows that it is ethically necessary to centre Indigenous knowledge(s) as the epistemic reference for Indigenous health research. Indigenous knowledge is broadly defined as knowledge that is specific to an Indigenous community and accumulated over generations of living and protecting and transforming their environment (Brant-Castellano, 2000). Indigenous knowledge encompasses all forms of knowledge including technologies, know-how and skills, health care practices, and beliefs, which enable Indigenous communities to achieve stable livelihoods on the land (Estey et al, 2009). The practice of Indigenous health research, therefore, should be based on respect for Indigenous knowledges, which would prevent what Mignolo taking from Kusch calls “cultural phagocytosis” (Kusch, 1970), or, the cultural assimilation of one group by another dominant culture.

A critical theory of community participation can guide conversations on what kind of research is required by Indigenous communities instead of what research is required by health researchers. Community-based research strategies are required in order to re-balance power and recognize isolated, discriminated and marginalized communities. Nevertheless, Western critical theory and Indigenous-centered research are not considered the same, critical and post-colonial perspectives

are often presented as routes to create Indigenous-centered research. They might interrelate with main goals of reconstruction of Indigenous communities centered on: “a) issues of partnership and “voice” in the research process, (b) a commitment to engaging in praxis-oriented inquiry, (c) understanding how continuities from the past shape the present context of health and health care, and (d) the colonizing potential of research.” (Browne, Smye, & Varcoe, 2005, pp. 17).

Indigenous worldviews are also rich in alternative ways to consider growth and change along the journey of life. While non-indigenous perspectives on growth emphasize linear, accumulative growth, rhizomatic perspectives (Deleuze & Guattari, 2004) focus on nonlinear growth, and intuitive, creative, and universal ways of knowing that are more consistent with Indigenous perspectives (Rodriguez, 2015). Health researchers may find new ways to research Indigenous health from different epistemological positions than biological empirical frameworks, or Indigenous perspectives and develop approaches that are respectful and ethical (Bhopal & Donaldson, 1998). From a critical, decolonial framework, the present research discusses research practices surrounding issues pertaining to Indigenous peoples’ health such as the recognition of Indigenous rights, pluralism, and the reconstruction of social power in Indigenous communities. Community-based health research should include conversations on the practice of ethical guidelines such as the “Four R” dimensions of Respect, Reciprocity, Relevance, and Responsibility (Kirkness & Barnhardt, 2001), Ethical research guidelines made by Indigenous communities are rooted in principles such as the right to self-determination, and the right to ownership, control, access, and possession of research, knowledge and information described in the OCAPTM principles (OCAP, 2007). These principles—along with the right to conduct research that involves Indigenous people, land, and knowledge, and that positively transforms Indigenous health and healthcare practices—constitute the first guideline to follow in designing Indigenous health research.

Indigenous worldviews include diverse Indigenous communities, which possess a multiplicity of languages, cultural beliefs, social practices, spiritual principles and ethical perspectives. Diverse Indigenous communities created, share, and use—both in the past and currently—more than 70 languages, as reported in the Canadian 2016 census, from 12 language families: Algonquian, Inuit, Athabaskan, Siouan, Salish, Tsimshian, Wakashan, Iroquoian, Michif, Tlingit, Kutenai and Haida. (Statistics Canada, 2016). The diversity of language is one of the most important

achievements of Indigenous communities, which create, share, and use rich knowledge and perspectives.

Development of knowledge and research are not new activities for Indigenous communities that for centuries developed and transformed land and human relationships. Some main knowledges are written, but many are preserved through oral traditions conveyed by the knowledge of Elders, Knowledge Keepers and blood memory processes. Within the plurality of Indigenous cultures, Indigenous worldviews include holistic perspectives of the world, and an understanding of interactions based on the circle of community, family, ceremony, and language (Brant-Castellano, 2004).

Recognizing the principle of self-determination of Indigenous people, the historical harms caused by oppressive practices of research, and the need to search for alternative ways to change Western systems and structures in relation to ethics of health research, this research utilizes an open framework and an understanding of the disjointed relationship between what is on the paper (norms) and what is practiced in reality (research). Researchers involved in this project are interested in knowing more about how health ethical guidelines are carried out and adhered to. This research depends on partnerships with research institutions, and draws on ethical guidelines designed by the Tri-Council Policy Statement (2014), the OCAPTM (2007) principles, and many other guidelines relevant to Indigenous communities. This project also works with the Medicine Wheel, which represents the balance between the spiritual (East), mental (North), physical (West), and emotional (South) (Linklater, 2014). Additionally, this study includes a holistic approach to healthy and sustainable societies (Canadian Public Health Association, 2015), and takes into consideration how health, social exclusion, and poverty (Rodriguez, 2011) are intertwined. These approaches are considered relevant to updating and improving research ethics guidelines, as well as understanding how they influence, transform, and produce concerns about the well-being of Indigenous peoples. As it was shared in an academic event called, “Public Health Reconciliation Forum,” it was discussed how health reconciliation among Indigenous people might start from within an individual and depend, initially, on self-reflection, and one’s own positionality about how to address historical, current, and future Indigenous health concerns (Waakebiness-Bryce, Dalla Lana School of Public Health, May 22, 2018).

Health research that is based on Western perspectives does not attend to Indigenous well-being. Westernized health research is typically conducted without fully acknowledging individual health concerns, or affirming and incorporating the knowledge and practices of Elders, Knowledge Keepers, Indigenous authorities, and/or communities. In the past, Elders, Knowledge Keepers, Indigenous authorities, and Indigenous communities were open to receive scientific health knowledge under the promise of change and improvements of their concerns and needs. Instead, “Research has a mixed reputation among Indigenous communities, who have previously considered research harmful, damaging, insensitive, and exploitative” (Maddocks, 1992). Hayman and Cols (2015) tell us, “... a large number of research projects have been implemented to serve the professional, political, and academic needs of non-Indigenous researchers, with little or no translation into improving health outcomes”(para. 7). Health researchers may feel under pressure to change perspectives, yet they are already confident with the western approach to collecting and evaluating data, the knowledge generated, and the tools they used when working with scientific frameworks. In this framework “the scientific method, a method in which deduction (the primary method of the rationalists) and induction (the method of the empiricist)” (Webb, 2018), was presented as a problem-solution approach in attempt to address concerns and needs of Indigenous peoples without incorporating Indigenous knowledge, cultural appropriateness, reasoning, or opening dialogue with Indigenous communities. An expert-novice dichotomy approach was imposed where health researchers positioned themselves as experts while Indigenous peoples were unfairly relegated to the role of naïve-novice position or viewed through a culturally romantic lens while Western health researchers were positioned as experts and “real” knowledge producers. This dynamic negates the richness and value of Indigenous knowledge that for thousands of years had been developed and carefully carried forward from Indigenous Ancestors.

As a result of practices of health research outside Indigenous perspectives, health research is perceived by many Indigenous peoples as practiced from utilitarian approaches where, as Smyle argues that in the past, researchers used a “helicopter” way to conduct research when they arrived in Indigenous places, collected data with no or low participation of Indigenous peoples, and then returned to institutes or universities to produce and publish knowledge in books or journals that are not accessible to that Indigenous community. (Smyle et al, 2004, pp. 213).

Indigenous communities thus tend to view health research with suspicion. Health research conducted primarily outside of Indigenous frameworks does not address the needs of Indigenous communities who ask for solutions and action such as intervention programs, social reality transformation, reconnection, and the reconstruction of their culture as the basis for building and sustaining healthy communities.

Health researcher's education based on scientific, experimental-empirical, synthetic-analytical, subject-object, logic-evidence frameworks impose on Indigenous peoples' health a framework where knowledge is developed by using Western protocols, norms, tools, and epistemologies that are not necessarily positive, nor improve Indigenous health conditions. In contrast, ethically-produced knowledge with and by Indigenous communities may be intrinsically grounded and transformed from inside Indigenous communities and intrinsically connected by relationships with the land, earth's creatures, and humans. Health knowledge generated from practical Indigenous knowledge (Brant-Castellano, 2000) and that underpins transformative health practices is obtained through patient observation and the recognition that multiple realities emerge at a range of points along a timeline of relationships. Through a sharing process of transformative knowledge based on Indigenous participation possibilities arise to reestablish and strengthen Indigenous communities that have been debilitated by ongoing colonization.

Restoring Indigenous wellbeing that has been compromised by Western colonization requires a process of building new health knowledge based on Indigenous ethics of health research. By following the assumption that *all knowledge matters* in the effort to restore the balance of power in Indigenous communities in Canada, this research presents the ethics of Indigenous health research as a network of meanings, positions and compromises where the ethics of Indigenous health research, is considered a set of responsibilities that are intrinsically part of the strategy required to build and support healthy Indigenous communities.

In this research, I argue that we need to reevaluate how scientific health knowledge pretends to be the "unique solution" to "health problems" of Indigenous people— including data, big data, primary and secondary data analysis, machine learning and health diagnostics and interventions—and experimental science that claims to attend to the health of Indigenous peoples. Instead, I will argue for the potential of using new knowledge created under Indigenous

health ethics that would produce and sustain healthy Indigenous communities by removing individual, family, community, social and structural and systemic barriers to Indigenous health that are causing health unbalances on Indigenous peoples. This implies a decolonizing and re-positioning process that places Indigenous ways of knowing at the center, detaching Western epistemologies, ontologies, and methodologies generated by current Western health research while finding opportunities for commonalities in which scientific knowledge could be applied to restore nature and social balances. It may open dialogues that work to rebalance power and knowledge, dissolve the colonial mindset of inferiority of knowledge of non-scientific approaches and expand possibilities for researchers who engage in Indigenous health research actions grounded upon the principles of inherited and acquired rights of self-determination and Human Rights of Indigenous knowledge.

2.2. Health Knowledge Perspectives

This section explores how health knowledge research frameworks intersect with discourses and practices of health based on Indigenous knowledges. It also discusses how the power-knowledge dynamic of Western health science and health systems need to be reframed and expressed in new understandings by incorporating alternate ways of knowledge creation, dissemination, and usage.

As a response to the TRC's Calls to Action, Canadian institutions are mobilizing resources to transform their policies and practices to acknowledge Indigenous history and address their current concerns. Government institutions are slowly changing to meet protocols that acknowledge Indigenous people as the owners of the land that we settlers now inhabit. But these changes would only be considered positive to Indigenous peoples if they support social changes and improve conditions of Indigenous communities, otherwise these changes may represent ongoing limited recognition of their social condition and struggles. Yet, it is important to acknowledge that these changes in government policies and practices are the result of the persistent efforts by Indigenous leaders and authorities who demanded that government leaders publicly acknowledge Indigenous rights, the harms perpetrated on Indigenous people and the governmental and institutional treatment of Indigenous people, both historical and current.

In terms of relationships of knowledge and power, recognition of harmful policies imposed on Indigenous communities evidences a long and troubled history between Indigenous peoples and

settlers in Canada. It may show, as Foucault signaled in the 1970s that, “what emerged in the last ten or fifteen years is a sense of the increasing vulnerability to criticism of things, institutions, practices, and discourses” (Foucault, 1976).

Currently, there is increasing awareness that continuing to do things as they were done before is to continue to harm Indigenous people. Many people are coming to acknowledge and understand the trauma experienced by Indigenous people at the hands of settler colonialism. Local, regional, national, and international social justice movements are working to gain equality and respect for Indigenous peoples. In the case of the field of science, progress is slow. There is a growing awareness of “differance”, a term used by Derrida, which signifies one’s difference from others or from the context itself in such a way that one experiences exclusion and alienation (Derrida, 2016). The fields of social sciences and humanities were the first disciplines to open dialogues on difference, while the physical sciences have been more reluctant to accept changes in knowledge and power construction based on multiple visions of understanding and reality.

“The Ivory Tower”—a metaphor for the ways in which some knowledge is generated inside laboratories and is based on strict and objective protocols with little regard for reality and practical application—is an iconic image of some forms of knowledge production. Inside the Ivory Tower, science and research can easily become detached from reality and the political implications of knowledge (Shapin, 2012). Analytic and experiential scientific methods are still considered today as the best methods for producing “real” scientific knowledge. This belief has been effectively installed into the social imaginary: the scientific method results are absent of researcher’s values and knowledge obtained represents the unique source of truth. However, one of the consequences of the acceptance of the scientific method as a guarantee of “real” knowledge is that many researchers disconnect themselves from the social implications of their research and fail to consider and address socio-political issues and community dynamics as part of scientific knowledge production.

Contemporary perspectives of knowledge production in communities, however, work with the idea that reality is constructed as a complex coordination of interchanges between objects, the observer, and the context inside a social enterprise. As Berger and Luckman (1966) noted, “Man's self-production is always, and of necessity, a social enterprise. Men together produce a

human environment, with the totality of its socio-cultural and psychological formations. Not one of these formations may be understood as products of man's biological constitution...". (pp. 69).

The pillars of objectivity, purity, prejudged absence, applicability, replicability and evidence that sustain science are moving slowly towards more complex theories of reality. Defined by scientific discourses, reality may comprise different representations than reality perceived and experienced by people in their everyday lives. However, Berger and Luckmann (1966) consider both representations—the one described by the scientist and the other experienced by a person living within their community—as social constructions of communities. Similarly, through social interactions with Indigenous peoples, Indigenous epistemologies can be considered ways of producing valid and reliable knowledge.

2.3. Knowledge frameworks of health research

In a recent exploration of epistemologies commonly accepted by health researchers, Khushf (2013) presented three alternative classification of knowledge systems—descriptive, normative, and meta-epistemology—to describe medical health research and practice. In the descriptive system, health science is focused on learning how “people come to know the things they know, and how they use this knowledge...[by] diverse methods, ranging from introspective reflection of experts on their own reasoning processes to more traditional experimental methods” (Chapman & Sonnenberg, 2003). Normative epistemology “involves accounts on how people ought to arrive at knowledge and use it” (Khushf, 2013). These two alternatives focus on knowledge that can be extracted from simplistic and primarily observational data by eliminating errors and misconceptions, and distinguishing “genuine” knowledge from presumed knowledge (Jenicek, 2003). Thirdly, the meta-epistemology system “involves investigations into higher-order concepts that are used in both descriptive and normative epistemologies” (Khushf, 2013). Meta-epistemology, then, is a source of knowledge that deals with logic and inferences as well as abstract reflections on medical epistemology. Descriptive and normative levels of medical science use knowledge derived from meta/epistemological health research.

Khushf's framework provides a context to understand the variability of health research, and how Indigenous knowledges may find a place within medical knowledge frameworks. Meta-

epistemology, the third system proposed by Khushf recognizes the difference between individual and social epistemologies. For Khushf, the practices of descriptive or normative health research do not include the influence of social, cultural, educational, political, and institutional, professional organizations as factors affecting either health knowledge or disease (Khushf, 2013). However, meta-epistemology still partially recognizes the possibilities of non-Western approaches to health research. Alternative epistemologies, however, cannot be considered as the last resort to understand human complexity when scientific methods and discourse do not “efficiently” address health conditions. The incorporation of social context into health research requires deep modifications of what we consider science and knowledge.

The shift of perspectives in the field of science from single to multiple versions of reality could be described by what Seidman (1994) refers to as the “postmodern turn.” Following the modernist enlightenment era in the social sciences that occurred in many Western countries, including Europe, the United States, Great Britain, Germany, and Australia, the postmodern turn is an ideological, socio-political, and cultural movement, which reverses Western assumptions and perspectives of development, unity, science, and progress. As postmodernists see it, the loss of institutional credibility, the decline of science as “truth-producing,” and the questioning of the assumption of Western superiority characterizes the current age. Postmodernism challenges the assumption that scientific knowledge is the unique way to unveil and control reality through systematic and logical reasoning. People are beginning to understand reality as a social construction. Postmodernists also question scientific realism—the assumption that reality exists and is reflected to our senses at invisible levels, where it is accessed through experimentation and technology (Liston, 2016).

Antirealists also believe that scientific methods do not inform our understanding of reality, because reality cannot be not fully captured by any single human intervention or research method. The belief that truth is obtained by credible experimental evidence and the assumption that knowledge can be replicated are related to the ideological-conceptual framework of scientific realism. As science relies on the researcher’s ability to predict and verify events, the impressive technological achievements guided by an experimental mindset are difficult and often impossible to question. Nevertheless, using other sources of knowledge allows scientific credibility to be challenged. Because health research is strongly based on technology and

experimentation, it may appear to capture reality as it is. Yet, the contrary is also promoted by scientific knowledge: that reality is frequently dictated by health technology and health science. The absence of understanding the relationships between individuals with their socio-political, economic, community, and cultural environment in Western health research and health practices is severely questioned by researchers who engage in Indigenous health research. In the scientific apparatus, the voice of Indigenous people, their communities, and their traditional knowledge—important dimensions of health for Indigenous Nations related to the Medicine Wheel—are absent. For example, in an analysis of the epistemological basis of the doctor-patient relationship, the dominant, positivistic paradigm is reflected when a doctor rejects a patient’s explanation of their cancer diagnosis. The patient might say: “I think I know why I’m ill,” while the doctor replies, “Well, that doesn’t make any difference to the way we treat you” (Hamish, 2000, pp. 203). From an Indigenous health perspective, self-determination and individual pathways are necessary to rebalance individual and community health.

Developing an understanding of nature as expressed in Western science is a prerequisite of what could be considered “pure” knowledge production. Concepts of scientific knowledge and data are cohesive and structured, meticulously contrasted to new knowledge and previous knowledge, and rigorously classified by applying many theoretical and practical categories. The goal of the scientific method is to unveil the nature of reality through the construction of scientific discourses that aim to describe, predict, and control. The scientific method is criticized from those outside and inside science-based disciplines specifically in relation to how Western science has obstructed the progress of research (Foucault, 1980) by creating and propagating a reality grounded in Western perspectives and practices. Furthermore, knowledge produced by racial minorities has often been silenced, romanticized, localized, and generally considered intuitive and naïve, because it is viewed as incomplete or unsystematic when compared with Western scientific knowledge discourses (Mignolo, 2006). In the case of Indigenous people, the right to access and produce knowledge has been suppressed through the processes and practices of colonialism, and has disconnected Indigenous people from their languages, cultures, traditions, lands, sources of food, and ceremonies (Schouls, 2002). Furthermore, when the principle of scientific determinism is practiced to obtain knowledge “from” Indigenous people, this “egocentric” and ethnocentric method negates the cultural beliefs, history, values, context, and

knowledge of Indigenous peoples by classifying, stereotyping, and cataloguing them as artifacts of cultural expression but not as knowledge producers.

In contrast to the pretense that scientific knowledge is pure, extemporal, ahistorical, apolitical, individual, and private, the congruence between knowledge and context emerges as a condition of validity. Social context has become understood as a point of reference that needs to be included in and associated with scientific knowledge. The inclusion of social context is considered inseparable from knowledge creation by Indigenous scholars and health researchers engaged in decolonizing or Indigenizing health research. These scholars and researchers understand that valuable knowledge is local, it “is an autonomous non-centralized kind of theoretical production, one whose validity is not dependent on the approval of the established regimes of thought” (Foucault, 1980). Foucault’s (1980) notion of the locality of knowledge signals the urgency to ground scientific knowledge in the circumstances and the history of the context in which knowledge is, or was, created. This locality includes a return to hidden knowledges and silenced contexts. Similarly, Freire’s (1985) discourse in relation to the dialectical liberation of the oppressed and oppressor, the locality of scientific knowledge may promote the reinvigoration of subjugated knowledges. Foucault (1980) outlines subjugated knowledge as “the historical contents that have been buried and disguised in a functionalist or formal systemization...[and]...a whole set of knowledges that had been disqualified as inadequate to their task or insufficiently elaborated...beneath the required level of cognition or scientificity” (pp. 81).

2.3.1. Colonial systems and Indigenous knowledges

In colonial systems, the significance of Indigenous knowledges was denigrated while other knowledge-power relationships were simultaneously imposed upon Indigenous communities. New ideals of progress, knowledge, and well-being were imposed by modern society where Western rules and culture were held as ideal, and “wild,” “uncivilized,” and “underdeveloped” Indigenous people were forced to assimilate into more “advanced”, “cultured” Western society. In sum, colonialism and the colonialist approach to knowledge was vehemently inflicted on Indigenous people, who also suffered violent impositions of Western epistemologies.

Furthermore, Indigenous people suffered harms caused by Western social, ethical, economical, and political principles of homogeneity and progress, through the power that resided in the figure

of the King (Foucault, 1980). In this encounter between the monarchy and the subject, knowledge is attached to power, which intermingles with economic growth, eventually resulting in the social degradation of Indigenous communities.

Unfortunately, silencing Indigenous knowledges through the imposition of the colonial triangle of knowledge, power and economy was a common practice in relationships between settlers and Indigenous peoples. Many restrictions were imposed upon Indigenous people such as the “pass system,” which affected Indigenous peoples between 1885 and 1941. The pass system prevented Indigenous peoples from leaving reserves or freely moving from one place to another—even if only to visit their relatives or children, go to the hospital, or engage in trade with another community—without a permit. This system was enforced and administrated on reserves in Canada by Indian agents who imposed strict controls and limits on Indigenous rights to self-determination (Carter, 1985; Barron, 1988). Like the pass system, the residential school system was created as a “solution to the Indigenous problem,” where Indigenous children were taken from their families and forced to attend residential schools often far distances from their communities with the goal of annihilating Indigenous culture. Indigenous children’s and families most essential human rights were negated and violated, and under false conclusions about their “inability” to produce “good citizens,” parents were prohibited from protecting, nurturing, and raising their own children. The summary of the Final Report of the TRC entitled, *Honoring the Truth, Reconciliation for the Future*, clearly defines this policy as “cultural genocide.” According to the report, physical genocide is a mass killing of a group, while biological genocide is de erasure of the group’s “reproductive” capacity. Then cultural genocide is the annihilation of cultural practices and supports that grant the group will continue as a group (The Truth and Reconciliation Commission TRC, 2015).

In the name of “modernization,” a regime of institutionalized violence was imposed on Indigenous communities in an attempt to civilize the “Indians” (Hoxie, 1984). An assimilation process was created to incorporate Indigenous people into the dominant European settler population with the hopes that the differences between Indigenous people and White settlers would be no longer clearly identifiable (Stote, 2014). Claiming the “altruistic goal” of civilizing the “wild West,” settler governments unleashed a regime of terror and violence on Indigenous people (Stote, 2014). As the process of assimilation was gaining momentum in the politics of

Canada, the main idea was to “contain” Aboriginal peoples, and force them to adopt Western practices. The intended result was that Indigenous people would be absorbed into Canadian society. The statement below exemplifies the motive behind the Indian Policy as expressed by Indian Affairs Agent, Duncan Scott:

I want to get rid of the Indian problem. I do not think as a matter of fact, that this country ought to continually protect a class of people who are able to stand alone. That is my whole point. Our object is to continue until there is not a single Indian in Canada that has not been absorbed into the body politic, and there is no Indian question, and no Indian department, that is the whole object of this Bill (D. C. Scott, 1920).

Through the residential school system and other policy initiatives, Indigenous people were killed, their movements restricted, their freedom to mingle and associate penalized, their language and cultural practices prohibited, and their self-governments dismantled. Residential schools were also an act of colonization: a maximum effort to create, use, and impose Western ideologies on colonized and yet-to-be colonized communities. Residential schooling, as well as other violent initiatives, silenced Indigenous rights and muted Indigenous identities. By 1841, Herman Merivale, Under-Secretary of State for the Canadian Colonies, implemented four policy alternatives to be used to solve “the Indian problem”: “extermination (by death or enfranchisement), slavery, insulation (reserves), and/or assimilation (Rheault, 2011, p.1).

Power, economics, force, and the creation of certain institutions were all used systematically to propagate Western cultural ways of creating, using, and developing epistemologies, while Indigenous knowledges were dismissed as simplistic cultural practice. Decolonizing Indigenous health research requires the unveiling of colonial machineries currently imposed on Indigenous communities by existing health research perspectives.

2.4. Indigenous Ethics Perspectives

2.4.1. Ethics Guidelines

Health research designed and conducted without the consideration of Indigenous perspectives contributes to a colonial project of health research. The sophistication of the colonial mindset is strengthened when power attached to socio-cultural or economic colonizing strategies is reproduced in an “modernized way” under the pretension of “modernity” because it pays out dividends to whoever is holding strategic power. As Elder Mr. Buzzacott argues, in Watson’s interview, massacres are now conducted through “sophisticated ways with their legislation and policies” (Watson, 2014, pp.47).

Since 1970s, Indigenous scholars have criticized the imposition of Western research on Indigenous communities (Peacock, 1996; Gilchrist, 1997; Barden & Boyer, 1993; Mihesuah, 1993; St. Denis, 1992; Deloria, 1991; Red Horse, Johnson, & Weiner, 1989). Many Indigenous communities currently respond to Western health research with resistance and hostility because of a long history of health impositions, intrusions, exploitation, systematic alienation of Indigenous culture in health systems and health research, (Trimble, 1977) and inappropriate representation of Indigenous ways of life (Peacock, 1996).

Currently, a negative history of overt and covert racial and social class discrimination (Browne et al., 2011; Denison et al, 2014), and intimidation and harassment of Indigenous peoples (Cameron et al., 2014) are barriers to trust-building processes between Indigenous populations and healthcare professionals (Horrill, McMillan, Schultz, Thomson, 2018).

Even though some researchers may intend to use decolonizing and anti-oppressive practices in health research, organizations and individuals declaring support to Indigenous causes may unknowingly reproduce Westernized ways of knowing. Eurocentric health research imposes colonialist ideas, beliefs, and practices on Indigenous peoples and racism: “... colonization of Indigenous lands and peoples was fueled by racist beliefs and ideas about Indigenous peoples, values, ways of knowing and being, customs and practices (Allan & Smylie, 2015). The harm caused by colonialism has been acknowledged by the Canadian government: “The Liberal federal government elected in the fall of 2015 has indicated a move from indifference to

engagement, a shift yet to be sustained by a track record of solid diplomacy, policy and budgetary shifts and importantly (Borrows 2016), by enabling legislation” (Green, 2006). This is a commitment to address current Indigenous health concerns and thereby improve health research for Indigenous peoples:

Saying that we are sorry today is not enough. It will not undo the harm that was done to you. It will not bring back the languages and traditions you lost. It will not take away the isolation and vulnerability you felt when you were separated from your families, communities and cultures... We share this burden with you by fully accepting our responsibilities—and our failings—as a government and as a country (Harper, 2008).

To reconcile the relationships between Indigenous people and Canadian settlers, and to heal the damage done to Indigenous populations requires significant changes to Canadian culture, government, and public policy and practices. It also means re-allocating health and education resources, and reconsidering the way that health knowledge is created, stored and used.

Western science commonly supports and conducts health research approaches that makes epistemological, methodological, theoretical, practical and social assumptions that are inconsistent with Indigenous worldviews and may not necessarily benefit Indigenous peoples. This dichotomy may be considered, superficially, to be a “knowledge transfer problem” focused on applying health research and transforming health for Indigenous communities based on research findings and scientific evidence. Foucault (1980) might call this a “regime of truth,” where worldviews of one group are imposed onto another without their consent. In a regime of truth, Western researchers may declare that they own “the truth” or ways to access truth, frequently detaching health knowledge from Indigenous cultures and contexts under the assumption that the human body is always the same and operates independent of cultural differences. Discussion on this topic ranges from naïve arguments about the need for best practices and guidelines, to continued debates on the imaginaries and assumptions involved in knowledge-making and the primacy of Western thinking. Concerns also surface about the ethical principles of authentic engagement such as what actions and thoughts are required to express and

maintain a shared respect; what methods can be practiced to acknowledge inherent Indigenous and Treaty rights; what are the implications of recognizing Indigenous cultural and language diversity; what are the correct ways of sharing authority and responsibility; and how health research might center First Nations, Inuit, and Métis community as priorities (Cook et al., 2014). Issues pertaining to the ethical guidelines concerning research with Indigenous communities are complex and cannot be addressed through a simplistic research approach because they are related with the culturally diverse Indigenous community in Canada and Indigenous people's struggles in political, financial, social, and historical-cultural dimensions. There are myriad of ethical guidelines available however, most visibly are the Tri-Council Policy Statement (TRC-2, 2014) and The First Nations Principles of OCAP™ (FNIGC, 2007). Other documents and agreements are written by universities and research centers, local, regional, federal authorities, in partnership with Indigenous authorities, organizations, and communities. In general, these documents attempt to facilitate and guide health research in ways that are meaningful for Indigenous communities. Despite these efforts, the shift from individually-based health research to community-based health research that is considered from a relational, holistic perspective of health rather than a biological, positivistic perspective is still a significant challenge that requires ongoing research and revision.

This controversy has a practical relevance to Indigenous communities, researchers who engage in Indigenous health research, and public policymakers. Discussions here recognize the work of the TRC which acknowledges the damage colonialism has caused to Indigenous people and communities, and the Calls to Action (2015) state that Indigenous people must be directly involved in any changes in our society in relation to Indigenous rights and well-being. However, to respond sincerely to these calls necessitates progressive shifts, in institutions, individuals, and in society. In the field of health research, the reconciliation process requires the development of new knowledge that is culturally respectful of Indigenous traditions; one that acknowledges and promotes Indigenous health improvement. Yet, compromises with Indigenous communities causes some tension inside institutions and among health researchers who are caught between adhering to Indigenous community ethics and the demands of Western scientific constructions of health.

In the health sciences, researchers—with some exceptions in nursing, epidemiology, public health and global health—receive training primarily in dominant body, biological, positivistic, and experimental scientific approaches and are required to practice medicine using Evidence-Based (EB), Medical Decision-Making (MDM), and Medical Knowledge Transfer (MKT) frameworks.

Western scientific knowledge continues to be imposed on Indigenous communities in an attempt to reduce illness, cure disease, and prevent future pandemics. This imposition exemplifies a sophisticated kind of colonialism, which positions Western science as the only valid solution, and Western health researchers' knowledge and methodologies as “superior” to the knowledge and beliefs of Indigenous communities who still suffer discrimination in the form of the modern neocolonial project of science (Browne, Smye & Varcoe, 2005; Ashcroft et al., 1998).

One way to begin transforming neocolonial practices is for health professionals and institutions to step aside and give space for Indigenous communities to address health concerns that are relevant to them. This research is focused on community-based research that acknowledges and draws on Indigenous beliefs and values, thereby shifting the meaning of concepts such as “valid,” “real knowledge” or “evidence-based knowledge.” Such discussions and changes in how research is conducted have the potential to develop knowledge that can be useful in transforming healthcare and health research in ways that promote and maintain healthy Indigenous individuals and communities.

Chapter nine of the “Tri-Council on Indigenous Ethical Guidelines” may be considered generic, abstract, and difficult to understand for non-Indigenous individuals doing research involving Indigenous participants. This point is discussed by Smylie (Smylie et al, 2004), who, through their study of the ethics of Indigenous research, identified there are several stages that need to be considered involving Indigenous people. The first is comparing Western science and Indigenous knowledge systems. Second, recognizing the historic harms of colonialism caused by health science imposed on Aboriginal communities. Third, creating cultural safe and grounded frameworks for knowledge processes and transfer, and fourth, inclusion of Aboriginal leadership, governance, and participation. (Smylie et al, 2004).

Indigenous ethical guidelines may be followed without a full understanding of the principles and knowledges that represent and may be embedded in health research, without complete Indigenous cultural, historical, and current knowledge. Further, these guidelines may also not be adopted in research practices in culturally safe or respectful ways. Indigenous health is one of the major public health concerns in Canada, and public health policymakers and ethics boards in charge of health research guidelines who oversee distributing the funding are required to conduct Indigenous health research.

2.4.2. The Ethics of this Study

Indigenous perspectives and Western perspectives of knowledge may find a commonality based on the ethics of Indigenous health research with and by Indigenous communities. This study presents insights into the barriers and challenges that researchers who engage in Indigenous health research encounter when designing, conducting, applying and evaluating health research in a manner that can honor and respect Indigenous people and simultaneously contributes to building healthy Indigenous communities. The research process applied in this research was an attempt to create safe(r) opportunities to open epistemological, methodological and practical discussions on health research ethics and knowledge with the intention to address health challenges experienced by Indigenous communities and mobilize health research education in the direction of the ethics of Indigenous health research.

From the perspective of decolonial and knowledge-power frameworks, this research explores how ethical health research can support healthy Indigenous communities by applying Indigenous Narrative Inquiry methodology (Stewart, 2008; Barton, 2004; Gubrium & Holstein, 1995), which is further refined in later projects (Stewart 2009, 2011, Stewart and Elliott, 2014; Stewart, Reeves and Beaulieu, 2014). In general, this research is grounded in Indigenous knowledges and ethics (Marshall and Stewart, 2004). Following this methodological approach, research is conducted with the participation of and guidance from Indigenous community members, beginning with the initial stages of project conception, right through to the end of a given study, when the results are analyzed and shared. Furthermore, this approach stresses that Indigenous communities maintain ongoing control and ownership of the knowledge generated by the research following the OCAP principles (2007). Particular to this study, Indigenous community

members were invited to participate in several ways including as a part of the research group, as an Elder, as a Community Key Informant, as an Indigenous health researcher, or as a trained student research assistant.

This research methodology is premised upon ethical practices of Indigenous health research that center knowledge-building and sharing in Indigenous communities. The community-based nature of the methodology is used to explore topics related to Indigenous health research methodologies and approaches and requires not only a shift from generating and disseminating theoretical knowledge as the single way to produce and share “real” knowledge but also requires that health researchers approaches outside of the mainstream Western culture and health science frameworks.

The epistemological and methodological approach used in this research can be described from different angles. It can be considered as a retrospective decolonizing study or an ex-post-facto analysis of a singular set of experiences. However, it would be better described as a multi-method, multi-level strategy to produce, access, and analyze data; understand relationships; and produce new knowledge. This new knowledge may transform the realities of Indigenous communities by improving Indigenous healthcare systems, services, research, and education and build better futures for Indigenous health research.

This research is a mixed method approach that uses quantitative and qualitative data obtained from a national consultation survey. Data obtained from the survey will inform the second phase, which will involve developing questions for individual interviews and include Narrative Inquiry methods as a source of knowledge. In general, this research explores the complexity of social systems that shape relationships from a dynamic perspective and investigates the adaptive transformation of culture, beliefs, public policy, resources, and relationships that operate in the context of power and knowledge imposed to Indigenous peoples.

Results from this study will be used to explore active areas of health research. This study will also engage explorations of epidemiology, which stems from the Greek words, “epi,” which means “upon;” “demos”, which means people; and “ology,” which means “study” (Harper, 2001-2018). In epidemiological theory, “the science and craft that studies the pattern of diseases

(and health, though usually indirectly) in populations to help understand both their causes and the burden they impose” (Bhopal, 2002).

This supports the idea that for any health concern, there is a relationship between health care and socio-cultural health conditions. This idea is relevant to this research because Indigenous health should not be considered as a singular problem. Rather, it is influenced by interrelationships of historical, cultural, political, and social determinants of health (National Collaborating Centre for Aboriginal Health, accessed July 2018).

2.4.3. Data Sources

Main sources of data for this research include advice and shared knowledge received from Elders, Indigenous and non-Indigenous persons working in the field of Indigenous health research, community members and public policymakers. Data used in this exploration uses combinations of quantitative-qualitative data theory interpretations rooted in Indigenous community. Using an online strategy, participants in this research comprised Indigenous self-identified health researchers and non-Indigenous persons working in the field of Indigenous health research. The survey opened participation to Indigenous researchers living and working in Ontario and all Canadian provinces. Even though the survey involved an ample group from researchers who engage in Indigenous health research, it is important to note that this research does not claim “representation” and “generalization” because the complexity of Indigenous Nations, communities, knowledges and peoples is understood. Under the right of self-determination all and each Indigenous person and community is entitled to define the right ways to conduct and limit health research. Generalization, representation, participant homogeneity, and finding “the truth,” were not concerns in this research. Instead, diversity of data was promoted involving participants from different Indigenous Nations on Turtle Island, as well as non-Indigenous persons who are working in the field of Indigenous Health from a variety of socio-cultural backgrounds. Data interpretation and analysis focused on developing possibilities for future dialogues, where conclusions are not considered truth, but approximations to conversations and particularizations that need to be guided and directed by Indigenous Elders and Knowledge Keepers.

In this research, Western analytical tools and statistics are investigated in order to inform the development of the second phase of qualitative analysis for this study. Here, Western analytical tools and statistics are considered as exploratory instead of “regimes of truth.” In this sense, the interpretation of the survey data should be considered only as one description of the holistic, broad, integrative, and complex systems perspective that will be integrated into the phase one and phase two of the research project. Results here should not be taken as a source of “truth,” but rather, as part of a path for where and how to guide further exploration.

The Steering Committee guided and proposed research questions and direction of this project. Data was gathered from an online survey and analyzed from descriptive statistics and multilevel framework. As a result, a national online survey was designed to gather the perceptions and opinions of Indigenous and non-Indigenous persons working in the field of Indigenous health research as the better way to explore this topic with ample participation and due limitations on resources. The quantitative and qualitative data from the survey was triangulated with health researchers, the Indigenous community, and research team. Then, in order to identify themes and meta-themes, the data was processed using quantitative statistical analyses, qualitative analysis, and content analysis. Qualitative data of the survey was coded progressively until the formation of major meta-themes became evident. The meta-themes were then de-constructed using several document analysis perspectives to explore ethical questions and inquire into whether Indigenous health research was conducted in accordance with Indigenous beliefs and attuned to community health concerns.

Under a decolonial approach, this research explores barriers and limitations to the practice of Indigenous ethics. It explored several notions of Western knowledge and scientific concepts normalized as representations of “scientific truth.” This approach will not restore centuries of history, represent all Indigenous knowledge or communities in Canada, or pretend to reconstruct a historical order, or include all knowledge on ethics and health research. As an archaeology of knowledge (Foucault, 1972), this methodology crafts knowledge and relationships between health researchers on ethical guidelines of involving Indigenous peoples in health research.

As it was discussed previously, Western health perspectives frequently underestimate the value of Indigenous perspectives, applying classifications such as “romantic,” “nature centered,” or

“holistic,” as if they were “exotic,” “naïve,” or “new age” understandings of life and its relationships. For this reason, this research is grounded in the commonalities of knowledge and builds on Indigenous community knowledge. As a decolonial endeavor, it values Indigenous knowledges as a self-validated knowledge.

Over the long term, this research aims to contribute to an ongoing discussion with and by Indigenous communities in Canada by encouraging and inviting health researchers to conduct research supporting Indigenous knowledge. Impacts of this research are expected on tertiary, undergraduate, and graduate health education by including discussions about epistemology, research education, power, colonialism and ethical challenges of Indigenous health research in the curriculum. In the short term, this thesis offers insights about how Indigenous knowledges, epistemologies, methods, and practices impact and transform health researchers and health education. Based on data analysis and results presented here, new pedagogies are presented and grounded in Indigenous perspectives and ethics—a set of ideas which I am calling, “pedagogmiologies.” I define pedagogmiologies as the ways in which the origins of illnesses and the concepts defining illness are created, shared through education, and applied to developing technologies, health services, and public policy. The possibilities of using alternative pedagogies are intended to support meaningful learning for future health practitioners, and provide them culturally safe environments in which they can develop the skills required to work in ways that are culturally safe and respectful for Indigenous populations.

It is in this sense that building relationships and Indigenous health knowledge is a process that should be controlled and managed by Indigenous communities. From a Western perspective, the progressive accumulation of knowledge is a valuable commodity, owned by the author, and regulated through licensing or payments. Knowledge is traded within a global economic system shared by Western societies, and protected under national and international law, as well as social, cultural, and economic agreements. In contrast, some practices of knowledge production can offer better alternatives for sharing knowledge for example, Open Source frameworks, free access, and Creative Commons movements in which economic power is detached from knowledge access and use.

It is understood in this study that technology is not always available to everyone. Internet provides access to online services such as the surveys in this study, but only to those who can access the internet, computers, smart phones, and data coverage. This reality creates barriers related to fairness, coverage, access, privacy, and regulation for those health researchers that are not able to access internet services. This situation is noted in the limitations of this study.

In this research, the methodology selected during the collaborative development phase of this project by the community participants aims to facilitate the construction of health and healthcare knowledge with a focus on wellness. This may also be useful in gathering data on static and inflexible concepts associated with knowledge transfer and applied knowledge strategies. In sum, by focusing on exploring perceptions and the field of Indigenous health research ethics, this study contributes to discussions on improving Indigenous health research.

2.4.4. De-colonialism and Indigeneity

With the intention of understanding the modern aspects and historic roots of colonialism, this section explores historical narratives of the first Western settlers for evidence of cultural superiority. This allows a clearer picture of how to work within a decolonizing framework in relation to Indigenous health research. The journey of decolonizing and rebuilding Indigenous health knowledges, which are rooted in Indigenous cultural respect and connected with the Indigenous community's challenges, can be describes as the harmonization of the passage from harmful knowledge to supportive knowledge towards Indigenizing health research. The concept of "indigenizing" opens middle theoretical and practical discussions about how Indigenous-based knowledge may subvert the Westernized ownership of "truth" in scientific health research (Durie, 2011). Harnessing Indigenous knowledge resists knowledge production based on Western power-based modes of science, and reconsiders Indigenous knowledges in meaningful contexts that are modern, dynamic, centered on everyday relationships, and universally understood. Decentering Western practices and affirming Indigenous cultural knowledges, practices, and beliefs guides Indigenous communities towards improved health and well-being through a process of decolonizing and indigenizing education (Pete, Schneider, O'Reilly, 2013).

Colonialism utilizes tools of economy, war, power, expansion that deploy global, religious, educational, and nationalist discourses. Thus, colonialism is a historical, cultural, and economic

process encompassing all strategies that impose “control of one people by an alien one” (Oliveira-Marques, 2001). Historically, the idea of superiority was first adopted as a strategy for domination and colonization. In this next section, it is explored how initial colonizing programs were integrated into institutions, regimes and knowledge after peace agreements were reached between Indigenous inhabitants and colonizers.

Colonialism can be traced from the beginning of human history and continues to persist in current times. Ancient colonial programs are responsible the expansion of the Roman Empire, and the unification of India by Asoka. Colonialism was not conceived by Europeans, but it certainly shaped the development of pre-European nations and influenced Spain and Portugal’s division of the world into two distinct groups (Stuchtey, 2011). The people from countries who profited—and continue to profit—from colonization mobilized religion as a tool of dominance, using what Kohn & Reddy (2017) refer to as the “three C’s of Colonialism:” civilization, Christianity, and commerce.

Understood as the beginning of European colonialism, Spain and Portugal began to set up colonies in the Americas and Africa after “discovering” them (Stuchtey, 2011). In 1494, the first contractual agreement to divide the entire world crystalized in the Treaty of Tordesillas between Spain and Portugal. The treaty established these two kingdoms as owners of the western and eastern parts of the globe, which they divided with an imaginary line traced from the North to the South pole. The parties agreed that 370 leagues west of the Cape Verde Islands would be controlled by Spain and the east side would be dominated by Portugal (Cuesta, 1994).

A second phase of global colonialism occurred in the nineteenth century, during which time there was not a single territory that was not a colony or under the control of European or American powers. The ongoing re-division of territories was the only alternative after the conclusion of the colonial project (Supan, 1906). In the twentieth century and currently, imperialist and globalization movements represent new versions of colonialism. These economic, religious, cultural, and social movements commonly use knowledge as a tool of dominance. Knowledge is considered a privilege of the colonizer—the master, against the colonized—the servant. In the case of science, some scholars have used the phrase “colonizing the mind” (Brunstetter, 2010) to refer to the notion that ideas of Western superiority have taken hold in

people's minds, and that only European and American scientists produce valid knowledge, while Indigenous peoples and those in developing nations around the world only produce culture. Political power and economic interests are only linked to scientific conceptions of knowledge (Mignolo, 2009, 2007). Delinking knowledge and power and decolonizing scientific discourses also decolonizes understandings about human beings. In "Dismantling the Doctrine of Discovery," The Assembly of First Nations (2018) reminds us that in order to justify acquisition in the "newly discovered" lands of America, it was necessary for Europeans to first argue that the discovered lands were empty and not occupied by human beings. Yet, these "new lands" were not empty. Rather, Indigenous people inhabited the land.

The Assembly of First Nations (2018) affirms that it is impossible to apply the doctrine of discovery on empty lands in the case of Indigenous peoples, because those lands were occupied by Indigenous communities thousands of years before any missionary or conquer from Europe. But Europeans did not respect the fact that Indigenous lands were already the lands of others and used the "discovery doctrine" to support their false right to disposes and remove Indigenous Nations and First Nations in what is called now Canada.

Then the importance of classifying Indigenous peoples as not human turned morally decisive in applying inhuman practices and enslave Indigenous peoples. Defining Indigenous peoples as "no more than animals" or "bodies without the ability to reason", merchants, mercenaries, religious authorities, and political actors favored the idea that Indigenous people in the Americas could not be considered human beings because they did not believe them to have souls, the capacity for higher thought, or other higher order human capabilities (De Las Casas, 1552). Concerned about the massacres of and the atrocities committed towards Indigenous peoples in America under the regiment of Spain, and after continuously demands from local missionaries as De Las Casas, the Spanish king Charles V ordered a meeting to determine if the Indigenous peoples of these lands were, or were not, "human beings". This discussion was crucial because if Indigenous people were not considered human, then slavery, war, and domination could be continued and ultimately their extermination morally approved under the power and authority of the King would be justified. In 1550, Fray Bartolome De Las Casas, a Dominican priest in favor of the pacification and religious domination of Indigenous people, and Juan Gines Sepulveda, a philosopher and academic representing the interests of Spanish merchants and colonists debated the topic. They

and others debated the issue in several books without a clear ratification or negation of the rights of Indigenous peoples. In order to prevent more harms and human exploitation, after the colonization was practically completed, the King suspended systems such as the Encomienda, which justified the expropriation of the land and enslavement of Indigenous peoples (The Gilder Lehman Institute of American History (n.d.), De Las Casas, 1552). In the absence of the Encomienda, the exploitation of Indigenous peoples continued in subtler and more sophisticated ways, as they were marginalized culturally, politically, socially and economically.

The debate on the humanity of Indigenous people is a window into the colonizing mind. Beliefs underlying such discussions can be seen in recent human rights violations connected with ethnic, political, religious and economic nationalist ideologies. Historical genocides in Europe referred to the “purity” and “humanity” of one “race” over another. The destruction of the “other” rests on the dehumanization and reduction of persons to objects in order to legitimize violence. This is how a false but enforced supremacy of one group over another occurs within a constellation of characteristics that make a person a human (Brunstetter, 2010). Categories that distinguish groups are generally defined through the power of the colonizer. The colonial mindset finds support from certain philosophies of natural law, which posits that some were born slaves by nature and others born to be masters (Brunstetter, 2010). European colonizers imposed their own visions of reality and values of superiority, exclusion, inequality onto Indigenous people by force.

The difference between the One and the Other is currently monopolized by the European definition of Human Rights. The colonial European version of humanity makes it impossible to acknowledge the legitimacy of Indigenous knowledge production. Viewed by others in a tokenistic manner, Indigenous peoples are understood as only capable of producing basic knowledge related to survival or cultural activities (Mignolo, 2009), which limits knowledge production to its cultural location. Mignolo points out that these kinds of assumptions are not made if a person comes from Germany, France, England, or the United States. Ascribing dominance to certain aspects of European culture and types of knowledge, colonialism enshrines Western scientific knowledge as the exclusive and valid source of knowledge, and relegates Indigenous knowledge to, simplistically, “cultural expression.” To carry out the colonization project, new ethics known as the Humanitas reflected Europeanized logic and what was

understood as “I human,” that is, the European Anthropos that ruled all other forms of human life (Mignolo, 2009). As described by Mignolo, the Humanitas presented Western thought as the unique truth through structured arguments. Through the Humanitas, Europeans imposed the belief that they possessed the right and assumed a “natural” supremacy to discover, divide, colonize and exploit non-European lands, people, cultures and knowledge. The Humanitas supports the wrong idea that the philosophy of the self-considered Anthropos European is the unique and “pure” human being kind.

As described by Mignolo (2009), decolonization may contain two interrelated pathways: dewesternization and decolonization. Mignolo defines dewesternization as the economic detachment of Western powers (capitalism) as a decolonial impact of a multiplicity of decolonial tasks. It is the transfer of regulatory authority from dominant Western powers currently in control of the capitalistic economy to others so that they are no longer in absolute control of economic dynamics (Mignolo, 2009). While decolonization might be defined as “the principle that the regeneration of life shall prevail over primacy of the production and reproduction of goods at the cost of life” (Mignolo, 2009), decolonization must also consider the origins of colonial thought. In Western society, originality the right of innovation, the purity of race, knowledge, origin, and culture. The concept of “originality” overrules the law of natural difference between lords and servants and is a fundamental element in legal decisions around property or the rights of the colonized to own intellectual ideas, their land, their culture, and their knowledge production. Decolonizing epistemologies consider the silences of Indigenous communities and other colonized bodies and geographies, exposing the hidden and visible repressions of knowledge of those who are racialized, cataloged, and archived as the “other” by Westernized modes of knowledge. (Mignolo, 2009). In this case, silenced voices are Indigenous peoples who are banned from their rights of ownership of Indigenous knowledges and manage them under the control of Indigenous communities.

If decolonization would allow suppressed knowledges to reemerge, it also opens possibilities for new knowledge construction. Decolonization may be carried out by participatory community-based methods or by individual reflection on assumptions about knowledge and subjective experiences. Indeed, decolonization shares its main claims with Gergen’s (1999) understanding of social constructivism, which first contests the assumption that all knowledge is free of bias or

assumptions and it is objective, and critics positivism and conventional empiricism. Second it acknowledges historical and cultural prejudice of knowledge traditions, then emphasizes the argument that knowledge is produced by interpersonal relationships and interactions and not scientific “objective” observations. Third it considers that socially constructed perspectives of the universe will change, conduce to ways of actions and produce new possibilities of theories and practices. (Gergen, 1999).

Mignolo accepts Gergen’s statements as the situated production and construction of knowledge. Decolonization theory specifically focuses on knowledge production and power relationships as processes of colonialism. Indeed, Mignolo accepts that to understand the social construction of knowledge is just the beginning. A bigger goal is examining for whom, by whom, when, and why knowledge is constructed (Mignolo, 1999). Thus, knowledge production is not apolitical, rather, it is attached to the intentionality of science and the process of inserting new knowledge into social existing social structures and productive, political, and economic dynamics.

Decolonization may be understood as an optimistic rejection of the prevalence of the “hybris of zero point” (Castro-Gomez, 2005), which can be understood by Castro-Gomez as the myth of an absence of interference, or purity, absolute objectivity, and uniqueness of the truth of knowledge developed under scientific methods using western epistemologies. Specifically, the use of this decolonial concept in my research circulates around deconstructive knowledge production alternatives where Indigenous communities are supported and encouraged to produce, use, and share versions of knowledge according to their own Indigenous epistemologies. Without stigmatizing Indigenous knowledge as “romantic,” “ecological,” or “naïve,” and the overvaluing of Western scientific discourses as “truth,” this research also explores barriers to Indigenizing health and well-being knowledge.

Intimately related to Indigenizing pathways is a decolonial set of practices which restore Indigenous knowledge as the primary knowledge required to understand and support Indigenous communities: a sense of knowledge awareness which relates Indigenous human knowledges with individual and community experiences and health practices. In a similar way that deconstruction outlines specific ways to decolonize, Indigenization is better understood as the transformation of imposed colonial knowledge and representations of knowledge to privilege Indigenous

worldviews. According to Shauneen Pete at the University of Regina, Indigenization should also include, a process of “re-centering indigenous world views as a starting point for that transformation, [as] a process of institutional decolonization” (McDonald, 2016). For example, Indigenizing knowledge critiques the individualistic focus of career counseling theory used in psychology because it dislocates Indigenous from their community. Widely accepted individualistic approaches to life-career exploration may not be appropriate for Indigenous communities where, “for First Nation youth, values such as family and collective community must be considered” (Marshall et al., 2002). The absence of community considerations and focus on the individual is evidence of Westernized modes of life and epistemologies, which are based on reason, the individual subject, and their capabilities. Indigenizing the life-career process can eliminate these barriers by using knowledge that centers Indigenous perspectives.

A second important reason for Indigenizing knowledge production involves restoring the power of oppressed knowledges. This may include exploring silenced topics, involving misrepresented participants, and opening possibilities for excluded ideas as main topics of research. Utilizing Indigenized knowledge, research would reveal socio-cultural, political, and economic gaps that have impeded the journeys of Indigenous community (Marshall and Spowart, 2005).

Indigenization may be an active movement in many fields. For example, the architect Douglas Cardinal successfully introduced new building designs and materials based on Indigenous knowledge to universities, research centers, and community buildings. (Cardinal, 2018) Currently, some universities are in the process of including mandatory Indigenous Studies courses for students, and faculty and staff in some academic institutions are transforming course content to acknowledge colonial harms and teach Indigenous history in respectful ways. Various recreational facilities often include Indigenous gardens, and Indigenous ceremonies are being introduced in some public schools, corporations, and public celebrations. Public campaigns are raising awareness about other examples of colonial appropriation such as the offensive names of sports teams such as the Atlanta Braves, Cleveland Indians, and Washington Redskins. Still, other institutions are transforming logos and trademarks that tokenize Indigeneity, and some cities are installing signs and re-naming streets in Indigenous languages (McDonald, 2016).

In such endeavors, processes of Indigenization move Indigenous knowledge from the background to the foreground. Including Indigenous knowledge and cultures reflects Indigenous worldviews, impacts other practices, and establishes new opportunities for relationships to be built on trust in a shared world. Indigenized knowledge may contain knowledge that is in-transit, in the sense that it is knowledge that is never completed, but rather, is always under construction and always intertwined with changing and improving relationships. Respectful health research based on the inclusion of Indigenous cultural backgrounds should center on relationships created through in-transit knowledges.

2.4.5. Real Science and Cultural Knowledge

Modern science relies on knowledge obtained through experimental, positivist, and analytical methods, and is understood to reveal a unique version of the truth that is considered to represent the “real scientific” knowledge of the problem studied. As Vanlandingham argues, this is considered a hard science perspective where knowledge is based on empiric and positivistic reasoning. (2014). The hard science approach remains as a predominant assumption in health research that is conducted through clinical trials, laboratory experiments, and controlled experiments. Health research based on evidence and experimentation crystalizes the differences between “intuitive knowledge” and “superstitions;” between what it is considered “real knowledge” and what is considered cultural knowledge in contrast with soft science that is considered knowledge non-based on evidence. The imposition of the supremacy of one kind of knowledge over other can be considered a regime of truth (Foucault, 1980).

An historical exploration of the assumed supremacy of scientific knowledge over other kinds of knowledge shows that science became valued as a superior form of knowledge in response to certain power struggles. A dichotomy between scientific and other knowledge forms exists in relation to current understandings of health conceptions and health practices. Specifically, in contrast to the “soft” sciences, which are intuitive, cultural, spiritual, and less valuable, there is a tendency to regard the “hard” sciences as the most valued expression of human knowledge (Vanlandingham, 2014). The division of the sciences between “pure-scientific” and “impure-intuitive-cultural” knowledge goes beyond the academic world and permeates societal, ethical, cultural, political, and economic discourse. This division not only exists between methodologies

and knowledge, but is also socially, institutionally, economically and culturally divisive. This belief in the validity and credibility of hard science over soft science exists because of a complex relationship between financial, political, and religious ideals, values, and power.

The historical root of this bifurcation occurred when science first became espoused as an institution of knowledge. In the thirteenth century, Saint Thomas Aquinas elaborated on the work of Aristotle and Boethius (Aquinas, 1261), which divided sciences into the categories of natural philosophy, mathematics, and theology based on apprehension and judgment, as functions of the intellect. Apprehension was concerned with the ability of the intellect to the form from sensible things and the universal idea of a thing (Kanne, 1979). From the notion of the intellect, two types of sciences were possible: sciences that focused on the discovery of what things are, by using apprehension of intelligible objects; and those sciences which work with the knowledge obtained by apprehension, judging not only what the object is but also the nature of its existence in the universe (Kanne, 1979). According to Aquinas, when we see a human being, we should recognize the unity represented in that human being as well as the matter that it shares with all human beings. We observe a person in their unitary way of existence, including emotions, biology, social relations, history, possibilities, and wishes. Based on this earlier division of science, scientists were encouraged to engage the theory of apprehension by partitioning human beings into these two main operations of the intellect.

The well-known Cartesian dichotomy, which holds there is a split between body and mind further cemented the division of human sciences into those who study the biology of the human body, and those who study the philosophy of human interactions. Since Descartes' (1641) *Discourse on Method*, science has been considered the study of biological and physical explanations of the body, while socio-cultural disciplines emerged as non-scientific fields. The biological perspective continues to dominate medical sciences, which is concerned with the mechanical study of the body and the interaction of its parts. Biological science has accumulated theoretical and practical knowledge based on the theory of the body as a machine.

More recently, Thomas Kuhn (1970) offered a different interpretation of the evolution of science. In Kuhn's view, science is not considered an incremental accumulation of knowledge based on trial and error, but rather, a discontinuous yet progressive puzzle where philosophical

and cultural historical moments dictate the kind of knowledge that is accepted or rejected in each moment. (Marcum, 2005). Kuhn describes how this process dictates what knowledge is considered valid and what happens when two or more competitive paradigms are imposed on each other (Kuhn, 1970).

Using experimental logic and data analysis, the hard sciences progressively polarized things like human existence and land, nature and history, individuality and community, body and mind. The hard sciences advanced technological achievement and dominance developed through empirical-experimental methods while the second level of the intellect was relegated to domains outside scientific exploration. As Aquinas pointed out: “Science, then, does not aim at empirical knowledge gained through experimentation, but rather at a knowledge of the being and intelligible structures of things as seen in relation to their ultimate causes” (1261). As the sciences evolved, empirical knowledge supported by technology became the most valued while metaphysical knowledge, or knowledge concerned with understanding causation and the existence of things, was of lesser value. The broad implementation of technological advances allowed for rapid control of the world’s land and resources, detaching human beings from nature (Battiste, 2013), replacing this connection with new human ideals, values, and goals related to advancing a modern technological world driven by expansion and consumption.

Since the European Renaissance, the division of science into secular science and secular philosophy created a series of new disciplines such as biology, economics, and psychology. From Bacon to Wilhelm Dilthey in 1991, the disciplinary division of knowledge offered ideographic, interpretative, or nomothetic perspectives of the social and natural sciences, which were based on laws and explanatory science. Fields of science that evolved from these dichotomic disciplines produced new knowledge niches within educational institutions, privileging “rational” scientific knowledge to the exclusion of other knowledges, which were considered irrational or superstitious. Thus, a set of knowledges and practices were set in place that dictated who could produce knowledge, what and how knowledge should be studied, and privileged certain concepts, perspectives, and methodologies over others. Mignolo (2009) referred to these set of practices as “cosmologies,” and understood them as a framework for understanding the universe based on theology or philosophy-science knowledges. These knowledges compete amongst themselves to a point, but taken together, they also work to

exclude other types of knowledge located outside of the limits of privileged cosmologies (Mignolo, 2009).

The colonization of Indigenous knowledges required the collaborative exclusion of Indigenous knowledge and practices from these privileged cosmologies as a “hard science cosmology” was imposed and supported by technological achievements. Supporting the superiority of one over the “other,” fundamental bifurcations between intellect and judgment arose between human beings and nature, the individual and community, and knowledge and intuition.

Hard science cosmology represents the belief in the preeminent value of knowledge developed by using analytical empirical-experimental methods, the strong control of variables, mathematical data analysis, falsification, and logical reasoning. This is supported theories, laws, and relationships to previously discovered knowledge detached from personal influence or research bias (Vanlandingham, 2014). Knowledge obtained within a hard science cosmology rejects Indigenous and other knowledge that originate through non-dominant cosmologies. As silenced knowledge, such non-dominant cosmologies included Indigenous cosmologies based on personal experiences, community integration, intuition and premonition, dreams and visions, Elder’s experiences, ancestral knowledge, practical solutions to day-by-day problems, ceremony, and spirituality.

Indigenous knowledge “comprises complex sets of technologies developed and sustained by Indigenous civilizations” (Battiste, 2002) for thousands of years, including effectively managed relationships with other humans, nature, and animals. Under colonization by the hard sciences, Indigenous knowledges or cosmologies are diminished through the application of stereotypes which consider them to be “simplistic” or “inferior” in comparison to Westernized knowledge. As discussed previously, the assumption that Indigenous knowledge or ethics require validation violates the human rights and self-determination of Indigenous peoples. Additionally, Western knowledge functions in written cultures and is presented, constructed, shared, transmitted, preserved, and negotiated using the written word and associated technologies. Much Indigenous knowledge is transmitted orally from Elders to youth involving the community in the development of complex language structures that are passed down between generations in practice and through community experiences. Simpson (2004) tells us:

Elders have always passed into the next realm and IK [Indigenous knowledge] systems have always been primarily oral, yet they sustained complex social, cultural, spiritual, and political systems long before the arrival of the Europeans. The answers to how and why our knowledge has become threatened lie embedded in the crux of the colonial infrastructure (p. 375).

Research is not new activity to Indigenous communities but rather, has been a natural activity in Indigenous community life from ancestral times. Former Chief Norman Bone (2016) of Keeseekoowening First Nation contends, “As Indigenous Peoples we have always done research, always searched for understanding, ways of being and knowing the world around us to survive, we just didn’t call it research” (University of Manitoba, 2016). Indigenous knowledge cannot be compared with Western knowledge because Indigenous knowledge has and continues to be generated from widely diverse cultures and epistemologies.

For example, in the case of integrative medicine between Indigenous and Western medicine, some of the medical services and interventions practiced collaboratively between Indigenous scholars, Indigenous communities, and non-Indigenous health service providers are radically different from interventions based exclusively on Western science. Ancient traditional healers had the ability to practice complex interventions and provide health services in Africa (Gone, 2010; Maneno, 2017) and Latin America. (Carrie, Mackey & Laird, 2015). In North America, the US Department of Health and Human Services defined a strategic plan for Integrative Medicine, with a priority to “advance understanding of the mechanisms through which mind and body approaches affect health, resiliency, and well-being, and develop complementary health approaches and integrative treatment strategies for managing symptoms such as pain, anxiety, and depression” (National Centre for Complementary and Integrative Health, 2016, p. 15, 19). From a dominant scientific perspective, the medicine practiced by Indigenous communities is considered as “primitive knowledge” or “superstitions”. This is exemplified by Sigerist (1967) who wrote, “we naturally feel tempted to fill in gaps in our knowledge of the past from the study of contemporary -primitive tribes-. The question is whether this is feasible and justifiable”. Here, Siegrist’s statement suggests how Western thinking was egocentric the root of countless assumptions made from a position of power. This perspective on science and knowledge is a

clear example of the colonial mindset. Scientists like Sigerist wrongly believed that Indigenous knowledge was inferior because their technology is “very simple” when compared with what are held as more efficient and “sophisticated” Western approaches and technologies.

Positioning Indigenous culture as inferior or incomplete, colonization justifies itself on a false inferiority of knowledge that works to disqualify and devalue the processes and products of Indigenous knowledge by taking them out of the context of Indigenous culture, history, land, resources, and community. Sigerist describes how abundant examples of this strategy can be found throughout history (Sigerist, 1967) It includes the Greeks who referred to other cultures as “barbarians,” and European settlers of the Renaissance who referred to Indigenous peoples as “savages,” even as Jean-Jacques Rousseau referred to them as “noble savages.” Other romantic perspectives on Indigenous people imply that they possess a certain naïve natural dependence. The French viewed Indigenous peoples as living in concert with nature, without the destructive influence of “modernity”. The Germans called Indigenous peoples “naturvolker”: or people whose life is highly dependent on nature while “civilized” people were called “kulturvolker” or those who mastered nature through their technology” (Sigerist, 1967).

From an Indigenous perspective, these assumptions were made according to the theory of cultural evolution which posited that Western civilizations had evolved and advanced while other “primitive” cultures were unable to evolve or had not yet progressed through the stages. Relying on a model of continuity, this proclaimed “inferiority” of Indigenous people was used to explain the difference between colonial ideals of “progress” and the progress of other cultures, who did not live up to colonial standards of progress. Continuity is the assumption that by studying primitive cultures, one can obtain insight into the origin of modern cultures, because “culture” is perceived as an accumulative progression of knowledge and achievements through stages from savagery and barbarism to civilization (Tylor, 2006). This philosophy disengages people from their histories, homogenizes human beings into groups, negates their rights to difference, and classifies oral traditions and knowledge as less valuable than science. Modern culture, science, and technology are considered the only methods through which a society or culture can evolve. Thus, the principles of accumulative cultural evolution and continuity imply that there is only one direction or model of cultural growth, and that the Westernized belief that technological dependency is the only way to sustain life.

Outside of the principles of evolution and continuity, Indigenous knowledge is “a complete knowledge system with its own epistemology, philosophy, scientific and logical validity” (Battiste and Henderson, 2000). A cyclical process represents a viable alternative to the Western idea of linear, accumulative progression of cultural evolution. From a cyclical perspective, Indigenous communities connect with nature, create history, design techniques, and produce economic and socio-cultural developments in a creative process, which may be used for extended periods of time, and then through circumstance, when needed, requires change. Some of the forces for change can arise from too-rigid application, disintegration of the techniques or the culture, or new people influencing developments who add new practices to attend to new challenges (Sigerist, 1967).

The principle of cultural evolution may be found in modern and current assumptions of science and society. In the health field, cultural evolutionary ideas depend heavily on research with medicines developed from evidence-based standards, which, in turn, define practices of health and research methods. Evidence-based practice is currently embraced by most, if not all, health care providers and professions. Practice and research are interconnected, and evidence-based practice can be considered “the integration of the best research evidence with clinical expertise and patient values for optimum care” (Institute of Medicine, 2003). The task force report for the American Psychological Association (APA) described a best practice for evidence-based research as “deriving from a variety of research strategies including clinical observations, qualitative research, systematic case studies, single-case designs, public health and ethnographic research, therapy process and outcome studies, randomized clinical trials, and meta-analysis” (American Psychological Association, 2006).

Evidence-based practice is also focused on research paradigms of efficacy and effectiveness. While efficacy is “focused on determining whether a treatment can make positive therapeutic change, with the proximal goal of isolating treatments from all other sources of variance ...effectiveness of research is to determine whether the treatment can produce positive therapeutic change as implemented under more externally valid (real world) conditions” (Steele et al., 2009). However, evidence-based practices also leave outside of their scope culturally-based knowledge, as it is grounded in cultural, practical, and transcendental knowledge.

Culturally-based knowledge is used to develop technologies that are not based on evidence, in the same way that evidence is conceived in Western scientific discourse.

Knowledge produced in a scientific context is considered evidence of truth and is assigned the power to dictate how other practices must be implemented in science and broader society. Scientific discourse is based on assumptions about nature of intellectual human capabilities, hard science cosmologies, continuity, and evidence-centered experimentation. Science is built on a process of congruence and progressive abstraction from the facts using explanatory and mathematical models, and the assumed impartiality and objectivity of the research process. This is to, supposedly, minimize personal, socio-political, and/or economic biases to ensure the process of creating scientific knowledge is pure and offers valid conclusions. The health sciences incorporate the same hard science knowledge production methods into their health treatments and social interactions.

It is frequently forgotten that hard science methods of experimentation also include soft methods. It is also often forgotten that “decades before these more complex models and techniques gained traction among scientists...statisticians and social scientists were employing multivariate analysis, multiple sources of simultaneous causation, survival models to address right-censored observations, multilevel analysis to address unobserved sources of influence, content analysis to effectively use qualitative data” (Vanlandingham, 2014). The distinction between the “hard and soft sciences” can be considered a reflection of the “overrepresentation of man” in Westernized culture (Wynter, 2003). By imposing dominant, scientific machineries and knowledges, provinciality and isolation (Vanlandingham, 2014), creates barriers to knowledge flexibility. As Wynter (2003) suggests, there is a privileging of the Western ideal and definition of a human being, in the same way that Western scientists privilege the value of science and present it as the only “real” knowledge. This movement away from humanity and towards scientific knowledge as the sole source of knowledge can be described as *cognoscente* purity: a process that is internalized in the collective mindset that, under the vigilance of colonialism, exposes the self to Westernized machinery. People develop notions of scientific knowledge that are attached to their positions of dominance. Education has been a key instrument in this colonial process.

2.5. University Health Education

As a starting point, in the words of the TRC, the Canadian educational system has and continues to cause harm to Indigenous peoples:

Governmental failure to meet the educational needs of Aboriginal children continues to the present day. Government funding is both inadequate and inequitably distributed. Educational achievement rates continue to be poor (TRC, 2015, p 5).

Education for Indigenous communities is perceived as a double negative. First, it was pivotal in the expansion of Western science and progress, while simultaneously separating Indigenous people from their communities, lands, and nature. Secondly, education contributed to the repression and socio-economic oppression of Indigenous peoples, and there is a need to explain “the importance of recognizing the violations committed against indigenous peoples and encourage and facilitate cooperation of different communities, indigenous and non-indigenous, to overcome the legacies of conflict (Arthur, et al., 2012, p. 52).

By promising modernity and social mobility that was never possible within colonial systems of exclusion, education was designed, regulated, and dispensed as part of the imposition of Western ideologies on Indigenous communities, where “the coming of Western civilization (meaning Western European) with its Western forms of Education, to this continent was the autumn of traditional Indian education.” (Battiste, 2004, p. 215). Furthermore, harms perpetuated in the past continue to materialize in present practices. As dominant force, Eurocentrism coerced Indigenous communities in abandoning their land, language, cultural knowledge, social and religious practices, and many of their ancestral ways of living. Under the guise of social improvement and charitable support, colonization acted and continues to act by homogenizing Indigenous communities as a group, rather than recognizing the “difference” of the individual, who is guided by self-determination as a free human being. In addition to negative associations ascribed to terms such as “native” and “Indian,” Indigenous peoples were further discriminated by the legal system. They were viewed as “primitive” and unable to advance themselves beyond what Western culture saw as “inefficient” modes of living. Within a colonial mindset, primitive peoples represented a model of an imperfect culture, which according to theories of cultural

evolution, meant they had not completely evolved in the process from being barbarians to becoming civilized people (Moss & Gardener-O'Toole, 1987). In short, the Western notion of progress as the ideal model of society was imposed by colonizers and internalized in the minds of the colonized.

Through the paternalistic practices and beliefs of Canadian government and society towards Indigenous peoples (Coates, 2015), the problem-solution approach was sustained by defining Indigenous communities as in need of assistance and merely surviving in the absence of Western scientific knowledge. Education was seen, by colonial powers, as the preferred way to promote the construction, maintenance, and supremacy of western worldviews of knowledge and regimes of truth through all disciplines (Burns, et al., 2016).

The goal of Canadian education was to Westernize Indigenous communities by first teaching Indigenous students the language of the colonizer. The residential school system, the Sixties Scoop, the pass system, and socio-cultural stigma and discrimination faced by Indigenous peoples in and outside of educational institutions were key to the Westernization of Indigenous people and communities. Health education was and is distributed exclusively through a positivistic paradigm of health research, which unquestionably focused on evidence, empiricism, experimentalism and objective science.

The education system focused predominantly on Western perspectives of knowledge, discipline, and science considered Indigenous and other non-Western modes of knowledge production to be “low level knowledge,” “incidental,” or “expressions of cultural beliefs” (Mignolo, 2000). As Duran (2006) describes, Western epistemologies are based on an individualistic orientation where linear perspectives include a specific time orientation that positions “humans against nature” and imposes hierarchical modes of comprehension that incorporate a Cartesian dualism and an illness-disease focus. Colonial educative systems were imposed under the Western epistemology or learning and cultural appropriation. This system is perpetuated in current society in the form of teachers, or, “curricular Indian agents.” Rogers (2014) tells us, “instead of decolonizing education, today’s curricular agents typically misrepresent the historical and future agency of Native peoples while reinforcing the patronizing, normative, dominant-culture narrative” (p. 649).

In a comparison between Western and Indigenous epistemologies, Duran (2006) demonstrates that Indigenous epistemologies are collectivist, non-linear, generally time oriented, based on perspectives that link humans with nature, and recognize the holistic (spiritual, physical, emotional, and intellectual) dimensions of health and wellness.

Even though university health education is changing in response to the TRC's Calls to Action, current tensions within the field of public health and pressures to address public health concerns are increasing the gap between Western and non-Western knowledges. The need to make changes in health education can be seen in and outside of Canada. For example, in 2012, Columbia University, one of the largest universities in North America, initiated a program to change the curriculum offered in their Master's in public health program to focus on six new issues, which include addressing 21st century needs and challenges, focusing on disciplinary work, integrating science and practice, promoting leadership and innovation, improving cultural awareness and evaluation methods, and increasing interdisciplinary training (Begg, et al., 2013).

These curriculum modifications were made in response to relevant 21st century concerns. Yet, they represent only the beginning of the inclusion of non-Western approaches in university health education, which, even still, is "more rigorous, more interdisciplinary, and more comprehensive than any we have previously offered" (Begg, 2013, p.36). From a decolonial perspective, however, the program is still incomplete because it still lacks non-Western science perspectives and does not recognize the importance of Indigenous health knowledge. It is perhaps because this radical curriculum change incorporated some of the most current, critical health influences including globalization, urbanization, climate change, and the aging population (Galea et al, 2015), and that it has not yet addressed Indigenous recovery, recognition, and inclusion. While the program includes what they are referring to as "community engagement," their definition of "community" remains narrow and is represented mainly by university students, staff, faculty, as well as immigrants, members from various women's associations, and Afro-American representatives. As this project illustrates, one of the major challenges in this field is to overcome the disconnect between community realities and curriculum planning and design at the university level.

In Canada, despite some efforts to restructure university health education programs, Indigenous health education and Indigenous health research is still underrepresented in university curricula. In 2010, the Western University Health Sciences program restructured their curriculum to “produce humanistic health care professionals who practice collaborative patient-centered care” (Aston, Mackintosh & Orzoff, 2010). Designed in three phases, this curriculum first focused on non-technical competencies such as communication, collaboration, scope of practice, ethics, cultural awareness, and quality of life. In this first phase, the topics of ethics and cultural awareness may potentially facilitate discussion, however, the inclusion of Indigenous-based health research continues to be absent in this curriculum.

Indigenous health research requires that researchers abandon positions of power as well as Westernized knowledge and approaches to health in order to design, conduct, and evaluate health research with and for Indigenous communities. Indigenous health research cannot be considered only as an inclusion, or a topic of health concerned with Indigenous communities. Instead, Indigenous research and epistemologies must be taken up in respectful dialogue among equal partners and valued equally as knowledge produced, controlled, and protected by Indigenous communities. Without this kind of ongoing and conscious commitment, university curriculum will not see the inclusion of Indigenous epistemologies beyond anything other than the simple recognition that to incorporate Indigenous perspectives means a curriculum is taking up “culturally sensitive” practices.

A curricular change requires public policy and different levels of curriculum transformation: perspective of knowledge, “metaorientation, curriculum foundations person’s philosophy, view of history, view of psychology and learning theory, and view of social issues, curriculum domains and curricular theory and practice.” (Ornstein, & Hunkins, 2013, pp. 20).

On June 11, 2008, the Government of Canada offered an official apology for the harm residential schools caused to Indigenous peoples in Canada. Seven years after the official apology declaration, and with the culmination of the Truth and Reconciliation Commission’s Report on 2015, the education system began to respond officially to the TRC’s Calls to Action in a way that attempted to recognize and stop perpetuating harms, and to work at creating new possibilities for Indigenous peoples in Canada. This movement was largely initiated by several universities

before, which already valued the inclusion of Indigenous knowledges prior the official apology. In June 29th, 2015, University Canada's Board of Directors, which represents 97 universities in Canada, agreed with 13 principles to induce Canada's universities to support and include Indigenous peoples in higher education. The resulting document entitled, Universities of Canada Principles on Indigenous Education, includes guidelines to close the education gap between Indigenous and non-Indigenous people in Canada. According to the association, "closing the gap will strengthen Indigenous communities, allow Indigenous peoples to continue to strive for self-realization, enhance the informed citizenship of Canadians, and contribute to Canada's long-term economic success and social inclusion" (Universities Canada, 2015, para. 1).

The Association's Principles of Indigenous Education understands that greater consultation, inclusion, access, support, recognition, respect, services are necessary to increase Indigenous student participation in higher education. From the current perspective of knowledge-power and the decolonizing goal of this research, some key factors are missing. They are related to a response than can be assumed by levels between peripheric towards central, as educative reforms can be considered external modifications or/and internal-fundamental transformations. Some of the most important concepts of Indigenous health are often missed, such as, some of the ways in which health is understood from a human-nature perspective—where health is achieved when one is in balance and harmony with nature—and the mental, physical, spiritual, and emotional aspects of a person's nature. Some of the important specificities of Indigenous health knowledge are models and practices of spirituality and healing that include storytelling, advice from Elders, family and community, healing circles, ceremony, and traditional healers and medicines (Blue & Darou, 2005; Duran, 2006; McCormick, 1996). Traditional knowledge embraces respect for all interconnected and interdependent life forms (Corsiglia & Snively, 1997), including community members, lands, and non-humans such as wild animals, insects, trees, rivers, and grass (Gadgil et al., 1993; Blue & Darou, 2005; Mussell et al., 1993). Education programs that incorporate Indigenous health perspectives should improve the current imbalance between the real needs of Indigenous peoples and those needs as understood by a largely Eurocentric health care system (Stewart, 2008).

While there are increasing expectations to include Indigenous-based knowledge, perspectives, and medicines in university health education, there remain barriers inside educative institutions

because knowledge production within these institutions is still largely based on Western educative and scientific conceptualizations of health and health science. However, one area of medicine that is actively changing its foundational approach is public health. Largely in response to new illnesses and concerns about infectious diseases—which requires recognition of the interdependency of human, animal, and ecosystems health worldwide—public health takes a “One Health approach to research, training capacity, and service infrastructure, [and is] focused not only on disease, but also on health at the individual, population, and ecosystems levels” (Conrad et al, 2009).

The inclusion of Indigenous epistemologies, pedagogies, and knowledge in higher education is a large and challenging goal for post-secondary institutions. This shift challenges knowledge defined exclusively by Western perspectives of science and technology in which progress is accumulative instead of rhizomatic, and societies are defined by an evolutionary mindset based on socially exclusive Western values. Education reforms, social justice movements, and Indigenous self-determination will guide the curricular dimensions of socio-educative reforms, an approach to Indigenous health research ethics begun in this study.

Chapter 3

Method

This chapter presents details of the research method, design and of the study, the population and how the sample was arrived at, instruments for data collection, validation and administration of the questionnaire, and the data analysis processes.

3.1. Method

This research incorporates a community-based approach. It includes the participation of and input from an Indigenous research team composed of Elders, Indigenous community members, Indigenous service agency members, researchers who engage in Indigenous health research, and Indigenous respondents.

Elder Albert Marshall's principle of Two Eyed-Seeing (Marshall, 2017) informed the research design. Two Eyed-Seeing is built on Mi'kmaq knowledge, and brings together two perspectives—Western and Indigenous—to engage in close collaboration. Specifically, Two Eyed-Seeing invites us to:

learn to see from your one eye with the best or the strengths in the Indigenous knowledges and ways of knowing...and learn to see from your other eye with the best or the strengths in the mainstream (Western or Eurocentric) knowledges and ways of knowing...but most importantly, learn to see with both these eyes together, for the benefit of all (Marshall 2017, p. 2)

The task of decolonizing and Indigenizing health research must occur in order to bring about systemic transformation, and to benefit Indigenous populations. Whereas decolonizing methods aim to disrupt the status quo (Adelson, 2009; Duran et al., 1998; Episkenew, 2009; Linklater, 2014; Prussing, 2014; Schwan & Lightman, 2015; and Tuhiwai-Smith, 2006), Indigenizing

includes a shifting of power relations and the incorporation of traditional knowledge (Funston, 2013; Rothe, et al., 2009; and Walker, et al., 2014). These two methods can be used together.

The survey method selected for this exploration is an example of working to decolonize the field of Indigenous health by challenging the status quo of health research and the ethics of health research. To do this, we used a method (the survey) to gather relevant data about the practices and ethical guidelines used by health practitioners.

Using the survey method from this decolonizing perspective shifts the focus away from Indigenous communities and concentrates on health researchers instead. This methodological shift prevents and protects Indigenous people from being viewed as “objects” of research and “people to be studied,” and instead explores the structural practices and underpinnings of harms perpetrated on Indigenous populations. With this shift in focus, health researchers and their assumptions and practices come under scrutiny, instead of Indigenous peoples.

The research University-based team consisted of five researchers: three graduate students one community advisor, and one health researcher, who together evaluated different methods to conduct this research. They decided to administer a survey, which was an affordable way to include as many Canadian researchers who engage in Indigenous health research as possible in all provinces across Canada. Because of the lack of quantitative data in the field of the ethics of Indigenous health research, the survey was considered an exploratory project that would provide preliminary answers to key questions, which could then be explored by further research.

The survey was designed to investigate the meta-themes and points of intersection between the needs and struggles of Indigenous peoples as reported in the literature. Main topics obtained through the literature review and the research group’s discussions were transformed into survey items. This study followed a quantitative method approach (Larkin & Thompson, 2012) where answers to the Likert survey questions were grouped, percentage agreements calculated, and the differences were interrogated conceptually. The creation of questions for the survey were informed by the research group who also designed questions and participated in a piloting process where the survey was tested.

Key informants from Indigenous communities as well as Indigenous community-trained research assistants offered their perceptions and input from the beginning of the research.

The research group agreed on a descriptive pilot research design. As a descriptive approach, the main data capture tool was an online asynchronous survey including qualitative and some quantitative questions. The Survey Wizard 2 developed by the Ontario Institute for Studies in Education OISE (OISE, 2018) was used as a survey online tool for this research. This web application allows minimum web browser requirements, access from any computer, tablet, or smart phones, and offer secure, centrally collected and ready for analysis. Data can be exported in Excel format which is then compatible with most data analysis tools.

Due to the lack of studies and data-based descriptions in the field of Indigenous health research, the validity and representability of the data obtained by an online survey (Nworgu, 1991; McBurney & Middleton, 1994) was understood as preliminary, and that it had been collected by an exploratory survey tool. Primarily, representativity is considered an opportunity to allow the expression of Individual voices and perspectives. This approach, from community to individuality was explored in the survey by including open-ended questions and then processing this information through a qualitative analysis. However, interpretations of the responses to the quantitative questions were the focus of this thesis study.

3.2. Participants

This study involved 228 health researchers (Indigenous and non-Indigenous persons) working in the field of Indigenous health research in Canada between 2010 and 2015. Participants received a link to an online-survey and the description of the research and ethical considerations.

Ethical clearance for this study was granted by the University of Toronto Social Sciences, Humanities, and Education Research Ethics Board (REB) on May 27, 2016. The initial approval was obtained until May 27, 2017 but due extension of the research processes it was required to renew Ethical approval until end of August 2017.

In order to develop ethics for this research, we drew from different sources of ethical guidelines, as ethics was integral to this community-based study. This research follows also the principles outlined in Marshall, Shepard, and Leadbeater (2006), Marshall and Stewart (2004), and the

TCPS-2 (2014). Chapter 9 discusses the relevance of community-based Aboriginal research, which should necessarily be grounded in respect, reciprocity, relevance, and responsibility (Kirkness & Barnhardt, 2001).

The principal investigator Dr. Suzanne Stewart and PhD candidate Juan Rodriguez are immersed in Indigenous community and Indigenous health research in Canada. Stewart's work as a researcher in Indigenous health field has underscored the need of respectful and reciprocal relationships (Marshall & Stewart, 2009; Stewart, 2010). Given the history of knowledge appropriation and lack of community involvement that has occurred because of unethical research practices, this research was designed to involve Elders, community members, PhD students, MA students, Indigenous scholars, and Indigenous service agencies as a research partner. The team established a Memoranda of Understanding (MOU) with Indigenous agencies, an ethical practice pioneered in the Coasts Under Stress Project (Ommer et al., 2007), which was refined by other scholars (Marshall, Stewart & Begoray, 2014; Stewart & Elliott, 2014), and WIMW (Stewart & Marshall, 2012). Training was delivered and local, Aboriginal youth—preferred to as Community Research Assistants (CRAs)—were hired to assist with recruitment, data collection, resource development, and dissemination.

In the process of a community knowledge-building process, ceremony was considered as an Indigenous protocol that was used to open and close all team meetings. The collective research group discussed the selection of research approaches, methods, and questions, and then designed the research project through consensus. Several workshops were required by the team to learn more about the research methods and the process of conducting and analyzing data from the survey. Research instruments were selected and designed with the participation of all members in an equal distribution of power. The group deliberated on the entire structure of the survey and worked closely together to develop each question, where opportunities to explain, revise, or delete questions or research processes were consistently available. Members of the group offered feedback to improve the final version of the instrument. In order to invite health researchers to participate in the survey, an email was designed outlining information about the research, the intention, the process, and the guidelines for filling out the survey. Participant consent procedures were included in the first page of the survey, and personal information and participation was made completely anonymous and hidden from the research group. In the data

analysis process, community workshops and team meetings were used to analyze and make sense of the data. Preliminary results were shared with the research group and first draft report was written. Results were shared by using different methods to reach various populations. For example, a policy report was designed and sent by email to policy makers and researchers; a brochure was designed to reach external community members in Pow Wows; community meetings were held where researchers could have one-to-one conversations on the research, ask for feedback and suggestions, discuss the results and possible implications for education and research; and finally two presentations were given to other researchers who engage in Indigenous health research—one in Canada and a second one in Sidney, Australia—to share results of the survey and to gain input on the topics of discussion.

Once the second part of this research is completed, the research group will be able to access an online network and a quick reference of the ethical guidelines based on the results of both phases. A final report will be distributed to all participants by e-mail and be posted on the website of the Waakebiness-Bryce Institute for Indigenous Health.

Participants were selected from first authors of research articles published in academic journals under the following criteria:

- 1) Research must involve any of the Indigenous communities in Canada (First Nations, Inuit or Métis). And,
- 2) Research will include “health research” in any of the medical, nursing, psychology, social work or any other of the health-related disciplines as main descriptors. And,
- 3) Research must be published in any academic journal nationally or internationally between 2010 and 2015.

With these criteria and by using searches with main academic data bases, a preliminary scan list of 410 potential participants in this research was created. Then a matching email author by author and deleting repetitions (the same main author was publishing twice or more) a target list of population was compiled. A verification of emails was required by using public information available.

After the initial list of 410 potential participants the size of the population was adjusted with an external directory of health researchers. The list of Canadian researchers who engage in Indigenous health research was narrowed by matching first authors names with the directory of researchers who engage in Indigenous health research compiled by the National Collaborating Centre for Aboriginal Health (NCCAH, 2014).

As a result, of 410 preliminary participant list, 314 researchers were included in the final data base after matching emails, deleting repetitions and checking existence of contact information. This number of health researchers represents a growing amount of interest in research involving Indigenous people (Panel on Research Ethics, 2015).

Ideally the sample of a study will be the total of target population (Aday, 2006). But this situation frequently is not possible due restrictions in participation and valid contact information. After the process of finding reliable email and matching names was conducted it was clear that emails were not stable information due mobility factors that would limit the possibilities to contact some participants. Then it was considered that the total of participants in this study will be 100% of the target population of 410 health researchers.

When the survey was ready to distribute, of the 314 health researches initially listed 300 emails were valid and 14 emails were rejected or returned “undeliverable”. As a result of the combined email and social networks campaigns, a total of 293 survey’s responses were received.

The survey’s link was sent to 314 health researchers’ emails, and it was widely shared through social and research networks, universities, and research groups with the goal of increasing the size of the participant group.

The research group selected a preliminary quality analysis conducted through the Statistical Package for Social Sciences V. 14 (SPSS). This tool was selected under the premise that the use of qualitative or quantitative knowledge tools do not necessarily reproduce colonialism. What reproduces colonial harm is how those tools are employed to impose colonial ideas under the pretension of truth. The mixed methods approach is relevant in this research because it provides different yet more integrative approaches to investigating a topic. In this respect:

the term “mixed methods” refers to an emergent methodology of research that advances the systematic integration, or “mixing,” of quantitative and qualitative data within a single investigation or sustained program of inquiry. The basic premise of this methodology is that such integration permits a more complete and synergistic utilization of data than do separate quantitative and qualitative data collection and analysis (Wisdom & Creswell, 2013, p. 1).

The preliminary analysis revealed that 65 of the returned surveys had incomplete responses for more than 50% of the questions and did not qualify to be included in the analysis. As a result, only 228 of 293 surveys were considered valid in the analysis.

Thus the 410 total target estimated population yielded 228 valid responses received, a middle level response rate of 0.56 was found (response rate = responses received/target population). Further partially incomplete answers in surveys that passed the quality test were eliminated item by item.

3.3. Sampling Techniques

This survey used a combination of intentional and self-selection sampling techniques. An intentional selection of respondents was initially used to define the population. The selection criteria developed for this study was the first to be published in any academic-scholar database, in response to the search for “Indigenous health,” and “Canada” between 2010 and 2016. This preliminary database was compared with the National Collaborating Centre for Aboriginal Health–NCCAHA (2015) database of active researchers who engage in Indigenous health research in Canada.

Then a self-selection sampling method was used to reach more people in the target population that were originally missed.

3.4. Measures

This research uses an online-survey developed by the research group with the input of Indigenous Elders, community members and Indigenous research participants. (See complete survey in Appendix A).

The survey was designed with the objective to describe the main perceptions about the current ethical guidelines being used for Indigenous health research and identify the perceived barriers and strengths in these instruments. This task was approached in two steps. In the first step the survey requested demographic and researcher information to explore what common elements describe the current field of Indigenous health research in Canada, by asking who is doing what kind of research, where, how, when and with which of the Indigenous communities in Canada. In the second step the survey included a set of questions that explored the level of agreement or disagreement by respondents to statements about characteristics of the ethical guidelines of Indigenous health research that they use. (See full structure of the Survey in the Appendix A)

3.5. Instruments and Data Collection

With the input from the community, the research group planned the survey as the data collection instrument for this study. Validity is established through the triangulation of community, the researcher and the pilot process (Denzin & Lincoln, 2000). The survey design was informed by a literature review of the important considerations that are involved in the understanding and practice of Indigenous health research. After defining concepts to be covered by the survey, a question bank was created, and the first draft of the survey was designed.

To ensure the survey's face and content validity, experts provided in-depth feedback. Face validity refers to the ability of a given test or set of survey questions to measure the particular variables or constructs it purports to measure, whereas content validity ensures that all aspects of a given concept of the study are tested (McBurney & Middleton, 1994).

The members of the research group, over several rounds of review, evaluated the set of questions proposed in order to ensure the clarity, relevance, and coherence of each question in relation to Indigenous knowledge and practices. After the process ended, a set of changes modified the structure of the survey, the questions to be included, the grammar and order of presentation of the question in the final version of the survey. This phase was an important step in the process and offered contextualization of the instrument inside the Indigenous context.

After finalizing the previous process of contextualizing the instrument and gaining an agreement with the final question bank, it was decided that no new questions were required. Then a clean

version of the survey was digitalized by using the Survey Wizard tool. A second revision of the test was conducted and input received from the research group was included in the final version of the survey. Then, the research group conducted a pilot analysis where the whole survey was tested, and changes were made depending on feedback received. Similarly, the final order of the questions and the correct functioning of statistics and the data collection system used were established.

3.6. Procedures

This research was carried out in seven phases. The first phase comprised a brainstorming session among the members of the research group to allow the generation of topics to be studied and the best way to investigate the problem. The group scheduled meetings in order to complete research-associated tasks. During the design phase, at least one meeting was held per week. After the design of the research was agreed upon, frequency of the meetings took place once per week or per month, as required. As a result of these meetings, which included Elders, Knowledge Keepers, Indigenous community members, representatives of Indigenous service agencies, self-identified Indigenous person working in the field of Indigenous health research, and non-Indigenous heritage health researchers, it became clear that the ethical concerns of Indigenous health research should be addressed through a broad, pan-Canadian consultation process.

In the second phase, a scan of methods revealed that an online survey was a good choice as it was inexpensive, practical, and provided an open and effective tool to explore the research problem. Then the survey design started using the main topics derived from the earlier literature review on current ethics where a group of major topics were proposed as the initial structure of the survey. (See Appendix A).

The third phase consisted of defining the population for the study. It was important to define the population based on the criteria that would be used to identify how many health researchers are conducting research involving Indigenous peoples in Canada. The preliminary analysis of relevant researcher publications across Canada was defined by the criteria agreed by the research group. A process of data-base construction matching full names and emails was initiated.

The fourth phase began before the third phase was completed. The research team began to design the survey's structure by dividing into small groups in order to explore topics, questions, and examples. A literature review was conducted by the research group and several examples of research surveys were shared by the group. After selecting the main topics of interest, the preliminary structure of the survey and questions were discussed.

In a fifth phase, the survey initial structure was presented in a Word document and in a pdf format with all questions created by the research group. The research group evaluated each of the questions taking in consideration clarity, coherence with the main goal of the survey, spelling and language use. All observations were incorporated into a final draft that was presented this time in electronic format by using the web application. This clean draft was open to all members of the research group who then answered all questions and offered feedback on the final draft, this time looking for possible repetitions and pertinence of questions. The database with the research group responses was exported into Excel and analyzed by using descriptive statistics to test the potential of each question to contribute to the central question of the survey.

Once the survey was considered ready, including questions, instructions and ethical consent (see Appendix B), the sixth phase of data collection was initiated with an advertising strategy using a massive email database and initiating advertising through social and research networks.

Once the survey reached the deadline date, it was closed, and the seventh phase was initiated. The database was exported to allow data analysis to begin. After completing the data analysis, results were shared with the research group who conducted a second analysis. The results of these two data analyses were compared and the best methodology was selected by the research group. Explorations of the quality of the responses varied the number of respondents and the total of participants by question, as well as identifying the best way to analyze and group the responses from the Likert scale questions to obtain clear values that would clearly describe the general level of agreement in general as well as within each of the dimensions. After this work, the results were shared through several research conferences.

3.7. Data Analysis

The survey contained two sets of open ended and close ended questions. Quantitative data was analyzed using descriptive and non-parametrical tests avoiding the use of hypothetical-deductive parametrical analysis and open-ended questions were analyzed by themes.

In the special case of 11 questions that asked respondents to choose “all that apply,” the total of answers or general frequencies were taken as representing the total of answers instead of all respondents, thus the percentages of these questions refer to frequency (number of times selected by all respondents) instead of the number of participants. This is true for these eleven questions where the frequency of an answer can be higher than the total number of respondents.

In the sets of questions that asked for agreement or disagreement in relation to the quality and characteristics of ethical guidelines, several analyses were performed: the median of agreement, grouping dichotomous scales (agreement vs. disagreement), and through item by item tendencies. The internal consistency of this scale was tested by Cronbach’s Alpha test.

Open and closed-ended questions included in the survey were interpreted by using quantitative data. The survey’s analysis of all items is presented in the next Chapter, including frequencies, percentiles, percentages, and other measures as required.

As it was accepted to include incomplete answers that missed less than 30% of the answers, the total of answers varies between questions due the elimination of incomplete answers. For all cases the total of answers is specified in each of the following questions.

Chapter 4: Results

4.1. Preliminary Analysis

The first data analysis shows an acceptable response rate of 0.56 considering only the target population and valid responses received (228 responses / 410 target population). It is important to note that if we consider only the total of emails sent, the response rate is higher (0.73, 314 emails sent/228 received). But any response rate analysis of these data should be viewed with caution because the survey link was later shared with social networks and universities and responses from these sources might not reflect the same response rate of those generated through the email strategy but would rather represent the combination of both strategies (emails and social network). Additionally, the response rate analysis is relative because it was not possible to track separately the responses from participants who received links through the later recruitment using social and academic networks and which ones were a response to the individually addressed emails.

A second analysis was carried out in order to verify the internal consistency of the Likert Scale used to explore health researchers' perceptions, using Cronbach's Alpha test (Table 1).

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.936	.936	14

Table 1. Reliability Analysis by Cronbach's Alpha Test

In theory, the scale validity analysis verified by the Cronbach's Alpha test should show the consistency of the scale, where low internal consistency ($\alpha < 0.40$) and extremely high values ($\alpha > 0.95$) are considered invalid. The first test conducted was the Cronbach's Alpha test for the survey's scale (Table 1) showing strong α coefficient of 0.936 based on 14 items in the second set of questions. This result shows that the scale had strong construct validity, very close to maximum value considered valid. It is reasonable to infer that these items did tap into an underlying construct of adequacy regarding the use of ethical guidelines, but it requires more efforts to control the consistency of these concepts.

A third test was administered-- the Median General Analysis- which was applied to each participant's responses for the second main question of the study. This test reveals differences in the perception of characteristics of the ethical guidelines. Results indicated that most respondents *somewhat agree* with the value and quality of the ethical guidelines in-use in relation to Indigenous health (Mdn= Somewhat Agreement, IQR= 1). Twenty-five percent of the valid answers (51 of 203 participants) said they *agree* with the quality of ethical guidelines in-use by participants (Percentile 25=Agree), while 75% (152 of 203 participants) checked *somewhat agree*.

The median analysis (Table 2) showed that even though all participants agreed with the quality of the ethical guidelines, there were fewer responses indicating “*Strong Agreement*” and more indicating “*Agreement.*” Only 12% of the total participants (24 of 203 participants) indicated that they *strongly agree* with current ethical guidelines, 33% (67 of 203 participants) *agree*, and 41% (83 of 203 participants) *somewhat agree*. Additionally, 12.3% (25 of 203 participants) expressed that they *somewhat disagree* with the quality of the ethical guidelines in-use.

	Frequency	Percent	Cumulative Percent
Strongly Agree (1 to 1.50)	24	10.4	11.8
Agree (2 to 2.50)	66	28.9	44.3
Somewhat Agree (3 to 3.50)	84	36.8	85.6
Somewhat Disagree (4 to 4.50)	25	10.9	97.9
Disagree (5 to 5.50)	3	1.3	99.4
Strongly Disagree (6 to 6.50)	1	.4	100.0
Total	203	89.0	
Missing System	25	11.0	
Total	228	100.0	

Table 2. Median Analysis of All Items

A simplified scale using “Agreement vs. Disagreement” (See Figure 1) shows that all participants agreed with the quality of the current in-use ethical guidelines, but this agreement varied by item. The “Agreement vs. Disagreement” scales were built by placing all categories

and answers on a positive scale beginning at 0% (Weak Agreement) up to 100% (Strong Agreement). Based on this analysis, it appears that items with *strong agreement* are related to the issue of easy access of ethical guidelines (84%) and the amount of information offered in those guidelines (81%). On the other hand, items with *low agreement* were referencing items that indicated that current ethical guidelines may not be fully clear for health researchers who are not familiar with Indigenous worldviews (24%). Finally, 35% of respondents were in *mild agreement* with the idea that ethical guidelines completely reflect the current social context of Indigenous peoples, 37% *mildly agreed* that ethical guidelines completely reflected current Indigenous paradigms, and 38% *mildly agreed* that the guidelines enhanced health researchers understanding of Aboriginal paradigms and worldviews. The following section describes in detail the quantitative results of the questions in a question-by-question analysis.

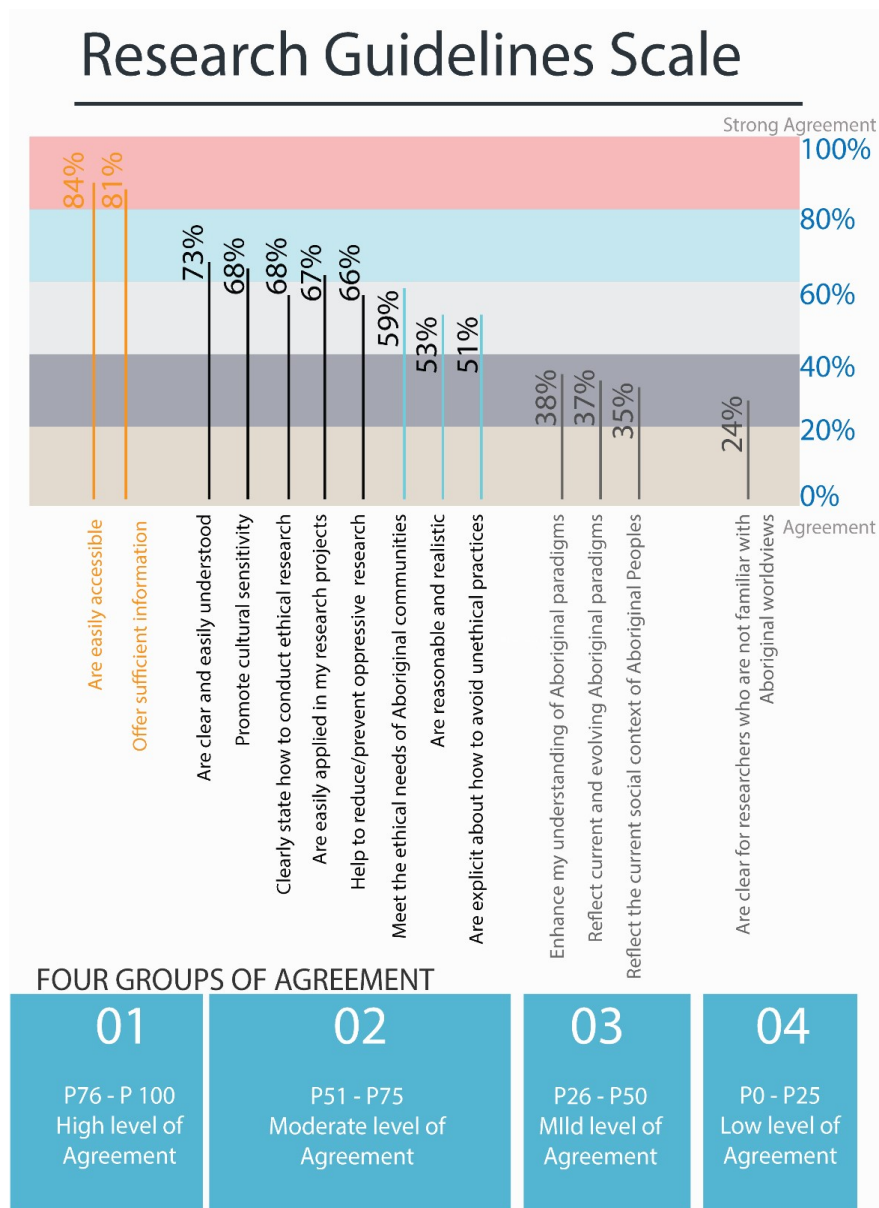
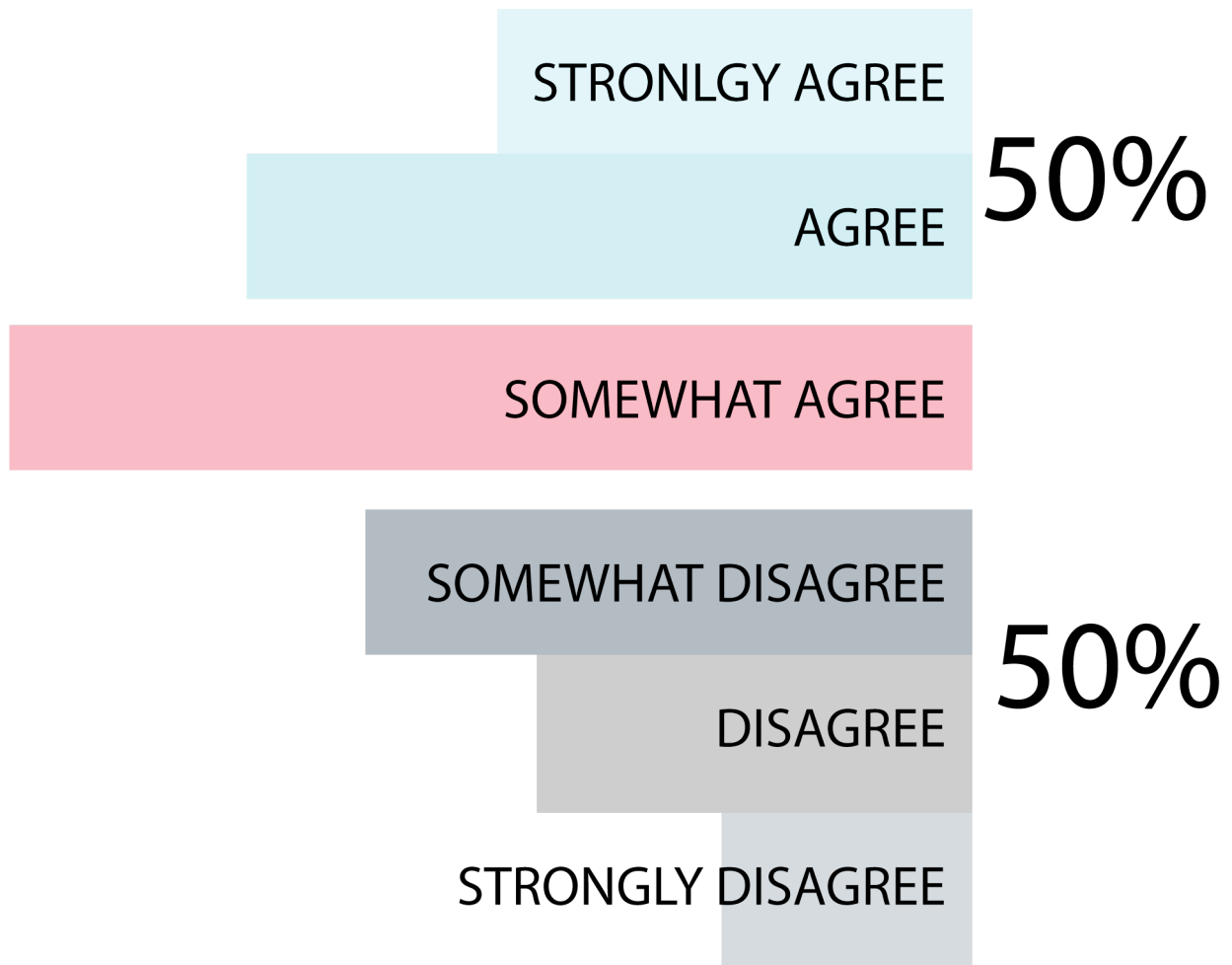


Figure 1. Agreement Scale for Perceptions of In-Use Guidelines

4.2. Closed-ended Questions Analysis

Sub-theme: Health researchers' years of experience conducting Indigenous health research.

(Questions 1,2).



*Question 1: When have you done research with Indigenous participants?
(check all that apply)*

From the total of selections (373 answers) being currently involved in Indigenous health research 45.6% (170 of 373 answers) was the most frequent response, followed by 35.7% answers indicating they were involved in health research in the past (133 of 373 answers). A small portion of answers (18.2%, 60 of 373 answers) signaled that at least 60 health researchers exclusively or not are planning to be involved in future research with Indigenous communities.

Notice that for all questions, the total number of respondents will change depending on the null answers deleted, or if the question allows participants to check more than one answer per participant.

*Question 2: How long have you been conducting research with Indigenous participants?
(check all that apply)*

The largest proportion of the health researcher respondents revealed they have had lengthy experience conducting research with Indigenous participants, predominantly between 11 and 20 years (29.1%=68 of 234 answers), others had between 6 and 10 years (26.1%=61 of 234 answers). A slightly smaller group of respondents revealed involvement between 0 and 5 years (23.1%=54 of 234 answers), and the smallest category indicated they had over 21 years of experience (21.8%=51 of 234 answers).

Sub-theme: Main area of study. (Question 3).

*Question 3: In which disciplines have you conducted research with Indigenous Peoples?
(check all that apply)*

Health promotion was selected 17.1% times (96 of 562 responses, see Table 3), as the predominant discipline of Indigenous health research, followed by 11.6% times (65 of 562 responses) were in Mental Health research. Other medical specialties were present, and the lowest representations were from Psychology 0.4% times and Physiology 0.4% times (2 of 562 responses).

Disciplines	Responses		Disciplines	Responses	
	N	%		N	%
Health Promotion	96	17.1%	Nursing	21	3.7%
Mental Health	65	11.6%	Nutritional Sciences	14	2.5%
Epidemiology	48	8.5%	Genetics Biomedical	13	2.3%
Pharmacology	46	8.2%	Environ. Geography	13	2.3%
Social Work	46	8.2%	Kinesiology	10	1.8%
Education	46	8.2%	Occupational Therapy	7	1.2%
Psychiatry	37	6.6%	Dentistry	6	1.1%
Environmental Health	33	5.9%	Physiology	2	0.4%
Medical Diseases	31	5.5%	Psychology	2	0.4%
Medical Anthropology	26	4.6%	Total	562	100%

Table 3. Disciplines of Research

Sub-theme: Methods used: (Question 4).

*Question 4: What type of research do you do with Indigenous people?
(check all that apply)*

There was a balance between the use of qualitative 35.1% and mixed methods research 35.1% (142 times selected of 404 answers), while quantitative methods were selected 24.8% times (100 times selected of 404 answers). Other methods were mentioned in the 5% of the total answers (20 times selected of 404 answers).

Sub-theme: Current practice of research: (Questions 5, 6, 7).

*Question 5: Have you ever done Indigenous Community Research?
(yes/no)*

The survey revealed that 91.7% of participants (209 of 227 respondents) have experience doing Indigenous Community Research. Negative answers amounted to 0.4% (1 of 228 participants). No response (invalid) mounted 8%.

*Question 6: Are you currently doing Indigenous community-based research?
(yes/no)*

In the survey, 68.4% of participants (156 of 228 participants) are currently involved in Indigenous community-based research.

Question 7: Do you intend to do community-based research in the future? (yes/no)

Of health researchers surveyed, 83.8% of participants (191 of 228 participants) will be involved in future Indigenous community-based research projects. Negative responses amounted to 2.2% (5 of 228 participants).

Sub-theme: Community-based Research: (Questions 8, 9, 10, 11).

*Question 8: Does your research involve community partners?
(yes/no)*

Community partners are involved with 93% of participants (212 of 228 participants) in their research. Negative answers amounted to 1.8% (4 of 228 participants).

*Question 9: How you would describe the relationship with your community partners?
(check only one)*

In total, 44.3% of researchers (101 of 228 participants) said they established *close relationships* with community partners, while 36.8% (84 of 228 participants) claimed they maintained *very close relationships* with their community partners, and 11% (25 of 228 participants) said they did not maintain neither close or distant relationships with community partners.

*Question 10: At what stages of the research process do you involve community partners?
(all that apply)*

The survey revealed that 22.7% of the total answers (201 of 886 answers) included community partners who were involved in pre-project consultation for the main stage of the research process. Similarly, 20.3% community partner involvement in the proposal stage (180 of 886 answers), 20.1% reported community partner involvement in the data collection stage (178 of 886 answers), and 20.1% times was reported community partner involvement in the dissemination phase. A lower percentage of 16.8% (149 of 886 answers) reported they involved community partners at the data analysis stage.

*Question 11: On average how often do you meet with your community partners?
(check only one)*

Community partners met with health researchers once a month in 33.8% of the cases (77 of 228 participants), and once every three months in 18.4% of the cases (42 of 228 participants). Respondents that amounted to 17.1% (39 of 228 participants) reported various other commitments of time from their community partners.

Sub-theme: Time and Dissemination: (Questions 12, 13).

Question 12: The typical length of your research is:

(check one)

The typical length of research reported by respondents was three to five years (45.2%=103 of 228 participants), followed by projects that took place between one to two years (35.1%=80 of 228 participants). It was less frequent to find projects that ran from six to seven years 6 %, then years or more 4% and eight to nine years (0.9%= 2 of 228 participants).

Question 13: How do you disseminate your research?

(check all that apply)

The most frequent dissemination channel was through academic journals (19.1%=205 of 1074 answers), followed by academic conferences (18.6%=200 of 1074 answers), and meetings and/or workshops (18.3%=197 of 1074 answers). Other less frequent dissemination channels were media releases (8.3%=89 of 1074 answers), and policy documents (9.5%= 102 of 1074 answers).

Sub-theme: Indigenous Community Involvement: (Questions, 14, 15, 16, 17, 18).

Question 14: What Indigenous peoples are involved in your research?

(check all that apply)

Primarily, health research was conducted with First Nations (49.7%=216 of 435 answers), followed by Metis (28% = 122 of 435 answers), and Inuit (18.9%= 82 of 435 answers).

Question 15: What is the geographic location/source of data collection in your research?

(check all that apply)

Similarly distributed, health research conducted involved Indigenous people who live the *on reserve* (35.2%= 160 of 455 answers), those who live in *urban* Indigenous communities (33.4%=152 of 455 answers), and finally, those who identify as *rural* Indigenous people (31.4%=143 of 455 answers).

Question 16: In what province/territory/geographic area do you focus your research?

(check all that apply)

In a first group, most researchers were centered in Ontario (20.3% =129 of 637 answers) and British Columbia (13.3%=85 of 637 answers). A second group included Manitoba, Saskatchewan, Quebec, Alberta, and Nunavut. (between 6.6% and 9.7%). A third group of few researchers was led by Prince Edward Island (2.4%= 15 of 637 answers), Yukon (2.8%= 18 of 637 answers), New Brunswick (3.3%= 21 of 637 answers), and Newfoundland and Labrador (3.6% = 23 of 637 answers).

Province	Frequency	General Percent	Province	Frequency	General Percent
Prince Edward	15	2.4	Alberta	46	7.2
Yukon	18	2.8	Quebec	47	7.4
New Brunswick	21	3.3	Saskatchewan	54	8.5
Newfoundland and Labrador	23	3.6	Manitoba	62	9.7
Nova Scotia	26	4.1	British Columbia	85	13.3
Outside of Canada	33	5.2	Ontario	129	20.3
Northwest Territories	36	5.7			
Nunavut	42	6.6			
			Total	637	100.00

Table 4. Research in Provinces

Other province/territory/geographic area outside of Canada

Australia, (6 times selected), New Zealand (6 times selected) and United States (6 times selected), Colombia, (3 times selected), Circumpolar regions (2 times selected) and India (2 times selected). Other regions mentioned one time were: Africa, Alaska, Greenland, Norway, Sweden, Argentina, Caribbean, Tanzania, Central America, Chile - Huiliche Territory, , Dominica, Guatemala, French Guyana, Southeast Asia, UN Indigenous, Pan-Canadian work, Russia, Hawaii - Cherokee Nation, Louisiana, New York State, Peru, Chile, Bolivia, Argentina, South India, Uganda, Peru.

Question 17: What is the typical age group of the Indigenous peoples involved in your research? (check all that apply)

The most common age group included in research projects was 20 to 34 years old (78.1%= 178 of 228 participants), 35 to 44 years old (18.3%= 170 of 930 answers) and 45 to 64 years old (16.6% = 154 of 930 answers). The group less frequently included in research projects was the Prenatal (2.0%=19 of 930 answers).

Question 18: Where do you find participants for your research?

(check all that apply)

Two of the most common recruitment strategies used by researchers were *Aboriginal organizations* (25.1% = 156 times of 621 answers), and *word of mouth* (21.4% = 133 times of 621 answers). Two of the least commonly used strategies were: *recruitment agencies* (0.5% = 3 times of 621 answers), and *paid advertisements* (1% = 6 times of 621 answers). Additionally, 6.8% of the total answers (42 times of 621 answers) stated they use other sources of recruitment such as meeting with food and community events.

Sub-theme: Researcher's Indigenous Identification: (Questions 19, 20).

Question 19: What is your ethnic background/identity?

(check all that apply)

In a first representative group, health researchers who participated in this survey predominantly identified themselves as *Caucasian* 60.7% of the total answers (145 times of 239 answers), followed by *Aboriginal* identity (21.8% = 52 times of 239 answers). A second group includes Asian Pacific Islander (4.2% = 10 times of 239 answers), Multiracial (2.1% = 5 times of 239 answers) and Latino Hispanic (2.1%). A third group of few responses included other identities such as *Black African American* (0.8% = 2 times of 239 answers), and *Arabic* (1.3% = 3 times of 239 answers).

In this question, 7.1% (17 times of 239 answers) respondents claimed the following 'other' identities: *Euro-Canadian* (3 three times), *Jewish* (2 two times), and one time: *Indian, Ismaili, Muslim, Canadian, Italian, Maori, Polynesian, Middle Eastern, non-Arabic, Settler, South Asian-Indian, Sri Lankan*. Other participants questioned the meaning of these categories, arguing that these identifications did not have -anything to do (besides politics) with research-.

Question 20: What is your Indigenous Identification?

(check one)

Out of the 228 total participants, 98 participants (43%), cited an Indigenous identity. The most common Indigenous sub-group was *Other Indigenous identities* (18.9%= 43 of 228 participants) which represented 43.8% of the total of self-identified Indigenous respondents (43 participants of 98 self-identified Indigenous respondents), followed by *First Nation* (16.2%= 37 of 228 participants), near to the second half of the group of self-identified Indigenous researchers (37.7%= 37 of 98 self-identified Indigenous participants), *Metis* (5.7%= 13 of 228 participants; 13.3%= 13 of 98 self-identified Indigenous participants) and *Inuit* (2.2%= 5 of 228 participants; 5.1%= 5 of 98 self-identified Indigenous participants). Other Indigenous identities included were: not Aboriginal (8 times selected), None (6 times selected), *ally* (3 times selected), *n/a* (3 times selected), and selected one time were: *citizen of Cherokee Nation* (Oklahoma, US), Cree, Euro-Canadian, European ancestry, adopted by First Nations, Maori, part Japanese and part euro-white Canadian, Tagalog (Philippines).

Sub-theme: Ethical guidelines in-use: (Question 21).

Question 21: Do you use any of the following guidelines in your research with Indigenous peoples?

(check all that apply)

The most commonly used ethical guideline is the TCPS-2, which was selected 31.8% times (191 times of the 601 answers provided from a total of 204 respondents). A second group of 25% answers (151 times of 601 answers) reported using the OCAP™ guidelines, and 23.8% of the answers (143 times of the 601 answers) selected CIHR’s guidelines. In a third group, 12.8% responses (77 times of the 601 answers) was reported using SSHRC’s guidelines. Responses on other guidelines followed are analyzed later in the open-ended analysis section.

	Responses		Percent of Cases
	N	Percent	
Ethics in-use TCPS-2	191	31.8%	93.6%
OCAP	151	25.1%	74.0%
CIHR	143	23.8%	70.1%
SSHRC	77	12.8%	37.7%
Other	39	6.5%	19.1%
Total	601	100.0%	294.6%

Table 5. Frequencies of Use of Ethical Guidelines

Sub theme: Perceptions on the Ethical guidelines

Question 22: The ethical guidelines for research involving Indigenous communities: (check only one)

The scale's internal consistency was measured by the Cronbach's Alpha test with a strong coefficient $\alpha = 0.936$ based on responses of 228 of the survey's participants. This result shows that items in this scale exhibit strong validity and construct validity, and therefore these items do tap into an underlying construct of adequacy regarding the use of ethical guidelines.

N	Valid	203
Median		Somewhat Agree
Mode		Somewhat Agree
Percentiles	25	Agree
	50	Somewhat Agree
	75	Somewhat Agree

Table 6. Median Guideline Perception

As it is showed by the median test of all items in the scale (*strongly agree, agree, somewhat agree, somewhat disagree, disagree, strongly disagree*) it is possible to say that most respondents indicated they are in *somewhat agreement* with the value of the ethical guidelines they use in researching Indigenous health (Mdn= *somewhat agree*, IQR= 1), with 25% of the participants showing *agreement* (Percentile 25=*agree*), and 75% of the participants signaling *somewhat agreement* (Percentile 75= *somewhat agree*). A detailed analysis of medians as a total score for each participant may show differences in some aspects of the perception of ethical guidelines. Median tests show 11.8% of participants (24 of 203 participants) *strongly agree* with current ethical guidelines (medians between 1 to 1.5), while 32.5% *agree* (66 of 203 participants), 33% *somewhat agree* (84 of 203 participants), and 12.3% *somewhat disagree* (25 of 203 participants).

An item by item analysis (Table 7) shows the level of agreement or disagreement for each of the questions 33 to 46 (See the list of questions in the Appendix A). From table 7 it is possible to observe the highest levels of agreement marked with yellow.

Likert Scale Results

Answers/ Questions		33	34	35	36	37	38	39	40	41	42	43	44	45	46
Strongly Agree	<i>f</i>	46	61	37	31	31	26	26	32	19	24	24	31	27	20
	%	20.2	26.8	16.2	13.6	13.6	11.4	11.4	14	8.33	10.5	10.5	13.6	11.8	8.77
Agree	<i>f</i>	93	91	65	68	79	53	50	66	33	40	62	70	52	43
	%	45.8	45	32.5	33.5	39.1	26.1	24.8	32.7	16.4	20	30.5	34.8	25.6	22.1
Somewhat Agree	<i>f</i>	45	34	66	70	65	61	85	72	73	71	69	66	76	71
	%	22.2	16.8	33	34.5	32.2	30	42.1	35.6	36.3	35.5	34	32.8	37.4	36.4
Somewhat Disagree	<i>f</i>	13	11	26	22	20	34	23	21	46	47	29	19	30	40
	%	6.4	5.45	13	10.8	9.9	16.7	11.4	10.4	22.9	23.5	14.3	9.45	14.8	20.5
Disagree	<i>f</i>	3	3	4	8	6	17	13	8	22	14	17	9	8	13
	%	1.48	1.49	2	3.94	2.97	8.37	6.44	3.96	10.9	7	8.37	4.48	3.94	6.67
Strongly Disagree	<i>f</i>	3	2	2	4	1	12	5	3	8	4	2	6	10	8
	%	1.48	0.99	1	1.97	0.5	5.91	2.48	1.49	3.98	2	0.99	2.99	4.93	4.1
Total Valid Answers		203	202	200	203	202	203	202	202	201	200	203	201	203	195
No Answer	<i>f</i>	25	26	28	25	26	25	26	26	27	28	25	27	25	33
	%	11	11.4	12.3	11	11.4	11	11.4	11.4	11.8	12.3	11	11.8	11	14.5
Total		228	228	228	228	228	228	228	228	228	228	228	228	228	228

Table 7. Likert scale for questions 33-46 (frequencies and percentages)

Likert Scales are summative in nature, allowing for the grouping of items of the scale in order to reduce alternative answers into two or one direction category. Because there is evidence of the homogeneity of the scale based on the previous analysis, we decided to transform the 6 points categories into a more comprehensive category. For this analysis, the Likert Scale was first transformed into a dichotomic 2-point scale (agreements vs. disagreement), and then, it was transformed into a single-direction scale identifying levels of agreement. A general dichotomous analysis of the items was grouped to create an *agreement* vs. *disagreement* analysis. *Agreement* included *strongly*, *somewhat* and *agree*, while *disagreement* included *strongly*, *somewhat*, and *disagree* categories. The summative frequency analysis shows that 85.2% of the respondents (173 of 203 participants) *agree* with the quality and characteristics of current ethical guidelines, while 14.2% (30 of 203 participants) *disagree*.

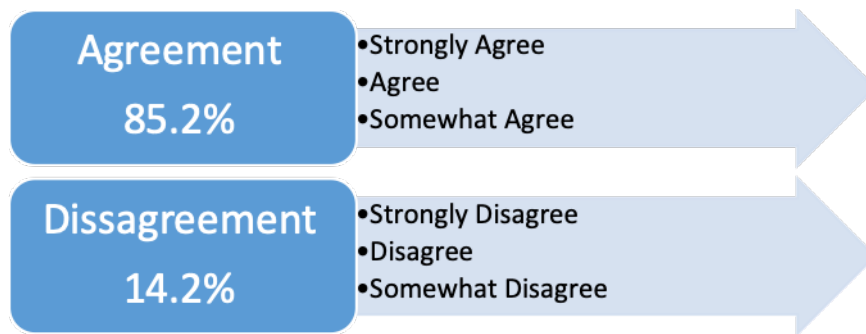


Figure 2. Dichotomous Agreement vs. Disagreement Scale.

The high-level of agreement presented in the previous scale indicates that in a one-way scale of agreement, value resultant will be positive because the percentage of agreement is greater than the percentage of disagreement in this survey. A one-way scale was created by adding positive values of agreement and negative values of disagreement (Figure 2).

Several levels of agreement were marked (Table 8): **Strong agreement level** (located between Percentile 76 and Percentile 100, between 76% and 100% of agreement) 85% of respondents are agreeing that there is easy access to ethical guidelines and 81% affirmed there is a reasonable amount of information offered by ethical guidelines they follow.

Items which yielded a **Moderate agreement level** (Percentile 51 and Percentile 75, between 51% and 75% of agreement) are: health researchers perceive ethical guidelines as clear and easily to understand (73% =), ethical guidelines promote cultural sensitivity (68%), guidelines clearly state how to conduct ethical research involving Aboriginal Peoples (68%), ethical guidelines are easily applied in my research project (67%), ethical guidelines help to reduce/prevent oppressive and harmful research with Aboriginal Peoples (66%), ethical guidelines meet the ethical needs of Aboriginal communities (59%), the guidelines are explicit about how to avoid unethical practices involving Aboriginal Peoples (53%), and ethical guidelines are reasonable and realistic in research involving Aboriginal peoples (53%).

The questions generating a **Mild agreement level** (Percentile 26 and Percentile 50, between 26% and 50% of agreement) are the following: ethical guidelines as they Enhance -my- understanding of Aboriginal paradigms and worldviews (38%), the ethical guidelines reflect current and

evolving Aboriginal paradigms and worldviews (37%), and the guidelines reflect the current social context of Aboriginal Peoples (35%).

The **Low agreement level** (P0 and P25, between 0% and 25% of agreement) was found for the following question: Indigenous ethical guidelines are perceived as clear for researchers who are not familiar with Aboriginal worldviews (24%).

Items	% of Total Agreement
Are clear for researchers who are not familiar with Aboriginal worldviews	24
Reflect the current social context of Aboriginal Peoples	35
Reflect current and evolving Aboriginal paradigms and worldviews	37
Enhance my understanding of Aboriginal paradigms and worldviews	38
Are reasonable and realistic in research involving Aboriginal peoples	53
Are explicit about how to avoid unethical practices involving Aboriginal Peoples	53
Meet the ethical needs of Aboriginal communities	59
Help to reduce/prevent oppressive and harmful research with Aboriginal Peoples	66
Are easily applied in my research project	67
Clearly state how to conduct ethical research involving Aboriginal Peoples	68
Promote cultural sensitivity	68
Are clear and easily understood	73
Offer enough information to design and conduct ethical research with Aboriginal Peoples	81
Are easily accessible	84

Table 8. General Agreement vs Disagreement

4.3. Open-ended questions

In the survey, two questions were open-ended questions that required qualitative analysis. The two topics analyzed here inquired about where researchers who engage in Indigenous health research find participants for their research (question 18), and whether health researchers use one or more of the most commonly consulted Indigenous ethical guidelines (question 22).

Question 18: Where do you find participants for your research?

The option “Other sources” was included to explore if there were other sources of recruiting participants used in addition to the “most available and representative” sources. This option was required due the exploratory nature of this research, and the complexity of Indigenous cultural-socio-linguistic characteristics and diversity of knowledge, which might impact the use of

strategies that are less visible to other health researchers unfamiliar with Indigenous communities.

Respondents supported the assumption that there are other sources of recruitment that were not included in the survey, and in some cases, respondents reported using a much more personalized approach to engage Indigenous communities in health research. The survey revealed that 18.4% of health researchers (42 out of 228 respondents) employed *other sources* to recruit Indigenous participants in research.

Below are the various places from which researchers who engage in Indigenous health research recruit participants for their research.

Community connections sources:

- Indigenous authorities: (Community band councils, Tribal councils)
- Advisory group (Aboriginal Steering Committee)

Partners on-reserve recruit:

- Organizations (NAHO's, through community research partner, on-reserve service programs)

Indigenous people:

- Suggestions from key stakeholders, community requests, investigator living in the community, communities recruit (or advised us on recruiting) directly in the communities,
- Relationships with communities (previous and existing relationships)

Personal relations:

- Family or personal relationships (personal contact)
- Previous working experience
- Community colleagues (core searchers)
- Networks (in owned research centre, networks)

Community events:

- Cultural events, meetings with food, door-to-door.

Active health programs:

-Health programs, health care clinics.

Other service organizations:

-Health organizations (medical registry, other health care organizations, midwifery practices, community health units, Aboriginal community health access centres and community health centres, working with the community through the Health Centres.

-Anti-violence organizations

-Housing organizations

-Physician offices

-Canadian Red Cross

Mass media:

-Broadcast on local radio channel, newsletters, flyers/posters, radio announcements/interviews, emails.

Secondary data:

-Administrative data, survey data, census, Health Card Registration Files, database studies, population list, pre-existing Statistics Canada survey (CCHS), secondary analysis, Aboriginal

-People's Survey, surveillance data, medical registry.

Question 21. Which national ethical guidelines do you following your research with Indigenous peoples?

(Check all that apply)

Other sources for Indigenous ethical guidelines named by participants, consisted of:

Community authorities:

-Band and community guidelines

-Community ethical guidelines held by Indigenous community partners

-Indigenous protocols

-Skidegate and Namgis Band Council guidelines for research with their communities

Specific communities:

- Guidelines for Ethics Anishinabek Research: Manitoulin Island Anishinabek Research Review Committee
- Cree Natural Laws to guide my work
- Inuit Tapiriit Kanatami guidelines for responsible research with Inuit communities
- Negotiating Research Relationships with Inuit Communities: A guide for researchers
- Assembly of First Nations Ethics in First Nations
- First Nations of Quebec and Labrador Research Protocol
- Newfoundland and Labrador Ethical Guidelines
- Mi'kmaq Ethics Board
- Community research frameworks/Ethics boards (e.g. MARRC)

Institutions:

- NAHO guidelines for research with Metis peoples
- Carleton University Institute for the Ethics of Research with Indigenous Peoples (CUIERIP)
- Disciplinary specific ethics guidelines
Provincial Health Services Authority (BC) Cultural Sensitivity Training
- Research Institute

Documents:

- Ethical issues that arise from the literature
- IGOV research protocols: <http://web.uvic.ca/igov/uploads/pdf/protocol.pdf>
- International protocols as appropriate
- The Kahnawake Schools Diabetes Prevention Project (*KSDPP*) Code of Research Ethics
- The 4 R's of Indigenous health research
- UNDRIP (United Nations Declaration on the Rights of Indigenous Peoples)
- Community literature (for e.g. Linda Smith, Manulani Aluli-Meyer, Shawn Wilson)
- Indigenous Cultural Responsivity Theory
- USAI Research Framework

Local and Regional Guidelines:

- Blue Quills (Blue Quills First Nation Indian Reserve, Alberta Canada)

-Local First Nation protocols

Own Panel-insights/relations:

My own insights honed over years of community-based research

We—the community-academic team—also developed our own code of research ethics

We have an internal Indigenous Ethics Advisory Panel at our University that reviews projects

Chapter 5: Discussion

5.1. Discussion

This research provides a preliminary description of the field of the ethics of Indigenous health research in Canada and represents the views of health researchers involved in the study. The study attempts to bring into focus new questions related to the main objectives of the research project on Ethics of Indigenous Health Research: Upgrading Guidelines Through Community-Based Research. Additionally, this study builds on the information compiled by the National Collaborating Centre for Aboriginal Health (NCCAH, 2015) by identifying active researchers in the Indigenous health research field. From data gathered in this research it is possible to detect gaps and trends required to improve ethical outcomes of Indigenous health research and open possibilities for transforming health research education.

As was intended, the survey presents some commonly shared perceptions of a sample of Canadian health researchers on several aspects of ethical guidelines pertaining to Indigenous research. In the field of Indigenous health research, researchers do not follow one, unified guideline in Canada even though the TCPS-2 2014 and OCAPTM, are the most commonly used guidelines. researchers who engage in Indigenous health research also conduct health research in consultation with other types of ethical guidelines in Canada (see Question 21). The variety of guidelines followed by respondents is represented by high response rates that reveal how researchers use multiple ways to design and conduct health research. Because of this complexity, the term *in-use* is used here to refer to the predominant ethical guideline followed by health researchers and the conclusions of this thesis should be interpreted in the same way—as representing a current moment in the evolution of ethical guidelines for health research with Indigenous populations.

General results from the survey can be organized into the following meta-themes:

Meta-theme 1: Strengths (agreements) of ethical guidelines in-use

- Value of ethical guidelines in-use
- The right amount of information offered

- Easy access to ethical guidelines

Meta-theme 2: Middle level of agreement (between agreement and disagreement) of the ethical guidelines in-use

- Are clear for researchers who are not familiar with Aboriginal worldviews
- Promote cultural sensitivity
- Clearly state how to conduct ethical research involving Aboriginal Peoples
- Are easily applied in my research project
- Help to reduce/prevent oppressive and harmful research with Aboriginal Peoples
- Meet the ethical needs of Aboriginal communities
- Are reasonable and realistic in research involving Aboriginal peoples
- Are explicit about how to avoid unethical practices involving Aboriginal Peoples

Meta-theme 3: Weakness (disagreements) of ethical guidelines in-use

- Clarity of the guidelines for non-Indigenous persons who engage in Indigenous health research
- Reflection of current social contexts of Indigenous communities
- Inclusion of evolving current Indigenous paradigms
- Ability of the ethical guidelines to enhance the understandings of Aboriginal worldviews
- Highly diverse and complexities on levels of ethical guidelines and ethical approaches.

Meta-theme 4: Indigenous community-based health research

- Geopolitical concentration in Ontario and New Brunswick where Indigenous communities are more frequently involved in health research
- First Nations, then Métis, and Inuit, in this order, are the Indigenous identity groups most frequently involved in health research

- Pre-natal, infants, and children between the ages of 0 to 12 are the least involved in health research studies.
- A group of health researchers' respondents (around 25%) identify as First Nation, Inuit, or Métis.

Meta-theme 5: The health researcher

- Health researchers' experiences conducting Indigenous health research
- Health researchers' disciplinary approaches to health research and the overrepresentation of the fields of health promotion and mental health
- Health researchers' ethnic background, which is predominantly identified as Caucasian
- The impact of health researchers on other international Indigenous communities

Meta-theme 6: Indigenous people's participation

- Community involvement primarily in the pre-consultation project phase
- Dissemination of knowledge mainly includes journals and academic conferences
- Recruitment is promoted by Aboriginal health organizations and word-of-mouth
- Half of the studies involve communities in a close relationship, but practically all health researchers include Indigenous communities in their health research
- Qualitative and mixed methods are predominantly used in health research, followed by quantitative studies.

This survey included two groups of results: the field of Indigenous health research and the perception on in-use ethical guidelines. The survey's results signal health disparities created by the dominance of the biomedical approach. This is evidenced in gaps in Indigenous health research. Some examples of this are: low numbers of self-identified Indigenous persons working in the field of Indigenous health research; limited participation of Indigenous peoples in health research; gaps in understandings about community-based health research; few studies including children between 0 – 12; regional concentration of research by provinces; and low participation of Métis and Inuit communities.

In the first set of conclusions, researchers who engage in Indigenous health research respondents of this survey are experienced in the field, and at least half of them are actively conducting research. They constitute a critical human force for future Indigenous health research. They also design Indigenous health research studies from many of the health disciplines but mainly from Health Promotion and Mental Health, while other areas of health are less inclusive. In their studies, participants use qualitative and mixed methods predominantly.

The approach followed in this survey explored the prevalence of community-based research, which affirms the right of Indigenous communities to self-determination, participation, control, and use of all knowledge developed with and by Indigenous peoples. This topic was investigated by inquiring into the relationships between researchers who engage in Indigenous health research and Indigenous communities. Results show that even though community-based research is included in practically all research studies, those studies do not necessarily value Indigenous rights to self-determination. Practically all participants involve community partners (see Questions 5-11) but these studies are not strongly attached to and directed by their Indigenous community partners. Only one third of participants create *very close* relationships with communities, while almost half of the participants develop *close* relationships. In their research, participants involve community partners mainly in *pre-consultation*, proposal development, data collection, and dissemination of results, but a very low percentage of the studies reported by participants include Indigenous communities in *data analysis stages*.

In this research, the involvement of community partners in research is still predominantly focused on Western perspectives of knowledge building and knowledge dissemination, where peer-reviewed journals and academic conferences are the most common forms of dissemination. Research has had little impact on public policy and often neglects to include community feedback and to allow Indigenous control of research results. While community-based Indigenous health research has been conducted, the prevalence, quality, and modes of knowledge-building and sharing are areas that may require further intense training and conversations.

Health studies that involve First Nations, Metis, and Inuit communities are based not only on population, distribution, and growth, but also on geographical distribution in Canada, allocation

of public and private research funds, access to and connections with centers of knowledge production (universities and research centers), and possibly, the invisibility of Indigenous ways of disseminating knowledge related to health and well-being.

The survey confirmed the need to explore more on the progress towards answering the TRC's call N. 23, which states:

We call upon all levels of government to (i) increase the number of Aboriginal professionals working in the health-care field; (ii) ensure the retention of Aboriginal health-care providers in Aboriginal communities; [and] (iii) provide cultural competency training for all healthcare professionals (p. 3).

It was observed that 43% of participants self-identified as Indigenous (98 respondents). However, less than half of participants (45 respondents) self-identified as Indigenous under the category of First Nation, Inuit, or Métis. The remainder of participants who selected "Indigenous" identified with various other labels, including other Indigenous groups outside of Turtle Island or no claimed Indigenous identity that all. In total, only 24.1% (55 participants of 228) were Indigenous persons, while most health researchers identified as Caucasian.

This finding shows that there is a need for more Indigenous self-identified persons within the Indigenous health research field, and it follows that more support is required for Indigenous students to access educative programs in the health sector. This research found that most health researchers in the field of Indigenous health are non-Indigenous.

Indigenous self-identification was confusing for some participants with non-Indigenous backgrounds (i.e. European; adopted by Indigenous communities; or no Indigenous background, such as an ally). Each time that the question of identity appeared, it caused confusion and sometimes, conflict. Some respondents shared that they were very upset with this question. The argued that self-identification might reproduce certain stigmas, individual history of harms and negativity associated with Indigeneity. This is a situation that needs to be addressed in future research, and, the resistance that some participants expressed in relation to identifying themselves by their Indigenous backgrounds needs to be explored.

Identity is a controversial issue not only because of legal implications, but also because there is a process of identity and Indigenous culture engagement that has historically been used against Indigenous communities. In this survey, researchers predominantly identified as Caucasian, followed by Aboriginal. In response to the question about identity, some of participants wrote, “Why do you ask? Why should I respond?”, which may be evidence that these respondents feel that self-identification is a political matter. More than half of the participants refused to answer the identity question, and for those who did answer the question, they predominantly identified as “*other identities*.” First Nations, Metis, and then Inuit were the Indigenous Nations selected. The number of self-identified Indigenous persons working in the field of Indigenous health research was comparatively low (say how many here) in relation to Caucasian and other non-Canadian identified health researchers.

Geographical distribution of Indigenous communities may also be related to the distribution of Indigenous health research in specific rural and urban regions, and provinces. This survey found there is no prevalence between health research studies conducted on reserves, or in urban or rural settings. It has been found that there is no prevalence for “location” of Indigenous participants. Therefore, research funding could be allocated to promote studies that respond differentially to Indigenous health concerns, which depends on geographic and cultural-economic micro-environments and structural barriers.

In addition, Indigenous health research was reported differentially between Canadian provinces. As stated earlier in this report, the largest percentage of Indigenous health research studies were carried out in Ontario, followed by British Columbia. Provinces such as Prince Edward Island, Yukon, New Brunswick, and Newfoundland and Labrador, conducted fewer Indigenous health research studies present in this research. Data obtained from Natural Resources Canada based on the Canadian Census (Statistics Canada, 2006) shows that the Indigenous population concentration in Ontario includes Indigenous communities with 30% to 59% of population density located in the north of Ontario, and Indigenous population densities between 5% to 14% in the rest of the province. The survey’s results may be congruent with the geographic distribution of Indigenous communities published in the Aboriginal Identity Population Report from Statistics Canada (2006) that reports, “eight in every 10 Aboriginal people, just over 944,000, lived either in Ontario or in the four western provinces in 2006” (para. 9). Other factors

mentioned such as, research funding allocations, existence of research centers, or concentration of human resources may be related to this distribution. However, these observations are limited in relation to the access and reliability of statistical data, a factor that is frequently questioned in Indigenous studies.

Researchers who engage in Indigenous health in Canada also conduct health research with Indigenous peoples from other countries, predominantly in the United States, New Zealand, and Australia but also with Central and South American Indigenous communities, as well as those in India, Africa, and Greenland. Based on this survey, it is possible to create at least two axes for Canadian international Indigenous health research connections: The Commonwealth and the American perspective. These two axes may represent future Indigenous international connections and opportunities to develop the concept of Indigeneity and Indigenous health research from a global perspective. This knowledge would be relevant to Indigenous communities in Canada because trends, lessons learned, options, and best practices can be discussed, evaluated and promoted if they can support better local, systemic and structural practices.

The survey also shows that in Canada there is an unequal distribution of the number of Indigenous health studies by age group. The least studied Indigenous age group is prenatal followed by infants between 0 to 1 year, and 1 to two years. There is a concentration of health studies on Indigenous adults older than 20 years old. This low percentage of health research is contrary to the recognition of the importance of the complete life cycle of Indigenous peoples as a decisive factor in the prevalence and balance of the dimensions of health signaled by the National Collaborating Centre For Aboriginal Health (Loppie & Wien, 2009). More research is clearly required including this underrepresented groups in health research. Not only because it is required to minimize infant morbidity rates, but because the extensively documented importance of early education in the future of a nation (Healthy Children Healthy Nation, May 2018), along with the requirement of better infrastructure, accountability, learning environment services, access, funding and public policy addressing inequalities and gender imbalances (Atkinson Centre for Society and Child Development at the Ontario Institute for Studies in Education/University of Toronto, 2017).

The second half of the survey explored both which sets of guidelines and how the ethical guidelines of conducting health research involving Indigenous participants were used. The TCPS-2 builds on the OCAP principles and even though language and restrictions based on the way official government guidelines are presented are different in these two documents, they are fundamentally very similar. The TCPS-2 (2014) chapter 9 was used the most, followed by OCAP™ (2010), CIHR, and SSHRC guidelines. Other guidelines were also mentioned and selected, although with reduced frequency compared to the first three and this speaks to the diversity of Indigenous communities, complex levels of government, and diverse levels of relationships with communities and Indigenous bodies, centers, and bands.

A general analysis shows that researchers who engage in Indigenous health research *somewhat agree* with the characteristics of ethical guidelines. These results show that guidelines are perceived as an incomplete reflection of current needs and concerns of Indigenous communities and researchers' expectations as asked by the survey. The one-way scale analysis indicates that there was a *high agreement* on the amount of information offered and the ease of access of the ethical guidelines. However, *low agreement* was reported in relation to the level of clarity of the guidelines felt by health researchers who were unfamiliar with Indigenous worldviews. Similarly, there was low agreement in relation to whether the current guidelines truly reflected current health struggles of Indigenous communities or included Indigenous paradigms. A need was also expressed for the enhancement of health researchers' understandings of Indigenous paradigms through additional training.

These areas should be understood as important necessities for improvement and should be utilized to guide health researchers in co-designing, constructively conducting, and sharing knowledge production in ways that positively impact Indigenous communities in health research.

The next step for this research (although not part of this current study) will be to share results of the survey so respondents can provide feedback on topics and questions presented in the survey. This feedback will then be used to inform the second half of this study where in-depth conversations will be conducted with key community informants and researchers who engage in Indigenous health research.

The call for new health knowledge that is centered on Indigenous ethics asks health researchers to use innovative approaches to resolve the complexities of systemic, structural and individual challenges of health for Indigenous communities. Health research education itself should additionally be challenged, perhaps in a way that takes up new Indigenous frameworks and creates collaborative options for research methods, knowledge creation, and transformation of Indigenous health realities. This would be consistent with the kinds of changes suggested in adaptive medical education proposed by Tackett, (Tackett et al, 2018). However, such an adaptation is challenged by the need to transform the conditions that are diminishing the natural environment, the availability of knowledge, the structure of social relationships, public policy and current government allocation of resources.

Community Conversations About this Report

On May 25th, 2017, the results of the survey were shared in a series of feedback sessions. First, an In-Progress report was shared with community and health researchers, then a brochure was designed to outline the study and survey's main results, which includes a full survey's report. The goal was to share preliminary and in-progress results with researchers who engage in Indigenous health research, community members, and participants in the survey. These knowledge transfer products created opportunities for community members to react and question research results shared in relation to various topics of Indigenous health research.

5.2. Lessons from the survey

The high number of respondents to this survey and their geographical distribution provided a good sample of the field of Indigenous health research in Canada. However, because it was not possible to contact 100% of the population defined, the sample gathered was not fully representative of researchers who engage in Indigenous health research in Canada. Despite sample and participatory limitations, the survey provides a preliminary approximation of what is happening in the field of Indigenous health research, and highlights issues and concerns expressed by both Indigenous and non-Indigenous health research participants. In this section, I outline three main lessons learned from the survey.

First, while the survey revealed that ethical guidelines of Indigenous health research are a complex field, it also reflects the richness and diversity of Indigenous communities as well as

highlighting the many different levels of government and academic boards involved in delivering healthcare and policy. Regarding the ethics of Indigenous health research, there continues to be a constant tension over how to avoid those practices of health research that reproduce assimilation and homogenization of Indigenous communities because such knowledge practices will be challenged and likely rejected by Indigenous communities. There is inherent complexity in doing work with Indigenous Nations because they cannot be considered culturally as a single group with one, unified culture, epistemology, and/or identity. Instead, Indigenous communities display rich, varied, and complex communities, families, authorities, languages, practices, and cultures. These variations are represented in the survey by the diversity of the Indigenous ethical guidelines in-use. It is required to recognize that research is a human activity that is not new to Indigenous people who observed, studied and managed nature and human survival for centuries without the “assistance” of scientific approaches.

The diversity of the ethical guidelines of Indigenous health research presented in this survey represents the diversity of Indigenous populations as rich sources of knowledge, inspiration, and effective in the healing of nature, animals, and human relationships. Indigenous knowledge pertains to Indigenous Nations as a way of social conflicts negotiation through consensus for centuries, in ways that create, honour, and respect Nation to Nation self-governance and relationships (National Centre for First Nations Governance, 2007).

A second lesson learned from the survey relates to the Western mainstream approach to health science. Participants revealed that Western-based disciplinary research approaches still dominate Indigenous health research. This situation presents a possible topic for future exploration in that the use of dominant perspectives prevent the use of alternative approaches to research where, from Indigenous perspectives, multiple dimensions based on epistemologies, axiology, and methodologies of Indigenous knowledge are necessary. The findings from the survey suggest a need to explore how multidisciplinary studies can be promoted, focusing on Indigenous perspectives of health which ask us to:

move beyond health as conceived as a matter of illness due to bio-medical cause and effect, or lifestyle choices. We take the approach that Aboriginal ways of knowing and being, including concepts of

spirituality, connectedness and reciprocity to the land and all life, self-reliance, and self-determination advance health equality and outcomes (National Collaborating Centre for Aboriginal Health, Accessed 2018, para. 2).

Because of the complexity of the field of Indigenous health research, it is proposed that approaches based on more contextualized health research should be explored and can offer useful perspectives. Indigenous research methods, community-based research, transdisciplinary approaches, and the use of mixed methods should be fully integrated into health research. These changes would better address health needs of Indigenous communities.

A third important topic to explore in the future is how health researchers use and conceive of community engagement. This area showed the need for conversations and training about what research implications need to be addressed in approaching community-based health research and the concept of “inclusion” in congruence with Indigenous research ethics in primary, secondary or meta-data studies. Transformative health research should also address the impact of new knowledge on public policy.

The fact that researchers who engage in Indigenous health research in Canada also conduct health research with Indigenous peoples from other countries, is a factor that may support the creation of an International Network of Indigenous Health Research to study topics related to Planetary Health as it is proposed by the Lancet Commission on Planetary Health (2005) and to expand Indigenous health research ethics globally.

Overall, we came to agreement on the characteristics of the ethical guidelines and which areas should be explored as possible strengths and possible areas to improve. This was important in order to figure out ways to help health researchers to co-design, constructively conduct, and share knowledge production with Indigenous communities so that health research could have an increased positive impact on Indigenous populations. The relevance of the general agreement shows that not all participants agreed with the ethical guidelines they use. For example, in the area of community partnership engagement, participants answered four questions related to community partners' involvement: whether they were involved in respondents' research; if their relationship was distant or not; at what stages healthcare personnel were involved; and how often

health researchers had contact with community partners. It is possible to describe these factors based on participants' responses, but it is not possible to define how community engagement is defined, what is relevant for participants, or why they believe they should involve community partners. To find the answers to these questions, another set of questions will need to be developed. The second type of questions should be pursued through qualitative interviews and community-based methods.

The next step in the process of producing this knowledge will be to share a report with survey's participants to provide feedback on the topics presented. A database openly shared with the public and health researchers would provide actual information about researchers who engage in Indigenous health research, and facilitate future collaborative research and knowledge sharing processes.

5.3. Impacts on Health Research Education

The following section seeks to contribute to conversations about Indigenous health knowledge in terms of what challenges and barriers need to be addressed in courses about health research, and what strengths and possibilities offer health research when is meaningfully integrated with the ethics of Indigenous people. One way to approach this conflict, consists in to have curricular conversations followed by discussions about health research perspectives that enhance awareness about the limits and restrictions of the bio-medical model used in scientific and technological knowledges and how health is defined as a social construct instead of a bio-medical reality. Such conversations also need to be held in safe educational contexts where Indigenous student's participation is promoted, valued and sustained and in which non-Indigenous students are exposed to the orientation and focus of the practice of Indigenous health.

Self-identified as non-Indigenous person and health researcher who engage in Indigenous health research might experience difficulties in both understanding and respecting Indigenous knowledge and the differences between Indigenous traditions, knowledge and cultures of Indigenous communities in Canada because simply they did not receive proper training in their undergraduate or graduate courses. Thus, this chapter is grounded in the idea that health researchers who are interested in working with Indigenous communities should have appropriate training, as well as be provided with opportunities to be self-reflexive, engage in experiential

learning and gain critical awareness of the ethical implications of involving Indigenous people in research. These processes should also necessarily involve teaching researchers to develop personal awareness of their own positionalities, developing respect and honor toward Indigenous knowledges and understand the ways that knowledge and reality may be alternative paths to those proposed by prescriptive, Western perspectives of health.

In sum, both Indigenous and non-Indigenous self-identified students who engage in Indigenous health research would greatly benefit from a range of Indigenous pedagogies such as community learning, land-based and experiential learning, and other Aboriginal pedagogies such as talking or sharing circles and dialogues, participant observations, experiential learning, modeling, meditation, prayer, ceremonies, or story telling as ways of learning and knowing (Stiffarm, 1998). The method used to convey survey data and educational decolonizing theory triangulates theory and data (Jackson and Mazzei, 2012) and power – knowledge approach (Foucault, 1972) and epistemic disobedience approach (Mignolo, 2009). Jackson and Mazzei propose that thinking with theory is a process that serves to create new knowledge from data that is more complex and contextual. This section presents suggestions on how multi-perspectives of knowledge might be applied to the curricular design of graduate and undergraduate courses on health research applied to key areas of curriculum: knowledge creation (epistemology, ontology, value systems), contents and pedagogies.

5.1.1. Knowledge creation

5.3.1.1. Owners of Knowledge

As the survey data suggests, scientific knowledge does not make neutral statements about nature and ideas but rather includes socio-political, ideological and economic dimensions. When scientific knowledge is developed, or modern technology is advanced or patented, it mobilizes the dynamics of a social system with the potential of perpetuating and reproducing harms to Indigenous peoples. Scientific (and techno-cultural) advances create “*differance*” between certain people and the Other, an elite dichotomy that mobilizes power-knowledge systems that indirectly and directly harm Indigenous communities. However, if knowledge engages Indigenous ethical principles and worldviews, research knowledge may mobilize and restore

health with, and by, Indigenous communities, but only if that knowledge is possessed, accessed and owned by Indigenous communities.

5.3.1.2. Triangulation Instead of Mono-Perspectives

Triangulation is a method of testing validity that uses multilevel strategies to work with data, and includes three dimensions: the method, the data, and the researcher (Denzin and Lincoln, 2000). Multilevel strategies include analyzing data obtained at different moments or by several participants, and/or working with data that is interpreted through different frameworks, which includes taking into consideration the method, the overall research, and moments of interpretation.

Triangulation helped to investigate different levels of data by applying layers and levels of analysis. Triangulation was used to analyze the various types of data in this study, including qualitative and quantitative data, observable experience, stories, drafts, discussions, and non-observable phenomenological experiences. Ethically sound data-knowledge in this context is best obtained by triangulation with researchers, Indigenous Elders, community members, and researchers who engage in Indigenous health research (Cohen & Manion, 1994). In terms of interpretation, triangulation is an opportunity to be creative, but it does not resolve the problem of knowledge translation, when previous knowledge was developed from non-Indigenous community-based perspectives.

Using triangulation methods was a way to work creatively in order to find innovative ways to transform reality and systems that are involved in health and health services. By considering discourse, emotion, embodiment, and spiritual guidance, this method seeks to critically interrupt the normalized division of thought, the scientific exclusivity on “truth,” and the uniqueness of objectivity and logic as privileged sources of knowledge. Alternative knowledge-building processes can then be incorporated into health research.

5.3.1.3. Indigenous Ethical Guidelines require a complex dynamic approach.

As mentioned before, Indigenous guidelines on the ethics of health research respond to the complexity of Indigenous identities, knowledges, traditions, and relationships with ancestors that

health researchers need to recognize and learn. The survey revealed that the three most used guidelines were the OCAP™ principles, USAI frameworks, and the TRI-Council 2 guidelines, but there were also other, Indigenous frameworks, that respondents considered relevant. These guidelines shared similar approaches to some topics that involved more contextual ways of understanding health and health systems. Indigenous knowledge is inherently built from multiple perspectives because it is based on community participation from a wide diversity of Indigenous groups across Canada.

Also, names and methodologies need to be flexible. The USAI guidelines describe “research spaces,” as incorporating a methodology called “orientation to research,” while taking a culturally relevant approach to the design and evaluation of research using certain measures and indicators. Using a decolonizing approach, the principles of the USAI framework rest on community participation, and the right to self-determination and control of the knowledge of Indigenous communities. From this perspective, knowledge is “community driven, community relevant, faithful to Indigenous identity, self-voiced, useful, accessible and produced by a relation-based research” (OFIFC, 2012, pp. 5).

Further, the USAI framework is key to understanding colonial dynamics that potentially reproduce the colonial dichotomy of high-quality knowledge being equated with science- and low quality of knowledge being associated with cultural knowledge. These viewpoints can be seen in in the survey data. From a decolonial perspective there are no “low cultures” because those designations are imposed as normative divisions of power. The main task here is to understand self-determination rights of Indigenous peoples, affirmed by governments and recognize the implications for training and reorganization of health and health services.

In the case of environmental pressures, the same colonial dynamic has been extensively documented (Luckey, 1995; McGregor, 2006; Simpson, 1999; Stevenson, 1999; Brubacher & McGregor, 1998; Bombay et al, 1996; Bombay, 1996). During the 1990s, environmentalists became interested in Traditional Ecological Knowledge (TEK), and envisioned Indigenous knowledge as way to gain awareness of and act on environmental issues (Simpson, 2001). Simpson points out that the interest expressed by ecologists was initially a “good thing” because after decades of appropriation, assimilation, rejection, and the degradation of Indigenous

knowledge, the dominant society conceded that Indigenous knowledge was important. But this interest was in fact very partial, only recognizing aspects of Indigenous knowledges that were specifically related to concepts and understandings of the environment as seen through the frameworks of Western science with no sustained interest for Indigenous ecological concerns (Simpson, 2001).

According to USAI and OCAPTM ethical guidelines, Indigenous communities should rather be at the center of knowledge production in the interest of preserving and honoring Indigenous culture and communities and transforming reality in accordance with traditional knowledge, accessed, controlled, and possessed by Indigenous peoples. The survey revealed that participants also thought that current ethical guidelines could better reflect the current needs, pressures, and social contexts in Indigenous communities as well as currently evolving Indigenous paradigms. Participants pinpointed these areas as important issues to consider, which signals potential topics for future exploration. Future research would help us to understand, in greater detail, how these issues relate to and impact Indigenous communities. In order to improve training on the ethics of health research, health researchers would have access to knowledge on ethical guidelines that would expose the vulnerabilities of narrower scientific approaches to health. Thus, *relationality* is a central issue in the education of health researchers interested in working in the field of Indigenous health.

5.3.1.4. Experiential Knowledge and Academic Knowledge

In the interest of acquiring meaningful learning to support Indigenous communities, simply reading academically oriented material like published theories and research created under the evidence-based and logically-oriented model will not provide adequate grounding. Health researchers would have greater opportunities to gain contextualized knowledge if they *experience* what it really means to practice the Indigenous ethics of health research, by working to understand the main issues, concerns and risks of Indigenous peoples. This knowledge is not fully gleaned from reading texts, which may indeed provide data and ideas, but do not always challenge students' understandings of reality and perspectives of health and well-being in relation to Indigenous communities.

Non-Indigenous persons working in the field of Indigenous health research may experience tension if they not only lack experiential knowledge about what it means to practice health research from the Indigenous perspective, but also if they are unaware of the historical and current issues and health concerns of Indigenous communities. This lack of knowledge creates a gap between what Indigenous ethical guidelines demand and the health services provide by non-Indigenous persons working in the field of Indigenous health research, as they may deliver care based on their own assumptions about science, society, health and recovery. Within this gap are other assumptions that health research imposes on Indigenous peoples, including pressures of modernity, technological dependency, the institutional control of resources, Western ethics and cultural representations. Instead of an assimilative approach, innovative programs, learning experiences, and educative programs can assist non-Indigenous persons who engage in Indigenous health research in using an ethical with-and-by approach when serving Indigenous communities. The inclusion of a community-driven, needs-based approach that is controlled and designed with and by Indigenous communities will benefit Indigenous peoples. This knowledge integrates Indigenous understandings of relationships between health, nature, humans, animals, and cultural production.

Some of the knowledge that should be included revolves around equal opportunities for participation and self-determination rights of Indigenous peoples. In the USAI framework, interrelationality includes four perspectives that generate knowledge: historical, geo-political, relational, and [epistemological] (OFIFC, 2012). From this interrelationality perspective, data from the survey shows that low levels of general agreement can be interpreted as the lack of knowledge of non-Indigenous researchers who engage in Indigenous health research about Indigenous worldviews and epistemologies. Without historical knowledge about the harms inflicted on Indigenous peoples, the lack of understanding of evolving Indigenous paradigms, and the absence of reflection on the pressures and issues experienced by Indigenous communities, it is not possible to guide health research and health research education.

Relationality that is assumed as involvement, participation, or partnership (in the Western sense of those terms) without engaged participation from a given community also puts the research process at risk. A lack of consideration for community relationships from the beginning to the end of the knowledge-building process, may contribute to health research designs that repeat and

re-inscribe harmful and prescriptive Western formulas based on power-knowledge dynamics. This process subsumes Indigenous communities according to the dynamics of dependence and new technological, institutional, and cultural colonialisms. If we assume that the survey shows the lack of opportunities, sources, programs, and ways that health researchers approach Indigenous health research using Indigenous paradigms, then interrelationality between the historical, geopolitical, and epistemological locations may also be missed or misunderstood. Improving the visibility, practice, and understanding of the interrelationality principle in relation to specific topics such as community involvement, the epistemological perspective of the study, the concepts of partnership and data-knowledge creation strategies is required in health research education.

The OCAPTM was reported in the survey as the second most frequently used set of guidelines after the Tri-Council guideline. Importantly, OCAPTM principles are not to be applied as a prescriptive doctrine, which aligns with what the survey revealed regarding answers about several agreements and partnerships that were specifically negotiated with Indigenous communities. As is specified by the OCAPTM:

the interpretation of OCAPTM is unique to each First Nation community or region. OCAPTM is not a doctrine or a prescription. It is a set of principles that reflect First Nation commitments to use and share information in a way that brings benefit to the community while minimizing harm. It is also an expression of First Nation jurisdiction over information about the First Nation. (First Nations Information Governance Centre, 2014, pp. 4-5).

From a prescriptive, Western science framework, the proliferation of ethical guidelines can be perceived as a lack of “unity,” or that one set of ethical guidelines may be “easily applied” to all Indigenous communities. For health researchers who expect and pursue uniformity, this framework would be considered as lacking coherence. Rather, Indigenous ethics is a highly coherent framework, expressed in the OCAPTM principles, which guides research according to the logic of community self-determination. Health researchers interested in building relationships around health and health care with and by Indigenous communities are invited to take a top-

down *and* bottom-up strategy through levels of governance that address the unique needs of individual Indigenous people, considering their relationships with family and community. This approach requires health researchers to learn new sets of skills where a key element is flexibility and a willingness to be open to diverse perspectives, which may not be included in their health research education.

As expressed in the OCAP™, principles and definitions should not be static rules, but rather, values based on the collective knowledge of First Nations:

OCAP™ goes beyond the strict definition of each word in the acronym. It represents principles and values that are intertwined and reflective of First Nations' worldview of jurisdiction and collective rights. (First Nations Information Governance Centre, 2014, pp. 5)

The OCAP™ principles cannot be defined in the way non-Indigenous persons who engage in Indigenous health research may expect in terms of laws or rules specifying definitions that offer a “recipe” to achieve ethical standards. If we consider that there is a dependence between what health researcher-students can understand and say about any concepts they use to understand and describe reality, and if the definition of what health researchers-students use is exclusively based on scientific and prescriptive empirical-analytical model of science, non-Indigenous persons may find it difficult to follow non-prescriptive concepts and principles. Most of them may continue to strive for clarity, uniformity, specificity, differentiation, validity, evidence, data analysis and prediction as they work with Indigenous communities. Instead, OCAP™ principles ask researchers to consult with each First Nations community around their understandings of ownership, control, access, and possession, which is what the acronym stands for. This community-based strategy includes consultation and involvement with several levels of Indigenous government and organizations.

Also important in relation to the OCAP™ principles are the laws that rule knowledge development. The principles of ownership, control, access, and possession locate power and knowledge within Indigenous communities. Any knowledge with and by Indigenous people's participation on research should be developed using OCAP™ principles.

This principle contradicts health research that is conducted according to Western scientific research practices. From the scientific perspective, knowledge is used to build cases, to develop empirical evidence, or impact specific populations based on scientific laws. These laws in turn inform theories and abstract knowledge that are shared under copyright restrictions and restricted publication access. Further, the ownership of such knowledge remains tethered to the author or the research institution associated with the research. Health researchers working on topics of Indigenous health may believe that the knowledge generated by their research, even in collaboration with Indigenous communities, automatically becomes the property of health researchers, institutions, companies, donors, or government agencies involved in the research. This belief conflicts with OCAPTM's principles and is an issue that needs to be renegotiated, addressed, and resolved with Indigenous authorities and communities. This important topic of ownership of knowledge should be included in the training of future health researchers who wish to work with Indigenous populations.

Scientific health research is used to create health innovations (procedures, strategies, interventions, and practical knowledge) that can be transformed into technologies (machines, techniques, approaches, pills, therapies, and vaccines) protected under copyrights laws and which are viewed by the health community as returns on investment by health researchers and institutions. In this way, private companies who access this knowledge may design technologies, interventions, and help to influence the direction of public policy based on evidence that ultimately creates systems that are imposed on Indigenous communities. The role of Indigenous communities is then relegated to one of following rules dictated by this new knowledge or technology that applies Westernized corrective treatments or measures.

Acquiring and paying for recent technological innovations that are developed through Westernized scientific research protocols contributes to Indigenous community dependency. Furthermore, researchers, institutions, and/or government agencies reap economic profits exclusively for such scientific innovations and knowledge gained from health research. In contrast, OCAPTM principles apply a new copyright rule that presents a new perspective about the ownership, control, access, and possession of the data and knowledge generated from the research conducted with Indigenous populations, which shifts the rights from private and public health researchers and institutions to Indigenous peoples and communities. Training,

conversations, and different perspectives on ownership of knowledge need to be a requirement of health research courses.

5.3.1.5. Course Contents

Drawing from the literature review and the survey results, below is a list of possible suggested topics to be included in future Indigenous health research training courses:

1. The History of Indigenous and Settlers relationships.
2. The Diversity of knowledges among different Indigenous peoples as well as Indigenous knowledge systems and Western paradigms.
3. Indigenous and socio-determinants of health, including Indigenous and Western definitions and frameworks of health.
4. Using a dynamic complex systems approach examine different systems of research and research knowledge.
5. The history of health research, and the process of community-based health transformation.
6. Indigenous health epidemiology and prospective studies of Indigenous health.
7. The socio-legal and economic implications of the ethics of Indigenous health.
8. The ethics of Indigenous health research including how to evaluate transformative Indigenous health programs.
9. The notion of planetary health and Indigenous knowledges and Indigenous food security and health.

In 1992, Dr. Marlene Brant-Castellano co-chaired a workshop for the Royal Commission on Aboriginal Peoples (RCAP) to address the ethics of research involving Aboriginal peoples. This consultation invited academics, lawyers, graduate students, project staff, and consultants

involved in advising the RCAP on health research from Indigenous perspectives to participate. From this experience, Brant-Castellano (2004) declares:

research acquired a bad name among Aboriginal Peoples because the purposes and meanings associated with its practice by academics and government person were usually alien to the people themselves and the outcomes were, as often as not, misguided and harmful (pp. 98).

Brant-Castellano's eight principles (Brant-Castellano, 2017) could also be included as part of the course: the right to participate as principals or partners in research, the mandate of the Government of Canada to protect Aboriginal rights, and to create a balance between regulations that protect Aboriginal rights, the right to protect all knowledge, languages, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples, the revision of legislation to include Aboriginal rights and to protect Aboriginal interests and perspectives, the inclusion of the costs of community consultation, development of research plans, negotiation and implementation of ethical protocols in research budgets, responsibility for education of communities and researchers in ethics of Aboriginal research.

These principles could also be discussed in relation to the survey data as they interact with those data and could provide some further direction for health research courses.

The eight principles described might also guide conversations about considerations on how to design, conduct and share health research involving Indigenous communities. The first principle about Indigenous participation in research, as it is shown in the survey, signals how health researchers are required to engage Indigenous communities. It was reported that health researchers engage the community in practically all research projects. However, this is only one step towards including Indigenous communities in research. In terms of the quality of that engagement, many respondents revealed that Indigenous communities did not participate in the complete research process from beginning to end. Frequently, respondents reported that participation was possible at the design and knowledge-transfer stages, or when recruiting Indigenous participants. However, participation was reported as less common when data decisions were made, or when conceptual and theoretical decisions were taken.

The recruitment of Indigenous participants was a concern frequently expressed by health researchers who consistently struggled with low numbers of participants in their studies. Health researchers continually look for new ways to get attract participants, but it seems that Indigenous communities, in general, do not respond positively to these alternatives because researchers lack meaningful connection with Indigenous communities. Health researchers have attempted to improve recruitment strategies by offering incentives and donations, or by using ethically questionable strategies such as looking for information in data bases or in health research archives. In short, changes in design and health research with and by Indigenous communities are not yet in place.

Voluntary participation may be valued as an indicator of the level of community involvement in the research project and how well the project appears to correspond to the needs of Indigenous people and communities. But, where few alternatives are available for Indigenous people, voluntary participation is also a response to the absence of other ways to address health issues. Participation implies considerations of Indigenous peoples as a “data cases” or units of information. Additionally, low levels of initial participation often mean continued low levels of involvement throughout the complete research process. Typically, when Indigenous communities and people evaluate research projects as “culturally safe,” the community supports individual involvement and research participation strategies. If research projects are built and conducted as culturally safe practices, then artificially constructed strategies are not required to “improve” participation. This does not mean that we should design research to attract publicity or engage processes that attempt to convince others that the research is “good.” A safe practice begins when *community members* feel safe: where all parties feel free to agree and disagree, decide to build the research relationship together, hold corresponding health research ideas and methods, and finally, when the researchers honor and respect the specific ethics of an Indigenous community.

The right of Indigenous communities to participate or not participate in research is guaranteed as a human right and Canadian right. Health researchers who receive funding from government agencies are required to respect and acknowledge this through several layers of ethics accountability, but this is not always a guiding principle when funds come from private agencies, companies, multinationals or investors. When health researchers develop knowledge that impacts

Indigenous communities, it is even more difficult to control access to secondary data. In these cases, it is not necessary to conduct ethical reviews. This represents a gap between studies that are theoretical in nature and other studies that are based on secondary data reviews. This often impacts Indigenous communities' consent to participate in research. Thus, the quality and nature of community participation, study coverage, the kinds of projects that are not receiving public funds, and secondary analysis are all issues that impact Indigenous community participation and should be addressed.

Principles 2 and 3 describe responsibilities of the Government of Canada to protect Aboriginal rights and to control ethical codes originated from Indigenous communities. (See Appendix C). Health researchers must navigate a complex system that includes Indigenous governments and community organizations, while interacting with levels of government and private agencies. The survey shows that the Tri-Council (2014) ethical guidelines are most commonly used, yet there is an overwhelming number of other documents, reports, community guidelines, boards, and authorities governing research rights, ethics, processes, and protocols that health research should adhere to. This complexity represents a challenge for researchers and health research designs that are evidence-based and structured systematically. Maintaining vigilance in tracking practices that infringe ethical guidelines is also a challenge. Tri-Council (2014) guidelines are clear and strong enough to allow all Indigenous peoples in Canada to be represented and feel confident that researchers will adhere to these guidelines. But, the notion of having only one ethical guideline, as a rule, would contribute to the centralization of power, and may be an imposition. Instead of imposing a rule for all Indigenous people in a prescriptive way, a research design framework must acknowledge the diversity and richness of Indigenous knowledge and then focus on the needs and strengths of each individual Indigenous community.

With the aim of recognizing the richness of Indigenous knowledges of health and well-being, and to promote the process of opening frameworks for Indigenous health research ethics, there is an epistemological perspective that may support the task of passing the control of Indigenous health to Indigenous communities. For non-Indigenous persons who engage in Indigenous health research who may be in this transitioning process, ethical guidelines can be considered from a complex adaptive system perspective. This perspective may enhance awareness about the need to mobilize resources, processes, language, and public policy while empowering *each* Indigenous

person and *all* communities. It may also provide valuable information to guide public policy design, funding allocation, and direct government programs by ending the exclusivity of Western frameworks that control and promote power-knowledge relationships.

With the intention to guide health research in an ethical way, Chapter 9 of the *Tri-Council Policy Statement* was written to guide research conducted with human participants. According to Brant-Castellano (2004), positivist scientific thought is at odds with Aboriginal ethics because Aboriginal ethics work within an ethical, spiritual context, and takes into consideration the social location of participants as well as physical location of the research. Positivist approaches to research neglect to consider the value of Indigenous culture, artifacts, medicine knowledge, art, and relationships with nature, animals, and any other material or immaterial dimension of Indigenous knowledge and intellectual property. As illustrated in the survey, Indigenous health research is not a single disciplinary field but a balance of four dimensions and is interrelated with culture, nature, and people. Health research that does not include people (such as the secondary data analysis) but discusses Indigenous people, culture, and heritage should be addressed with health research ethics guidelines and controlled by Indigenous communities.

No dimensions related to the social, cultural, economic, political, artistic, and natural way of living should be separated from Indigenous community experiences. All dimensions of knowledge and knowledge-building are relevant to the process of rebuilding confidence and removing barriers to self-determination and recovery.

Indigenous intellectual property and knowledge should be protected including “Language, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples” as Brant-Castellano describes in the Principle 4 (Brant-Castellano, 2004, pg. 110). Effective ways to design protective norms and modify public policy that affirm the rights of Indigenous peoples on their knowledge should be a topic included in health research courses. Perhaps this element is not common sense in the Western scientific world, where there exist two groups of knowledge developers: those who create the knowledge (the owners), and the subjects or participants of the research from whom knowledge is extracted. Because ethical health research guidelines mandate Indigenous community participation, Indigenous communities cannot be considered “objects” of or “subjects” in health research. With this epistemological

shift, it is not possible to design and conduct health research with researchers who place themselves solely in the role of “expert” and expect them to be objective judges of ethical research processes. Indigenous people are the only experts on issues affecting them, and on applying, developing, and adapting their own knowledge to resolve current and potential needs. Indigenous health concerns are better understood when the historical and current health systems imposed on Indigenous communities are understood as the socio-cultural, political, and economic causes of these concerns.

Even though immaterial, material, community, and participatory knowledge is protected by Indigenous communities, the survey showed that the way knowledge is transferred back to Indigenous communities continues to reproduce “expert-novice” dichotomies and knowledge-power positions where Indigenous peoples are positioned as beneficiaries and consumers of Western knowledge. Instead, the power attached to knowledge should be returned to Indigenous communities thus insuring that intellectual property is protected and the role of Indigenous communities in creating ethical standards should be considered as experts (See principle 5 and 6, Appendix C).

Respondents use a complexity of ethical guidelines that include several levels of accountability. On one hand there are federal, regional, and local government agencies, universities, research centers, non-governmental organizations, and private organizations that design, negotiate, and establish ethical relationships with Indigenous communities in multiple ways. On the other hand, Indigenous communities—with their own rights to self-determination, and their own levels of government and organizational structures—need to be addressed, involved, and consulted as experts on their own culture. Brant-Castellano not only included ethical standards and guidelines, but also invited the participation of Indigenous peoples on ethics boards and other decision-making bodies that reside in institutions, research hospitals, universities, and laboratories. Legislation to support greater Indigenous inclusion in the ethics review process may improve the way Indigenous health research is conducted.

Survey responses suggested that reasons be explored as to why there is pressure placed on researchers to observe project deadlines and apply for grant funding. The need to develop research that directly includes Indigenous peoples in the pre-approval planning phases of

research projects was an issue brought up by researchers in the qualitative portion of this study. This situation should be further explored in terms of grant applications, funding, and other institutional contexts that put undue pressure on Indigenous populations to work within institutional timelines and frameworks. Institutional pressure could directly affect the process of designing Indigenous community health research. Often operating under short deadlines, researchers indicated there is often not enough time and resources to create and develop enduring relationships with Indigenous communities. In order to apply for grants and research resources, preliminary connections and meetings with communities are often cut short in favour of meeting timelines for obtaining letters of consent agreements; or participation is limited because not enough time is allotted for Indigenous participation in the beginning stages of project design. Grants that are specifically designed to build relationships with Indigenous communities without the pressures of defining a project, area, specific interest, or concern in relation to an institutionally-imposed timeline would open opportunities for both Indigenous peoples and health researchers to develop long-term research relationships.

Community consultation requires time and resources that need to be included in the budget planning of health research (Brant-Castellano, 2004, pp. 112). As illustrated in the survey, community health research can be a fertile area for flexible approaches to Indigenous health research. By taking a flexible approach, an Indigenous community can be involved in a case-by-case basis, depending on their needs and interests in an evolving process. This epistemological approach ensures that research practices respect Indigenous knowledge and culture and responds to Indigenous authority and priorities. In this sense, ethical guidelines currently in use can be improved by specifically defining Indigenous community involvement, particularly with respect to research design and the ways in which health researchers conduct, evaluate, and store Indigenous knowledge and data, while practicing the principle of Indigenous ownership. This approach would allow institutional and researcher involvement to work respectfully with the complexities of Indigenous health research ethics.

Flexible data approaches can facilitate the inclusion of multiple perspectives and persons. In this respect, researchers who engage in Indigenous health research reported mixed methods and qualitative studies as the most commonly used methodologies because the flexibility they offer. However, this prevalence may be due to the predominance of health promotion and mental

health researchers as the principle investigators on Indigenous health research projects. Other health studies based on the spectrum of the health disciplines may include qualitative research as a part or secondary source of evidence. The mandatory requirement to involve community, knowledge, and Indigenous people's voices in health research could be easily addressed by a research designed using mixed methods, while health research designed to gather quantitative data exclusively may leave out the richness of other data sources.

Training of health researchers is a shared responsibility of government funders, professional associations, research institutions and individual researchers and should be designed and conducted by Aboriginal communities and organizations (Brant-Castellano, 2004, pg. 112). Ethical Guidelines for education play an important role in supporting the transition from prescriptive health research approaches to community-generated healthy knowledge. In this curriculum shift, learning strategies, evaluation, and research methods should take into consideration Indigenous history and current issues affecting Indigenous peoples in Canada. Acknowledging this experience in curricular designs and opening epistemologies, methodologies, and knowledges to Indigenous worldviews would support health professionals to understand and practice the respect and sharing of Indigenous health knowledge. From a top-down to a bottom-up process, and from reality to public policy and law, curricular changes would accelerate discussions and changes on health research that impacts Indigenous communities.

5.1.2. Perspectives of Power and Knowledge in Health Research Education

A major theme of this study focuses on the dynamics of power that are present in relation to health knowledge and health research. Health knowledge produced by Western researchers cannot be neutral because these researchers are immersed in specific social and knowledge systems that are built on Westernized beliefs and prioritize those beliefs and values about science and how research should be carried out. Because knowledge is both a product of social systems and is used to develop strategies for and processes of health care service, this can negatively impact Indigenous communities when the knowledge is based on Westernized ideas and

understandings of health. Because knowledge is developed socially, it connects to social responsibility and social justice principles.

It is important to recognize the interrelationality of knowledge represented by the expression *all knowledge matters* to Indigenous peoples. *All knowledge matters* for Indigenous communities means—from an Indigenous worldview—there is a necessary interrelation between the human knowledge developed (and yet to be developed) in any dimension of knowledge and discipline and culture, nature, humans, and land on which Indigenous people live that must be taken into consideration when working with Indigenous communities around health care. It is not possible to think of a kind of knowledge that is not interconnected with Indigenous communities. The phrase *all knowledge matters*, then, represents a cosmological view of Indigenous interconnectedness that draws on the Indigenous principle of “All My Relations” and the Seventh Generation Principle:

The Seventh Generation Principle is based on an ancient Iroquois philosophy that the decisions we make today should result in a sustainable world seven generations into the future. (Indigenous Corporate Training, 2012, para. 1).

Knowledge represents internalized social systems as well as the power required to build social structures, institutions, languages, and other systems in current western societies. Individuals located within these systems build processes, set public policy rules, allocate resources and work with knowledge-power dynamics and social structures built on socio-cultural beliefs and actions. The reproduction of power-knowledge systems translates into fixed policies and rules designed by a few “agents” who interpret legal, social, moral, religious, economic, and-political values and ideals. Person-to-person relationships grounded in those social systems frequently disconnect people from their own possibilities, self-determination and options in life, because the knowledge and power used to create structures and systems are based on Western values and knowledge that is homogenous. Access to structures and systems is typically limited to a few privileged people (usually White researchers) who use resources (laws, land, nature, money, and ownership of goods) as strategies to control and reduce the possibilities of interaction. This

approach controls reality in a prescriptive way that imposes power and knowledge on individuals and communities instead of welcoming diversity of approaches and perspectives.

The complexity of health systems operates within the dynamic knowledge-power system that is ruled, controlled and delivered through language. In this sense, neologisms are tools to deconstruct and move cultural representations beyond the status quo. New words, meanings, and representations produce dynamics that change reality in the same way that neologisms can be built, shared, and piloted within culturally safety learning environments. For individuals, the dynamics of neologisms may transform cultural representations, public policy, systems, and system dynamics in health research and health care guided by Indigenous ethics. With this, power, knowledge, and access to systems, is shared with Indigenous communities. Knowledge is intrinsically attached to social accountability. The task then, is to develop new health knowledge that is located outside of this power-knowledge system and is grounded in scientific knowledge that addresses Indigenous community struggles where they must cope with the pressures that Western social-scientific knowledge systems have imposed on their bodies and lands.

This reflection on power-knowledge dynamics draws on an intermediate theoretical approach to move research from a purely theoretical perspective towards practical and transformative action. However, it is necessary to recognize the importance of discursive practices in the production of knowledge. This study deals with middle level concerns that construct the content of frameworks by putting conceptual spaces and practical transformative approaches into action. (Leff, 1987).

In the next section, I explore health research and ethics from a power-knowledge perspective (Foucault, 1972), where the rhetoric of discourses, concepts, knowledges, and shared stories construct knowledge as a tool for practical living and the transformation of reality. As such, the context in which the discourses and content are produced and the impacts of them on the practice that are included in the framework (Foss & Gill, 1987) will be presented. Specifically, the survey results will be examined in relation to how respondents talked about discursive practices, rules, roles, power, and knowledge of health research.

5.3.2.1. Discursive Practices and Pedagogomologies

The analysis of discursive practices is a key concept in this study because health research, knowledge translation, and knowledge mobilization rely on discursive practices to create a scientific apparatus of health. According to Foucault (1972), discursive practice can be understood as a statement (knowledge) that follows rules or has passed the appropriate tests to be considered “true” in a culture. When a person says, “It is the rainy season,” or, “It is flu season,” these are not discursive statements. However, when a doctor, a nurse, or any medical personnel says, “It is the rainy season,” or “It is flu season,” whether in private consultation, through an advertisement, or from the position of being a health authority or working in a hospital, then the statement is judged *to be true* because of the power attached to the source of knowledge. This is a discursive practice. A discursive practice can be presented as truth in many ways through verbal and non-verbal forms of communication and by actions. The use of the safe spaces for education may inform the guidelines in Chapter 9 of the *Tri-Council Policy Statement* for example, or the way social relations are promoted and understood.

Perhaps the main conflict between Indigenous ethics and the way research is conducted by non-Indigenous Western health researchers is that Indigenous ethical guidelines lack power and authority, and for example, can be treated as “optional” or “external” guidelines. Non-Indigenous health ethics become discursive practices while Indigenous ethics are informed by culture, and community and individual approaches based on the principles of self-determination, which are often not included in the discursive practices related to Western education or the research practices and processes non-Indigenous persons researchers who engage in Indigenous health research.

The second part of the survey was designed to inquire into whether health researchers considered current discursive practices to be “true.” Survey results demonstrated that this is not the case. For health researchers who receive public funding, and for those who hold grants from private institutions that follow the TCPS-2 guidelines, it is mandatory that they closely follow the TCPS-2 ethical guidelines. In the survey, while some researchers stated that they viewed Chapter 9 of the *Tri-Council Policy Statement* as a mandatory approach to research with Indigenous populations, others reported that they relied on protocols produced through agreements with

Indigenous governments, individual connections, institutional relationships, or utilized practices that were grounded in other levels of relationality. There is a possible disconnect between what one *says* (the rule, the TCPS-2) and what one practices (other personal, local and contextual levels of agreements, protocols, and guidelines).

Because of this, Chapter 9 of the *Tri-Council Policy Statement* is at risk of being considered a theoretical document and a vague set of mandatory rules on paper. However, these guidelines must be translated into practice through real actions and real connections. In the survey, a high percentage of participants found the guidelines unclear. This could be due to unclear writing in the document; lack of training; lack of knowledge about current socio-economic conditions Indigenous people face; or lack of the inclusion of Indigenous paradigms and teachings, some of which were characteristics that were perceived by participants as weaknesses.

Why may Chapter 9 fail to define Indigenous health research ethics? Indigenous ethics can be enforced institutionally but must be done so by Indigenous communities and Indigenous authorities. (Brant-Castellano, 2004). Control of the correct use of ethical guidelines should be addressed properly by the inclusion of Indigenous voices and perspectives in health research education and in the design(s) and practice(s) of health research.

Those participants who are not familiar with Indigenous knowledges and systems also indicated that ethical guidelines were not completely clear. The lack of training and knowledge about Indigenous culture was evidenced in the low level of agreement on this category. For example, in relation to community participation, even though health researchers declared that they involved Indigenous communities in research, their concept of involvement was typically grounded in a Western definition of participation in the form of obtaining signed legal documents or consent forms, or worse, included only partial participation of Indigenous people in the research process and a lack of deep engagement with Indigenous communities' perspectives.

5.3.2.2. Rules

The second principle of Foucault's notion of discursive formation is the rule that defines how a discursive formation, episteme, or way to acquire knowledge, is formed. This rule can be implicit or explicit and defines how knowledge should be presented to reach the status of discursive

formation (Foucault, 1972). Some rules control acceptable topics of conversation, provide certain individuals with the authority to speak, and regulate the conditions under which specific discussions can take place.

In this highly regulated field, health researchers, government authorities, communities, agencies, institutions, and insurance and pharmaceutical companies impose guidelines, norms, and processes on Indigenous people and communities, and health research is highly controlled by Western public research procedures. The first rule is that knowledge is attached to the power of the health researcher because it is based on evidence they “discovered.” If new knowledge is considered true in health research, it is recommended as a pathway to other knowledges and is validated by other health researchers. Indigenous people who are experts on their own reality but possess knowledge that is not based on Western theoretical models of evidence, cannot access this system of validation and are subsequently excluded from decision-making in relation to their own health because of the clash of two systems of validation.

Health research ethics may have this effect. For instance, an individual who follows ethical research “rules” or regulations is considered an “authority” and can be placed in a position of power over aspects of Indigenous community health; directly contradicting the aim of ethical guidelines. Indigenous persons are then denied the ability to be experts on their own issues and the prescriptive model of Western science is imposed as a solution. This imposition upsets the balance with other dimensions of health, perpetuating the destructive system of knowledge-power imposition. As I argued previously, Indigenous knowledge and ethics do not need validation by Western systems and health researchers or practitioners. It is imperative that health researchers adhere to Indigenous ethical guidelines and empower Indigenous communities in health research to disrupt health research rules that perpetuate harm and introduce new processes of colonization.

The lack of involvement of Indigenous communities in the conceptualization of health research and participation in the data analysis stage is also indicative of some of the ways that Indigenous knowledges are excluded. This restricts Indigenous health experts from achieving the same status and respect as non-Indigenous persons who engage in Indigenous health research. These dynamics and the constant imposition of Western health systems on Indigenous communities

affects Indigenous peoples' capacities to discuss, define, transform, and improve their systems of well-being.

Self-identified as non-Indigenous heritage health researchers, institutions, and government can wrongly consider Indigenous health research ethics as a threat to current systems of power. However, by practicing research according to the principles of Indigenous health research ethics and supporting healthy Indigenous communities, researchers and institutions may facilitate restitution and reconciliation with Indigenous communities.

5.3.2.3. Roles

The third aspect of Foucault's discursive formation is the nature of roles prescribed according to power dynamics and knowledge systems (Foucault, 1972). Roles within a prescribed discursive system also define the discourse. Beyond person-to-person-interactions, roles can be analyzed as structures that guide knowledge, and include a set of rules, relationships, and practices that replace people in positions of authority with the knowledge itself. Scientific knowledge is attached to the specific role of the health researcher. According to the rules of "scientific knowledge," new knowledge must meet quality and evidentiary standards based on a set of rules and strategies that attempt or "pretend" to detach the "product" from knowledge producer. This is the myth of objectivity. Frequently, to meet objectivity requirements, knowledge must remain neutral and disconnected from the community and social impact of the use of the knowledge.

The myth of objectivity in health sciences is a natural step towards constructionism (Wilson, 2000). With this perspective, medicine falls under the false pretense of positivism, viewing disease as similar case to physics and natural approaches to "phenomena". Tools of knowledge-building such as randomized controlled trials, experimentation, or biochemical research, receives more funding than "soft" research based on community and qualitative interventions.

Constructivism as an emergent paradigm offers new perspectives on doctor-patient relationships and research evidence.

Because biomedical perspectives build discursive practices, rules, roles, knowledge-power systems, ethical guidelines play an important role in Western health research. If the role of a health researcher is to follow ethical guidelines as a distant and rational check list, then those

ethical guidelines are irreconcilable with Indigenous ethics that require personal involvement, integrity and actionable research projects designed in partnership with Indigenous communities: good relationships. A research-community relationship is severely damaged when health researchers do not know, acknowledge, practice, share, honor, or respect the mandate(s) of Indigenous ethics. To do this requires deep and ongoing self-reflection and a vigilant assessment process to ensure research is purposeful and beneficial to Indigenous people. If health researchers ignore Indigenous knowledge and ethics and continue to apply rules, processes, and discourses of health research based on the imposition of Western scientific norms, they will encounter resistance from Indigenous communities. Therefore, it is of great importance to examine ideologies that position certain people in roles of power in relation to appropriating Indigenous health perspectives when discussing the health of Indigenous populations.

5.3.2.4. Power

In Foucault's (1980) theory, power is conceived as a set of rules, systems, and processes, which control relationships in discursive formations. In this research, these dynamics correspond to disciplinary power; a set of rules that may define health knowledge through the differentiation between knowledge, opinion, community beliefs, philosophy, and culture. What is also interesting here is that health can be defined as a multilevel concept studied from multidisciplinary perspectives. Western science puts forward mono disciplinary approaches to health and health services, where health defined only as the biological absence of illness or as the "silence of the organs." As evidenced in the survey, this power is strongly enforced by the culture of health research, which requires researchers to follow discipline-specific approved and controlled approaches in order to have their work considered academic or "real" knowledge.

Health researches may use Western ethical guidelines that perpetuate current ways of doing things according to norms that authorize who can conduct health research and who cannot, as well as regulate research involving animals, new drugs or treatments, or new technologies. Those ethical guidelines are defined by authorities for the safety of participants, and to prevent possible cases of malpractice. These guidelines work both ways: they protect the public but also protect institutions and health researchers. By transforming the discursive formation of power attached to this field, health and health care may be redefined by including multilevel interactions and

dimensions within local, regional, and global contexts that may not necessarily be based on Western scientific methods. When this occurs, health research power is then extended to more diverse people, values, ethics, and practices.

Power is attractive, not only because it controls what cannot be done, but because it also allows those who hold power to do things under a regime of authorized knowledge. This power frequently accumulates through discursive formation instead of being crystalized in visible, explicit rules. In the discourse of power and knowledge, Indigenous health research ethics aim to shift the exclusive power of knowledge production from health researchers back to Indigenous peoples. This is an enormous change that requires considerable reflection about how we currently consider and define health knowledge and health research.

5.3.2.5. Knowledge

According to Foucault (1980) knowledge is anything that is claimed as “true” about a given object, subject, idea, or thing. As knowledge is a result of all other aspects of the discursive formation, knowledge involves a person in a position of power, who prescribes knowledge according to specific rules, and builds discourses that are held as true. In Western health research ethics, knowledge is “acquired” by the health researcher, who gains power by acquiring knowledge through the study and practice of the methods and rules of a health discipline, and who can code or decode discursive formations.

However, knowledge-as-power differentiates between what is considered and valued knowledge and what is not. What is considered knowledge is the knowledge that follows the logic of Western thought. What is not considered knowledge is historically defined as cultural, personal, representational, irrational, or superstitious knowledge from “less sophisticated” cultures. In the case of Indigenous health ethics, knowledge is self-validated. Indigenous knowledges do not require interpretation or testing to be considered valid knowledge. This can be a significant obstacle for non-Indigenous persons who engage in Indigenous health research who would like to partner with Indigenous communities in an ethical way yet are conflicted because Western health research practices dictate that knowledge be interpreted, tested, and validated.

As knowledge is also controlled through the methodologies applied to it, non-Indigenous persons doing Indigenous health research may have trouble applying Western logic and rules to create health knowledge with Indigenous communities. Indigenous logics and knowledge validation reside in practical, traditional, and ceremonial community knowledge. Focusing the discussion on knowledge and power may be a way to facilitate the transfer of these dynamics from the exclusive possession of researchers who engage in Indigenous health research to Indigenous communities so that they may control, access, possess, and use the knowledge.

5.3.2.6. Health Knowledge as a Commodity

All previous dimensions of the discursive formation interact within globalized and localized economic frameworks, where health knowledge is considered a commodity. In our society, health is an economic system like any other, and the economy of health is based on returns, investments, capital, profit, income, and interactions according to the balance of investment, cost, and profit. In the health economy, knowledge, power, roles, rules, and discursive formations are considered from the perspective of business. Health research becomes an activity that “should” inform and react to the health economy by installing systems of control at the local, provincial, federal, national, and international levels. From this perspective, health knowledge is considered as an asset, and health researchers are evaluated by the product, innovation, marketable ideas, and technologies they can produce.

“Knowledge as an asset” is a frequently coined discourse highlighting the fact that money plays a key role in health, healthcare, and health research. This is not to deny that systems require proper resources, however, not all systems are based on empowerment and self-determination as their main principles, and health research is frequently considered an investment. In health research ethics, the economic aspects of knowledge and power dynamics should also be addressed because Indigenous health research—by attempting to alleviate Indigenous community health concerns—should not be considered an activity aimed at producing profit for investors or companies.

Health research, as dictated by the principle of control, should reside with Indigenous communities, by detaching the knowledge and power assigned to health researchers and passing it to Indigenous peoples and communities. From this perspective, health knowledge and well-

being are inconsistent with the view of health as a commodity. As Webb (2018) states, the current Evidence Based Medicine (EBM) approach strongly favors empiricism instead of rationalism. This approach privileges “doing” versus theory reflection, but in practice methods of interventions are the same. Webb argues for a new synthesis based on the Galenic approach, where the best physician is a rationalist as well as an empiricist. Webb makes a case for a Galenic shift toward a more epistemically-balanced, scientific approach to clinical research. Webb (2018) states:

... consider the patient who—in a competent and informed state—rejects one treatment in favor of another less supported by the experimental literature. Granted that many proponents of EBM make room for *a priori* ethical principles such as patient autonomy, how would the committed empiricist be able to accommodate the principle of patient autonomy at all? (pp. 7).

A new synthesis of knowledge is required to move evidence-based medicine towards science-based medicine (Gorski and Novella, 2014). Gorski and Novella (2014) postulate that, building on Galen, leaders in academic medicine should take up empirical and rationalistic methods to generate an epistemologically supported perspective. In medicine and health classes, possibilities for discussion and experimentation with new perspectives of knowledge, and social transformation within health research systems are required as part of new knowledge frameworks.

New pedagogical perspectives on health research education should create safe and interconnected opportunities to develop individual and collective knowledge and practice that is grounded in Indigenous knowledges and uses respectful dialogue. A safe environment incorporates a multilevel approach to knowledge promotion, construction, and sharing in relation to health knowledge and power, and provides space to address current concerns expressed by marginalized communities. These new *pedagogomologies* engage collaborative Indigenous epistemologies for health research education that is immersed in a culturally safe environment for Indigenous and non-Indigenous students, teachers, and communities. Pedagogomologies are alternatives to Western perspectives that allow students access to both epistemologies—

Indigenous *and* Western—in a safe environment. *Pedagogiologies* offer learning designs that are based on healing and relational strengths, and research and knowledge are conceived as services. They connect the community, students, and institutions in transformative ways that are based on Indigenous ethics and can be considered multi-level and complex dynamic systems. These capacity-building practices are considered tools that eschew simplistic approaches to health by creating the opportunity to see health knowledge as intertwined with historical, current, and future Indigenous community concerns.

Multiple ways of teaching and learning from meaningful experiences can be achieved by working with the complexity of learning and social interrelatedness. New ways to teach health research includes teaching dynamic complex systems of health that respond to Indigenous ethical guidelines of health research. *Pedagogiologies* promote diversity, complexity, dynamic system analyses, and ways to understand knowledge based on community perspectives in the absence of power conflicts. Land-based education is fundamental in a pedagogiology to create meaningful experiential learning in connection with the self, others, nature, that is synchronous with the temporality (historical, present, and future) of human nature, and with an awareness of the complexities of Indigenous socio-determinants of health perspectives. The pedagogiological nature of learning I propose does not rely on the biology-nature deterministic perspective proposed by Kovac (2013), who argues that “biopedagogy” is a process of learning and teaching that draws on the biology of a given person and is pre-determined by natural laws of reinforcement, imprinting, and cultural modeling.

Instead of using reductionistic approaches to teaching and learning, pedagogiologies work with the infinite potential of human nature. They harness our capabilities to observe, transform, and produce cultural *relational artifacts* resulting from interactions between people and nature which involve knowledge, cultural laws, public policy, cultural representations, language, and creative, hybrid processes of knowledge. Pedagogiologies include learning from ourselves and others, from nature and culture, from Elders and novices. Land-based learning and experiential learning are considered main approaches to promote the Indigenous ethical principles of self-determination and to understand and incorporate the richness of Indigenous cultures and knowledges. A pedagogiological approach includes transformative relationships of doing,

experiencing, naming, and shifting health research, health education, and health practice to an Indigenous relationality with the world.

5.4. Limitations of the Study

This survey produced exploratory data that was expected and pointed towards a need to continue with phase 2 of this research. In this research, the understandings are not considered conclusive nor considered comprehensive knowledge.

Because the method and research perspectives in this research were drawn from a community process, the method was also flexible. The research team shared their desire to know “what is out there in this field.” It was perceived that the ethics of Indigenous health research is a complex field, highly controversial, and replete with high levels of uncertainty. As such, a multi-phase research strategy was required to explore the topic of Indigenous health research. Based on salient topics or themes that emerged from the survey, a second phase of research will be conducted to explore in detail ethical guidelines of Indigenous health research. The present report contains the first phase of this community-based process and the results of the initial survey.

There are some restrictions identified in relation with the target population, the method, and data analysis of the present study. This study included the perceptions of Indigenous self-identified persons and non-Indigenous heritage health researchers in the field of Indigenous health research. The field of Indigenous health research is understood from the perspective of the Institute of Aboriginal Peoples’ Health (2017) in engaging First Nations, Inuit or Métis communities, societies or individuals but secondary data analysis studies are not included. Ethics approval for secondary data analysis research is not mandatory and falls in another category within ethical boards because it is analysis “on data” exclusively and not with “people.” This affects the survey research because secondary data collection was not included in any of the survey questions. This topic could be included in the second phase with the recognition that the survey did not explore that dimension of ethical research.

A group of limitations of this study relates to the type of study selected. Descriptive studies cannot investigate cause and effect conditions of variables or follow changes in the population

over the time if they are not part of longitudinal studies (Denzing and Lincoln, 2000). Thus, the conclusions from this research should be taken as a descriptive contribution that may shed further light on the field of the ethics of Indigenous health research.

The online survey data collection method selected for this study presents some restrictions. As the online survey included mainly quantitative questions, knowledge generated by quantitative analysis can be considered incomplete compared with personal stories, arguments, and individual perceptions that required qualitative strategies are added. Here, the quantitative data should be considered as the numeric abstraction of thought and reasoning of the participants present in this exploration and not as definitive “truth”.

The survey instrument also represented some challenges. Limitations with population sample size, and systematic follow-up with participants could be improved for future research. One recommendation would be to the design, update, and ongoing management of a National Database and Community of Health Researchers as a strategy to facilitate future research. Having a national database from which to draw for research purposes—longitudinal research—would also ensure the representation of all levels of health researchers involved in Indigenous health research.

Other limitation refers to non-coverage error of the sample selected as not representative of target population. (Aday 2006). Currently there is no Canadian database of health researchers conducting Indigenous health research thus we do not know, for example the total number of researchers who engage in Indigenous health research. The National Collaborating Centre for Aboriginal Health (NCCAHA, 2014) has the most recent version of a list of health researchers working in the field of Indigenous health research, but this list does not include all active researchers in Canada. Additionally, there is little information about previous surveys in the field of Indigenous health research, making difficult to support this research based on evidence from previous surveys.

As a strategy to define a target population for this study, a pre-screening of health researchers who publish health research was conducted. However, this strategy only included the main health researchers. Co-authors, secondary authors and affiliated researchers were not included in the database. Combined with a target defined population and sample, the survey was widely

offered through social and research networks for participation by all health researchers not involved in the initial database. This situation made it impossible to track if the target population was included due to “spontaneous” health researchers’ participation.

The anonymity granted in the survey make impossible to match any respondent with specific responses or trends and it is a restriction of the representation of the sample because of the self-selection bias: specifically the possibility that some health researchers that are motivated to share and participate in the study will be over represented in contrast with other not self-motivated to participate in the online-survey (Aday, 2006).

Additional limitations were controlled in this study: the non-response bias was eliminated because all respondents are highly educated making them familiar with survey research strategies, and level of technical expertise was minimized by simplifying the survey design and access.

Because of these limitations, this research must be considered as an exploratory project and conclusions drawn from this survey need to be understood as in this context. While this sample is limited to published researchers, many health researchers distribute their findings outside of commonly accepted methods of knowledge dissemination. Due the nature of the questions and the intent of the research group, caution should be taken to not generalize the results.

5.5. Recommendations for Future Research

As indicated previously, recommendations for future research were made based on the results of this survey. This section includes a brief discussion about three possible changes that could improve future methods for this kind of research.

First, it is necessary to establish a supportive community network of Indigenous researchers in order to increase visibility of this work, share resources, and foster collaboration and support. Such a community would also be a growing research resource, both in Indigenous health and with the ethics of Indigenous health research.

Second, it would be important to duplicate this study in different Indigenous communities around the world, such as Australia, New Zealand, as well as in countries in Central and South America.

Duplicating this study in other countries may uncover parallels and differences in Indigenous peoples' colonial experiences and current struggles.

Third, it would be useful to have systematic data collection on health researchers' perceptions of ethical guidelines for Indigenous health research. This would allow the investigation of any changes and developments among this community, which could be useful in informing both government and higher educational initiatives relating to Indigenous health.

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Appendix A: Structure of the Survey

Part A: General Section

Please answer the following questions based on your own experience, knowledge, and beliefs.

1. When have you done research with Indigenous Peoples? (Check all that apply)
 - a. Currently
 - b. In the past
 - c. Planning to in the future
 - d. Never
2. How long have you been researching with Indigenous Peoples?
 - a. 0 – 5 years
 - b. 6 – 10 years
 - c. 11 – 20 years
 - d. 21 + years
3. What is your research discipline with Indigenous Peoples? (Check all that apply)
 - a. Genetics/Biomedical
 - b. Medical/Diseases
 - c. Mental health
 - d. Nutrition/Dietetics
 - e. Dental studies
 - f. Pharmacology
 - g. Health promotion/Community health
 - h. Epidemiology
 - i. Social determinants of health
 - j. Environmental health
 - k. Other (type)
4. What type of research do you do with Indigenous peoples? (Check all that apply)
 - a. Quantitative
 - b. Qualitative
 - c. Mixed Methods
5. Are you currently doing community-based research?
 - a. Yes
 - b. No
6. Have you ever done community-based research?

- a. Yes
 - b. No
7. Do you intend to do community-based research in the future?
- a. Yes
 - b. No
8. Does your research with Indigenous Peoples include community partners?
- a. Yes
 - b. No
9. If (8a) Yes. How do you describe your relationship with community partners?
- a. Very close
 - b. Close
 - c. Neither close nor distant
 - d. Distant
 - e. Very distant
10. If (8a yes) At what stage(s) of the research process do you involve community partners?
(Check all that apply)
- a. Pre-project consultation
 - b. Proposal
 - c. Data collection
 - d. Data analysis
 - e. Dissemination
11. If (11a) Yes. On average how often do you meet with your community partners on each project?
- a. Once a week
 - b. Once every two weeks
 - c. Once a month
 - d. Once every three months
 - e. Once every six months
 - f. Once every nine months
 - g. Once a year
 - h. Other _____

12. What is the typical length of your research projects?
- Less than one year
 - 1 - 2 years
 - 3 - 5 years
 - 6 - 7 years
 - 8 – 9 years
 - 10 + years
13. How do you disseminate your research? (Check all that apply)
- Journals
 - Academic conferences
 - Community meetings/ Workshops
 - Policy documents
 - Newsletters/Brochures
 - Executive/Research reports
 - Media releases
 - Other (type)
14. What Indigenous Peoples are included in your research? (Check all that apply)
- Inuit
 - First Nation
 - Métis
 - Other (type)
15. What is the geographic location/source of data collection in your research? (Check all that apply)
- On reserve
 - Off reserve
 - Rural
 - Urban
16. In what province/territory/geographic area do you focus your research? (Check all that apply)
- British Columbia
 - Alberta

- c. Saskatchewan
- d. Manitoba
- e. Ontario
- f. Quebec
- g. New Brunswick
- h. Newfoundland and Labrador
- i. Nova Scotia
- j. Prince Edward Island
- k. Yukon
- l. Northwest Territories
- m. Nunavut
- n. Outside Canada (type)

17. What is the typical age group of the Indigenous peoples involved in your research?

(Check all that apply)

- a. Prenatal (0 year)
- b. 0 - 12 months
- c. 13 - 24 months
- d. 3 – 6 years
- e. 7 – 11 years
- f. 12 – 19 years
- g. 20 – 34 years
- h. 35 – 44 years
- i. 45 – 64 years
- j. 65 + years

18. Where do you find participants for your research? (Check all that apply)

- a. Aboriginal organizations
- b. Non-Aboriginal organizations
- c. E-mail listserv
- d. Social media (Facebook, twitter, Instagram)
- e. First Nations
- f. Word of mouth

- g. Recruitment agencies
- h. Reserves
- i. Hospitals
- j. Universities/Colleges
- k. Schools Boards (Non-Aboriginal)
- l. Schools Boards (Aboriginal)
- m. Paid Advertisements
- n. Other (type)

19. What is your ethnic background/identity?

- a. Indigenous
- b. Asian/Pacific Islander
- c. Withe/Caucasian (Non-Hispanic)
- d. Latino or Hispanic
- e. Black/African American (Non-Hispanic)
- f. Arab
- g. Multiracial
- h. Other (specify)

20. If (19=a). What is your Indigenous identification?

- a. First Nation (Status or Non-Status)
- b. Métis
- c. Inuit
- d. Other (type)

Part B: Ethical Guidelines

The following questions are regarding your knowledge of the Ethical Standards and protocols for conducting research involving Indigenous peoples. Please answer each question based on your own experience and knowledge.

1. Which national ethical guidelines do you following your research with Indigenous peoples? (Check all that apply)
 - a. Tri-Council Policy Statement (TCPS) Best Practices

- b. Tri-Council Policy Statement (TCPS-2) Guidelines for research involving First Nation and Métis people in Canada
 - c. Ownership and Control Access and Possession Principles (OCAP™)
 - d. Canadian Institute of Health Research (CIHR) Guidelines for involving Aboriginal populations
 - e. Social Sciences and Humanities Research Council (SSHRC) guidelines for doing research with Aboriginal populations
 - f. Other (type)
2. Choose the best option that describes your opinion of the ethical guidelines you identified as following in question B1 (Strongly Agree, Agree, Somewhat Agree, Somewhat Disagree, Disagree, Strongly disagree)

Current ethical guidelines I follow:

- a. Offer enough information to design and conduct ethical research with Indigenous Peoples.
- b. Are easily accessible.
- c. Clearly state how to conduct ethical research involving Indigenous Peoples.
- d. Are easily applied in my research projects.
- e. Are clear and easily understood.
- f. Enhance my understanding of Indigenous paradigms and worldviews.
- g. Meet the ethical needs of Canadian Indigenous communities.
- h. Promote cultural sensitivity.
- i. Are clear for researchers who are not familiar with Indigenous worldviews.
- j. Reflect the current social context of Indigenous Peoples.
- k. Are reasonable and realistic in research involving Indigenous Peoples.
- l. Help to reduce/prevent oppressive and harmful research with Indigenous Peoples.
- m. Are explicit about how to avoid unethical practices involving Indigenous Peoples.

Appendix B: Recruitment Letter

RECRUITMENT LETTER



Are you an (**academic researcher (undergraduate, graduate, post-doc, faculty)/key community informant**) who has engaged in Aboriginal health research of any kind?

I am from the Yellowknife Dene Nation and am currently an Associate Professor in Counselling Psychology at OISE – University of Toronto. I am interested in exploring the strengths and challenges of currently existing Aboriginal health research ethical guidelines and protocols in addressing the ethical issues and needs of Aboriginal peoples in Canada in the context of health research.

To participate in this project you must:

- 1) Have engaged in current or past health research of any type with Canadian Aboriginal peoples.

If you might be interested in **filing out an anonymous online survey**, please contact me by phone or email.

Mahsi – Miigwetch -- Thank you very much!

In Spirit,

Suzanne L. Stewart

Appendix C: Acronyms Used

AHR, Aboriginal Health Research.

CIHR, Canadian Institutes of Health Research.

EB, Evidence-Based.

Four Rs, Dimensions of Respect, Reciprocity, Relevance, and Responsibility.

HIV, Human Immunodeficiency Virus.

IAPH, Institute of Aboriginal Peoples' Health.

IJH, International Journal of Indigenous Health.

JAH, 2014, Journal of Aboriginal Health.

MDM, Medical Decision-Making.

Mdn, Median.

MKT, Medical Knowledge Transfer.

NCCAHA, National Collaborating Centre for Aboriginal Health.

NSERC, Natural Sciences and Engineering Research Council of Canada.

OCAPTM, Ownership, Control, Access, and Possession established by the First Nations Information and Governance Centre (FNIGC).

OFIFC, Ontario Federation of Indian Friendship Centres.

OISE, Ontario Institute for Studies in Education, University of Toronto.

RCAP, Royal Commission on Aboriginal Peoples.

SSHRC, Social Sciences and Humanities Research Council of Canada.

TCP 2, Tri-Council Policy Statement 2015. Chapter 9 of the Policy Statement on the Ethical Conduct for Research Involving Humans of the Panel of Research Ethic.

TEK, Traditional Ecological Knowledge.

TRC, Truth and Reconciliation Commission.

UNDRIP, United Nations Declaration on the Rights of Indigenous Peoples.

USAI, Utility, Self-voicing, Access, Inter-relationality framework developed by OFIFC, 2012.

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