

A decolonizing approach in population health research: examining the impacts of the federal *out for confinement policy* on maternal and child outcomes in First Nation communities in Manitoba

by

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Abstract

Background: This dissertation documents a journey of an Anishinaabekwe student into the space where western and Indigenous methodologies meet. The Truth and Reconciliation Commission of Canada's (TRCC) Call to Action #19, challenges all levels of government to close the gap in measurable maternal and child outcomes. This study employs a decolonizing framework to examine the impact of the federal policy of evacuating women residing in rural and isolated First Nation communities in Manitoba to urban centres to deliver their babies. The overarching goal was to demonstrate how a decolonizing framework and positioning traditional Knowledge Keepers and knowledge at the forefront can inform quantitative research.

Approach and Methods: Decolonizing elements embedded within an Indigenous framework framed the retrospective cohort study by employing an Indigenous framework, a Council of Grandmothers/Knowledge Keepers/Grandmother Advisor to guide the research. A cohort comprising low-risk women residing in Manitoba First Nation communities who delivered a baby between the years 2005-2015 was assembled to compare women who travelled for birth and were subject to the "Out for Confinement" (OFC) policy (the practice of sending women out of their communities for birth) to those women who did not. Population-level administrative data housed at the Manitoba Centre for Health Policy were analyzed using logistic regression models to assess the association between the OFC policy on maternal, infant and child outcomes.

Results: Utilizing an Indigenous framework, this study generated evidence that the present-day colonial OFC policy harms Indigenous women, families, and communities. The OFC policy was associated with increased inadequate PNC (OR 1.64, 1.51, 1.79 CI) and small for gestational age births (OR 1.25, 1.02, 1.50 CI) and decreased breastfeeding initiation (OR 0.55, 0.50, 0.61 CI) and maternal psychological distress diagnoses (OR 0.43, 0.36, 0.51), after adjusting for various confounders.

Conclusion: To answer the TRCC call to improve maternal and infant outcomes, epidemiological and population health research requires epistemological frameworks that adequately incorporate the voices and realities of Indigenous people's lives, while remaining scientifically robust. Decolonizing and Indigenous frameworks are feasible and essential in population health research and do not detract from scientific rigor.

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A Decolonizing Approach in Population Health Research

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Dedication

This dissertation is dedicated to the memory of my dear brother, Little Black Bear Darrell Phillips who lived each day of his life like it was his last. He loved the natural world, he loved life, he loved his wife, he loved his family and he loved, above all, God our Creator - heart, and soul. He was a powerful force and a constant presence in my life until he passed into the spirit world in 2017, one year into my studies. I took some much-needed time to heal, reflect on my life course and to learn how to live my life without him.

Table of Contents

Abstract ii

Acknowledgements iii

Dedication v

Note on Terminology x

List of Abbreviations..... x

CHAPTER 1 – Introduction..... 1

1.1 Preface..... 1

1.2 Discerning 2

1.3 Defining the problem 4

1.4 A matter of bias 6

1.4.1 Selection and Information Bias 7

1.4.2 Epistemological bias..... 10

1.5 Discussion 13

1.6 Conclusion..... 17

References 19

CHAPTER 2 - Mapping..... 22

2.1 Preface..... 22

2.2 Introduction 23

2.3 Terminology first: Methodology, Conceptual Frameworks, and Methods..... 25

2.4 The emergence of decolonizing and Indigenous Methodologies..... 26

2.5 What are decolonizing and Indigenous methodologies?..... 29

2.6 Decolonizing and Indigenous Methodology and Quantitative Research 31

2.7 The way I learned (aka Methods)..... 33

2.8 Learnings (Findings) 36

2.8.1 Case 1 – Initiatives in Primary Health Innovation and Transformation (iPHIT) program of research. 36

 2.8.1.1 Shifting power and reclaiming governance over research/ meaningful engagement and involvement of Indigenous people..... 37

 2.8.1.2. Relationship building, relationality. 38

 2.8.1.3. Reflexivity/critical reflection and positioning. 39

 2.8.1.4 Context (acknowledgment of the historical, social, political and cultural reality of the people). 40

A Decolonizing Approach in Population Health Research

2.8.1.5 Privileging Indigenous knowledge, voice, epistemology worldview and holistic frameworks.	40
2.8.1.6 Respect/inclusion/acknowledgment of Indigenous culture & protocols.	41
2.8.1.7 Reconceptualization, including knowledge translation/sharing.	42
2.8.1.8 Purpose and implications of research oriented toward benefit for Indigenous people.	43
2.8.2 <i>Case 2 - My doctoral research: A path forward</i>	44
2.8.2.1. Shifting power & reclaiming governance over research & meaningful engagement & involvement of Indigenous people.	44
2.8.2.2 Relationship building, relationality.	45
2.8.2.3. Reflexivity/critical reflection and positioning.	47
2.8.2.4. Contextualization (acknowledgment of the historical, social, political and cultural reality of the people).	47
2.8.2.5 Privileging Indigenous knowledge, voice, epistemology, worldview, and holistic frameworks.	48
2.8.2.6. Respect/inclusion acknowledgment of Indigenous culture & protocols.	49
2.8.2.7 Reconceptualization, including knowledge translation/sharing.	49
2.8.2.8. Purpose and implications of research oriented-toward benefit for Indigenous people.	50
2.9 Mapping decolonizing research elements to Decolonization Action (Discussion).	51
2.10 Final thoughts (Conclusion)	57
References	60
CHAPTER 3 Doing research in a good way: “Mino-doodaman” (The Study)	65
3.1 Preface	65
3.2 Introduction	65
3.3 Methods	69
3.3.1 <i>Indigenous Framework</i>	69
3.3.2 <i>Study Design</i>	70
3.3.3 <i>Cohort development and exclusions</i>	72
3.3.4 <i>Outcome variables and covariates</i>	75
3.3.5. <i>Main exposure predictor variable</i>	76
3.3.6 <i>Covariates</i>	76
3.3.7 <i>Analysis</i>	77

3.4 Results	78
3.5 Discussion	83
3.6 Conclusion.....	89
References	91
CHAPTER 4 – Reflecting on:.....	95
4.1 Preface.....	95
4.2 Introduction	95
4.3 Why is a decolonizing approach needed in quantitative research?.....	97
4.4 Lessons learned	99
4.4.1 Tenet 1 (<i>Listen</i>) <i>Bi-zin-doi-zhen</i>	99
4.4.2 Tenet 2 <i>Weweni anokiin: move forward, working together with good intent</i>	104
4.4.3 <i>Share the research space and resources</i>	105
4.4.4 Tenet 1 revisited - <i>Bi-zin-doi-zhen (Listen inward)</i>	107
4.5 Final thoughts.....	110
References	111
Appendix A - Letter of Permission from HIRGC.....	113
Appendix B - Approvals from University of Manitoba.....	114
Appendix C - Approval letter from HIPC.....	115
Appendix D - Infographic on Decolonizing Strategies.....	116

List of Tables

Table 1 - Synthesizing the common decolonizing elements of 3 prominent sources.....	34
Table 2 - Mapping decolonizing research elements to Hart's Decolonization Actions	35
Table 3 - Variable descriptions and definitions	75
Table 4 - Regression models and covariates included in model.....	78
Table 5 - Characteristics and differences between mothers (both First Nation/non-First Nation) who had a live birth and residing in First Nation Communities in Manitoba 2005-2015	78
Table 6 - Odds Ratios of each outcome variable by presence of OFC Policy in First Nation Community 2005-2015	79
Table 7 - a) Model 1: Odds of Inadequate PNC and covariates	80
Table 8 - b) Model 2: Odds of Breastfeeding Initiation and for covariates.....	81
Table 9 - c) Model 4: Odds of maternal psychological distress and for covariates.....	82
Table 10 - d) Model 6: Odds for Small Gestational Age and covariates.....	83
Table 11 - <i>Decolonizing Strategies for Quantitative Research Design</i>	109

List of Figures

Figure 1: Manitoba Centre for Health Policy Population Research Data Repository.....72
Figure 2: Cohort Tree.....74
Figure 3: The Intersection of western research process and decolonizing research space.....108

Note on Terminology

Indigenous/Aboriginal: In this dissertation, I use the term “Indigenous” when referring to the broader original peoples native to the lands of Canada, New Zealand or Australia. I use the accepted term “First Nation” to refer to one of the three recognized Indigenous Peoples in Canada (First Nations, Métis, and Inuit), who have registered Indian status recognized by the federal government in Canada. However, where citations or references use other nomenclature such as “Aboriginal”, the original text or reference has been retained.

Elders/Knowledge Keepers

Indigenous Elders and Knowledge Keepers play a central role in Indigenous communities. They are both regarded as teachers within and beyond their communities, and the terms Elder and Knowledge Keeper are often used interchangeably. They have been gifted with their respective teachings by other Elders or Knowledge Keepers, typically over years of mentorship and teaching. The term "Elder" is bestowed to an individual by their community because of the spiritual and cultural knowledge that they hold. The term does not refer to one's age, but rather the level of cultural and traditional knowledge they hold.

The term "Knowledge Keeper" or "Traditional Knowledge Keeper" refers to someone who has been taught by an Elder or a senior Knowledge Keeper within their community. This person holds traditional knowledge and teachings and they have been taught how to care for these teachings and when it is and is not appropriate to share this knowledge with others.

<https://www.queensu.ca/indigenous/ways-knowing/elders-knowledge-keepers-and-cultural-advisors>. In this dissertation, I use the term Knowledge Keeper to identify those teachers whose name has been bestowed on them by the Indigenous community in Manitoba. The term “Elder” is used where the citation or text includes such terminology.

List of Abbreviations

ACSC	Ambulatory Care and Sensitive Conditions
CBPHC	Community Based Primary Health Care
CFS	Child and Family Services
CIHR	Canadian Institutes of Health Research
FNHSSM	First Nations Health and Social Secretariat of Manitoba
FNIGC	First Nations Information Governance Centre
FNIGRC	First Nation Health Information Research Governance Committee
HBB	Healthy Baby Benefit
HIPC	Health Information Privacy Committee
HREB	Health Research Ethics Board

A Decolonizing Approach in Population Health Research

ICT	Information and Communication Technologies
iPHIT	Initiatives for Primary Healthcare Innovation and Transformation
IRP	Indigenous Research Paradigms
IRS	Indian Registry System
LRA	Local Research Assistant
LGA	Large for Gestational Age
MCHP	Manitoba Centre for Health Policy
NO	Northern
OCAP	Ownership, Control, Access, Possession
OFC	Out for Confinement
OR	Odds Ratio
PM	Prairie Mountain
PNC	Prenatal Care
RCAP	Royal Commission on Aboriginal Peoples
Repository	Manitoba Population Research Data Repository
RHA	Regional Health Authority
SO	Southern
SGA	Small for Gestational Age
TLs	Tolerance Levels
TRCC	Truth and Reconciliation Commission of Canada
UN	United Nations
UNDRIP	United Nations Declaration of the Rights of Indigenous People
UNESCO	United Nations Educational Scientific and Cultural Organization
VIFs	Variation Inflation Factors
WP	Winnipeg

CHAPTER 1 – Introduction

1.1 Preface

The purpose of this first chapter is two-fold. Firstly, I describe, frame, and name the issue of systemic bias in western approaches to carrying out Indigenous health research. Secondly, the chapter serves as a primer for the following three papers that comprise the body of this paper-based dissertation.

The first section of Paper 2 is a critical reflection and evaluation of the dual experience of working as a Research Manager with the First Nations Health and Social Secretariat of Manitoba (FNHSSM), a community-based First Nation organization, and as a key member of the research team in the Innovation Supporting Transformation in Community-based Primary Healthcare Research Project (iPHIT). This research project was a collaboration between eight First Nation communities in Manitoba, the University of Manitoba and the FNHSSM to focus on First Nations experiences with community-based primary health care. This research was intimately intertwined with my graduate studies, in that these experiences and lessons learned helped shape the direction I chose for my dissertation search. The second part of Paper 2, therefore, presents a roadmap to conducting a population-based research study based on the lessons learned from working with First Nations communities, and knowledge I gained from other researchers, both Indigenous and non-Indigenous, when working in this collaborative environment during my doctoral studies. This planning also included the teachings and insights of many Indigenous leaders, mentors, scholars, and Knowledge Keepers in my doctoral journey.

Paper 3 presents the methods and results of my dissertation research study, where I utilized health administrative data and a decolonizing approach to examine the impact of the Out for Confinement (OFC) policy (the practice of sending women out of their communities to give birth) on selected maternal and child health outcomes. The voices of Knowledge Keepers and my Grandmother Advisor are central to this decolonizing approach.

In Chapter 4, in the last paper, I offer a reflection on my entire research journey and share some of my lessons of doing research “*mino-doodaman*”, in a good way. I offer my interpretation of an Anishinaabe quantitative action-oriented research framework. In its entirety, this dissertation documents a doctoral journey navigating between (and within) both western and Indigenous research space and posits a culturally informed and decolonizing framework for working with Indigenous people in population health research.

1.2 Discerning

In this paper, I contemplate why a decolonizing approach is necessary in population health research and provide the background and set the context for this dissertation. As such, it is the place where I locate myself. I am Anishinaabekwe, Gigizheba Waabishkaa Waabigwan. This is my spirit name given to me in my youth. It loosely translates to “White Morning Lily” in English. My baptismal name is Wanda Leanne, although I never could quite identify with it. I have been a nurse for almost thirty years at the time of writing and, for most of these years, I have worked for or with First Nations people in Manitoba, Canada. I am a member of the Hollow Water First Nation, and I grew up in the territory of my mother’s ancestors located on the eastern shore of Lake Winnipeg in Manitoba. I am the daughter of Henry Phillips; whose great grandmother was Mohawk and married into the Peguis First Nation in the early part of the 20th century and settled into the Red River valley now known as the City of Selkirk and surrounding area. I grew up among the Anishinaabe. However, due to colonization, in my early years I never learned to speak my language or practice my culture and ceremonies, although the values, stories and customs around childbirth remained. The most recent 40 years, however, have been a journey of discovery, relearning to practice my traditional spirituality and ceremonies. Today, most of my extended family have come full circle and practice our ceremonies and traditions unapologetically.

I now live in the land of my father’s ancestors and every day I acknowledge that I am still very much a student, learning from many teachers of Cree, Anishinaabe, Dakota and Métis descent. I have come to embrace the beauty and richness of my culture, and I participate in traditional gatherings and ceremonies. I have been blessed in my life with two mothers, Aurelia, and Isabel, the latter of whom I have called “mama” for most of my life. I am a mother, auntie, great auntie, and sister to five very intelligent women. My passion in life is my family. I have a wonderful husband and two adult sons whom I adore, and who support me no matter what adventure I am on in my career or in my educational aspirations. My family have long tolerated my grievances and grumblings with the historical and current state of oppression that resulted in the state of our people. They have endured many lectures that they must not be part of the problem, but part of the solution. “Be the generation of change” I would often say - the generation that puts an end to the cycle of oppression. At this point in my life and in my career,

the problem I am tackling is data quality, data governance and the inherent biases imbedded within western research methods and paradigms that are impacting First Nation people in a negative way. This dissertation is my endeavor to be part of the solution. In the following paper, I unpack what has long been told as truth: systemic bias in western quantitative methods, data and research involving Indigenous people.

There are many reasons why I choose to do this work. Among these are well-founded concerns about data quality and statistical methods used in research involving Indigenous people (First Nations Information Governance Centre, 2019; Freemantle et al., 2015; Smylie & Anderson, 2006; Smylie & Firestone, 2015; Steffler, 2016). Recent discussions in Manitoba around the inability to identify and respond appropriately to the unique groups of Indigenous people during the COVID-19 pandemic exemplifies these concerns. Joint efforts between the FNHSSM, the University of Manitoba, and province of Manitoba resulted in the successful negotiation and the expeditious signing of a data sharing agreement between all three parties regarding ownership and control of First Nations data. Manitoba now has the ability to capture and disaggregate First Nation, non-status Indians, Métis and Inuit data in the COVID-19 test results to allow the health system and their respective community-based health organizations to plan for and address their specific needs (L. Star, personal communication, June, 2020).

The concerns about data quality and statistical representation of Indigenous people have been referred to as “challenges” by some scholars, but what they are in the language of quantitative research is, plain and simple, “systemic bias”. These biases can arise at any point in the research cycle from indicator development to publication. The consequences of these biases can be serious and far reaching, and include misinterpretation of Indigenous data, miscalculation of standard health indicators, misrepresentation of Indigenous people, and underestimation of inequities in health determinants, health status and health care access (Smylie & Firestone, 2015). Others have noted that poor data quality impacts our ability to evaluate health programs and services appropriately, resulting in misguided health policies. (Freemantle et al., 2015). Most pressing, poor data quality, or inappropriate analysis and interpretation have resulted in negative portrayals of Indigenous people (First Nations Information Governance Centre, 2019). Population health researchers should be aware of these concerns, particularly those who specialize in and work with Indigenous data. In this dissertation, I present the issue of unchecked

systemic bias in western systems of research involving Indigenous people and present strategies and decolonizing elements to address and disrupt these practices through the research cycle.

1.3 Defining the problem

It is clear that the field of social epidemiology, dominated as it is by the trappings of positivism, is still in need of further development of epistemological frameworks that can adequately incorporate richer explanations of the phenomena we study (Dunn, 2012, p. 24.)

This critique reverberates in discourses relative to Indigenous people, statistics, and data throughout the colonized world (Walter & Anderson, 2013). The development and inclusion of Indigenous frameworks in epidemiology is one solution, but by no means the only one, or an easy task for that matter. Nor is this an issue unique to the field of epidemiology and population health. It cuts across many disciplines; from the humanities to biomedicine and intersects with many forms of quantitative data collection methods including national surveys, census, and any form of demographic, sociological, and environmental research involving numbers and Indigenous people. It is the reason that I, an Anishinaabekwe (Ojibway woman) decided to take a journey of learning western methods of population health research, and to understand how I might contribute to doing quantitative research differently. True to the Anishinaabe teachings I received, I sought to do research *mino-doodaman*, “in a good way”.

The calling to find a way to do research in a good way comes at a unique point in history. The discourse surrounding Indigenous statistics and research is appearing more frequently in the literature, notably on the heels of the release of the Truth and Reconciliation Commission of Canada report (TRCC) “Honouring the Truth, Reconciling for the Future” (Truth and Reconciliation Commission of Canada, 2015). The TRCC categorically and emphatically called for precise, complete, and appropriate information to monitor the health of Indigenous people, so that governments could identify and establish measurable goals and close the gap in key health indicators between Indigenous and non-Indigenous people. Understandably, along with the report came an increased interest in doing Indigenous health research.

It also follows the signing of the United Nations resolution and Declaration on the Rights of Indigenous People (UNDRIP) in 2007 and by the majority of its member states (UN General Assembly, 2007). The UNDRIP outlined broad parameters which constituted the minimum standards for the survival, dignity and well-being of the Indigenous peoples of the world

including the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures. Data, in this context, is one of the manifestations of their sciences and technologies. Interestingly, Australia, New Zealand, Canada, and the United States, four countries sharing very similar colonial histories, initially refused to sign the declaration.

It is important to acknowledge other influences in the broader community occurring in tandem with the release of the TRCC report, particularly those shaped by the growth in information technology. In the past twenty years we have seen an exponential increase in our capacity to collect data on individuals, communities and on the whole population. This is not entirely a bad thing for Indigenous people and communities, it is more like a two-edged sword. According to the United Nations Educational, Scientific and Cultural Organization (UNESCO), information and communication technologies are increasingly more essential for Indigenous people as they share information, inform leaders, educate members, generate new income revenues, and reinforce self-reliance. Information and communication technologies (ICT) have the potential to break through social and geographic obstacles and increased Indigenous communities' capacity to access information and to share experiences and practices more broadly in almost every part of the world (UNESCO, 2020). This growth in ICT capacity has exponentially increased our potential to collect data, analyze different types of data, and therefore expand our possibilities to make use of the data. This enhanced data capacity can potentially lead to more inferences, and inferential statistics about Indigenous people. It is no wonder that concerns about the integrity and interpretation of Indigenous data is at the forefront for Indigenous people. This brings us back to the opening passage about an urgent need to develop epistemological frameworks, particularly Indigenous frameworks, "to adequately incorporate richer explanations of the phenomena we study" (Dunn, 2012. p. 24).

This is a necessary dialogue we must have, and it is a dialogue about methodology and methods and not at all a rejection of western quantitative research. Walter & Andersen (2016) argue, numbers and data are as critical for measuring progress in closing the gap in health

outcomes between groups of people as they are for monitoring the health of the entire population. This is underscored by the TRCC Call to Action # 19¹.

The importance of health statistics and data in monitoring and evaluating specific health policies, programs, practices, and services is not in question. In fact, health statistics enable citizens, policymakers, public health workers and health-care providers to assess local or national health policy, mobilize to improve it, or evaluate the success of their efforts, if properly collected and communicated. Statistics are vitally important to provide information about aggregations of people, institutions, organizations, or information about populations and subpopulations within their respective regions (Friedman, Hunter, & Parrish, 2005). It is in this context that accurate numbers, rates, ratios, and counts become even more pressing for Indigenous people. Data and statistics are the means by which Indigenous people are able to speak and report back to government funders (Trevethan, 2019). Data are critically important for decision-making, measuring performance and planning within the community. There is no question that accurate data is essential for health planning, evaluating current policy, and for projecting future needs for Indigenous people. However, it is how we collect, analyze, and present the data that makes quantitative research problematic (Walter & Anderson, 2013). So, as population health researchers, it is imperative that we explore how quantitative research can be done better to disrupt the current status quo.

1.4 A matter of bias

The first order of business is a short explanation of bias and what it means for Indigenous peoples' statistics and data. Epidemiology texts typically divide biases into three general categories—confounding, selection, and information bias. However, different texts often use these terms to mean different things which hinders and confuses communication among epidemiologists (Schwartz, Campbell, Gatto, & Gordon, 2015). Therefore, a simplified classification of two major types of biases is borrowed from Petrie and Sabin (2013) and used in this dissertation: selection and information bias. What is often agreed upon is the fact that bias impacts the validity of the study, regardless of type. Validity can be one of two types as well:

¹ Call to Action #19 specifically states: We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

internal and external validity. Internal validity refers to the degree to which inferences drawn from the study are correct for the actual group being studied. External validity is sometimes referred to as “generalizability”, or in other words, can the inferences drawn from the study be applied to other groups not actually studied (Young, 2005)? Bias, whether it impacts the internal or external validity of the study, if left unchecked, clouds the current realities of Indigenous people. The inability to see through the cloud is a serious and sinister symptom of this bias.

There are two other subtypes of biases relevant for Indigenous people and population health research: funding and reporting bias. Funding bias occurs when there is a tendency to report findings in the direction favored by the funder. Publication bias refers to the tendency to publish only those papers that report statistically significant results, which renders publicly available studies misleading (Petrie & Sabin, 2013). While these two subtypes of biases are important, this dissertation focuses on selection and information biases which can be introduced earlier in the research cycle and can occur quite subtly, or in some cases, overtly. One other lesser discussed, but critically important bias found in Indigenous health research, is what I have termed “epistemological bias”. To confront and draw attention this bias, it is defined and discussed further on.

1.4.1 Selection and Information Bias

Selection bias, like the term implies, generally occurs in the selection and inclusion of participants in the study population. The result is a systematic difference between the results of the study and the actual situation in the real world. This type of bias may be introduced in the earlier stages of the research process. Failure to address bias in the data selection, collection or analysis will yield results that are not reflective of the true population or context (Petrie & Sabin, 2009). Selection bias can be defined as a distortion in a measurement of association (such as a risk ratio), due to selection of a sample that does not accurately reflect the target population. It can occur when investigators use improper procedures for selecting a sample population, but it can also occur because of factors that influence continued participation of subjects in a study. Information bias, on the other hand, occurs generally during the data collection and analysis cycle when measurements of exposures and or disease/outcomes are calculated. These can include misclassification errors or inappropriate use of instruments. In any case, whether errors occur in how the study population is selected, or in the inappropriate use of comparators in

calculating denominators/numerators or in the use of inappropriate measurements/instruments or whether they occur in the analysis that follows, the end results are biased (Petrie & Sabin, 2013).

It is therefore difficult to separate the discussion into clear cut categories, whether it be selection or information bias as it pertains to Indigenous people and data. As such, they are presented as they are found in the literature, interchangeably. Whether the type of bias is the result of selection or information errors, common to both is that several key challenges have been identified that affect the quality of Indigenous health data in Canada. These include data coverage, jurisdiction, utility, governance, relevance, infrastructure, and human resource capacity. These challenges arise from the use of substandard data sources, substandard methods, or both, and result in the misidentification, undercounting or misclassification of Indigenous people in information systems (Smylie & Firestone, 2015). These inaccuracies are further compounded by multiple data sources and systems of information that have been created with purposes other than for research (First Nations Information Governance Centre, 2019).

Inaccuracies in data are accentuated in Canada by the inability to respectfully, systematically, comprehensively and consistently recognize self-identified First Nations, Métis or Inuit ethnicity or ascertainment of groups such as First Nation, Métis and Inuit within the Indigenous population (Smylie, Firestone & Spiller, 2018). Most health data sources in Canada do not have a unique identifier for specific Indigenous people such as non-Status Indians or Métis within administrative data bases, although the Federal Government's Indian Registry System (IRS) can be linked to health data to identify First Nations only. Even so, inaccuracies in the reporting of population counts can result from delays or neglect in registering children born to registered Status Indians, inability to capture non-status Indians in the IRS, or from non-Indigenous people incorrectly identifying as Indigenous people, as well as the choice and consistency of procedures used to derive population estimates (Smylie & Anderson, 2006; Smylie & Firestone, 2015; Trevethan, 2019). In Canada, these inaccuracies are a concern also because health systems vary greatly according to ethnicity (First Nations people with or without registered treaty status, Inuit and Métis) and geography (remote, rural, on-reserve, urban), and by provider (provincial/federal/territorial). Researchers fail to recognize that Indigenous populations in Canada are diverse, multijurisdictional and impacted by health services and policies differently (Smylie & Anderson, 2006; Smylie & Firestone, 2015; Smylie et al., 2018).

Partial ascertainment of population groups and erroneous information due to the misclassification of Indigenous groups as non-Indigenous or by assuming homogeneity between groups within the population, result in inaccuracies in calculating mortality rates and other key population health indicators are only part of the problem. Another critical factor is the glaring absence of Indigenous involvement at the planning and data collection stage. In New Zealand, for example, Indigenous people and data users have historically not been involved in the planning process. As Bishop (2015) notes, this compilation stage is critical when collectors and producers of the data draw on existing statistical rules, guidelines, standards, or practices to make decisions. If Indigenous people and end users are not involved in this process, they do not always understand how and why compilation decisions are made, and what the implications of the data are. Adding yet more layers of inaccuracy into the mix are decision makers who have limited insights about the context and daily lives of Indigenous people but are judging those lives and making policy decisions based on some perceived notion of the truth conceived by non-Indigenous people using western statistical rules and practices. It is therefore important for users of the information (including Indigenous people), to be involved from the onset, to understand not only what is collected, but why, how, and what information is *not* collected (Bishop, 2015). The importance of involving Indigenous people at every stage of data management and the research cycle cannot be minimized.

These issues around data quality are relevant for any type of research and statistics involving Indigenous people and can have an impact on the decisions that are derived from the data. The size of the gap between those who are reported and those who are not reported in data sets, and any variation in the size of the identification gap that occurs over time, will also impact the quality and accuracy of Indigenous reporting (Griffiths et al., 2019). These inaccuracies and deficiencies or other data collection errors (in vital statistics, for instance) will result in inaccurate denominators and numerators upon which mortality and life expectancy indicators are calculated (Freemantle et al., 2015). Freemantle and colleagues called these numerator and denominator biases, but any factor that impacts the calculation of denominators, numerators or both, such as incomplete enumeration or the self-response nature of census data, produces inaccuracies in reporting rates and ratios (First Nations Information Governance Centre, 2019). For example, in Manitoba, the most recent release of the report entitled *Health Status of and*

Access to Healthcare by Registered First Nation Peoples in Manitoba, the Manitoba Centre for Health Policy (MCHP) and FNHSSM acknowledged that the focus was on First Nation people registered in the Manitoba First Nations Research File within the data repository². In this report, non-status First Nations were included in the ‘All Other Manitobans’ population (Katz et al., 2019). The authors noted:

This is a limitation resulting in a significant knowledge gap – although we know that many non-status First Nation peoples in Manitoba access healthcare services on-reserve through nursing stations in the north and health centres in the south, we are unable to identify these individuals in the data, and thus no reports of their health status or their use of healthcare services exist. There is presently no identifier in the provincial or federal databases that signifies who belongs to this important group (p.8).

Indicators such as life expectancy and mortality, reported most frequently in epidemiological or population-based research about the registered First Nations population in Manitoba therefore can miss a large proportion of the non-status First Nation population. Indicators such as mortality rates can be gross underestimations.

Other important considerations for researchers and statisticians occur at the analysis stage. Indigenous peoples are rarely considered within the analysis, if at all. Similarly, little attention is given to the appropriateness of the comparators that are used or to the utility of the statistical tools that are employed (Bishop, 2015). Regardless of whether the errors occur in the selection of the study population, or in the data collection or analysis stage, or if they are called information or selection bias, any calculation errors potentially lean the findings in one direction or another. These are not just limitations in the research, but are more accurately labeled as *biases*, and the end results do not reflect the true situation or population.

1.4.2 Epistemological bias

While we understand why accurate numbers and counts are required for the calculation of indicators upon which critical decisions are made or are used to evaluate health trends, programs, policies, and services, and we can appreciate how errors in any point in the data collection cycle can bias results, where and how, exactly, does context fit in? Why is context important to

² The University of Manitoba’s Centre for Health Policy

Indigenous people anyhow? And how do omissions of relevant context introduce bias into the presentation of numbers and statistics?

The answers come from many sources. Kovach (2009) stresses that contextual factors, deeply embedded within the colonial relationship, historical events or trauma are largely perceived as obscure, unmeasurable or “in the past”. They are factors that are either ignored or rarely acknowledged within the analysis phase of research. She argues that “while the visage of our ancestor’s time has shifted, the relationship [with the settler society] continues” (p.76). This relationship impacts our world daily, today, as do the colonial interruptions with Indigenous culture. There is no way to address tribal epistemologies and Indigenous research frameworks without considering these relations. She continues, in view of the contemporary challenges of representation and voice, research “must include a commentary on why a decolonizing lens matters within Indigenous methodological positioning” and on how decolonization is personally embodied within the lives of Indigenous researchers (p76). This is true of any analysis and interpretation, qualitative or quantitative, statistical, or otherwise. Western quantitative methods rarely ever contain any information about Indigenous people’s lives or reflect their worldview. As a result, their lives, families, communities, relationships, dynamics, and strengths are rendered invisible.

This view is shared and well-articulated by social epidemiologists. Michael Marmot, professor and director of the International Institute for Society and Health wrote in his forward to *Rethinking Social Epidemiology*: “the reality of people’s lives matters for their health. Their lived reality and the conditions that lead to it are responsible for the health of populations, provide explanations for health inequity and suggest solutions” (Marmot, 2012, p. v). He further argued that the debate about empirical purity and inclusion of social phenomena is merely a debate about how different disciplines view the world. These values have a huge effect on scientific conclusions and have implications for health policies. Marmot’s colleagues, (Ocampo & Dunn, 2012) emphasized that much of epidemiology focuses on downstream determinants of health, and too few studies examine the macrosocial determinants of health and “any cursory exposure to the media reveals the critical contemporary social issues of our day that, because of their direct and indirect impacts upon population well-being, should be the subject of our social

epidemiologic inquiries” (p. 9). Ignoring these factors can have profound consequences on the wellbeing and health of the population.

One of these consequences (and speaking to statistics, and associated analyses and interpretations, in particular) has been stereotyping and the public’s negative perception of Indigenous people. According to Walter and Andersen (2013), statistical depictions used to summarize the social complexity of Indigenous communities have been comparatively pejorative, tending toward a documentation of difference, deficit, and dysfunction (Walter & Andersen, 2012). Indigenous people have long questioned and have been troubled by this this race-based representation of themselves. An example of this misrepresentation has occurred in the field of chronic illness such as diabetes. From a western perspective, diabetes is regarded as a disease of lifestyle and a failure to moderate food intake or get adequate exercise. Therefore, many programs and services focus on individual level factors and attempt to modify individual behavior with the types of interventions they employ.

Indigenous people have also raised many concerns about the relevance of existing statistical frameworks, inability to capture Indigenous world views, or their lack of representation in data collection processes and data governance (Kukutai & Taylor, 2016). Whether covertly or overtly, statistics are not just the collection or analysis of numerical facts, figures or a numerical summary of reality; statistics construct *how* society understands Indigenous people (Walter & Anderson, 2013). In the words of Leona Star, Director of Research, FNHSSM, a vocal advocate for Indigenous data sovereignty, speaking at the Indigenous Research Symposium in 2019, “these figures, graphs and data are not just numbers, they are our babies, our children, our mothers, our Elders, and our families” (Star, 2019). Sadly, these numbers and figures exist without any story. Consistent with the criticisms voiced by social epidemiologists, numbers, figures, and data are just “out there” without any connection to historical events, context, or Indigenous voices.

Not only do statistics frame how we understand Indigenous people, but statistics are framed by dominant epistemologies (or ways of seeing the world), so they often reflect the needs, priorities, and concerns of governments. Epidemiology and statistics, along with ignoring important historical and contextual factors, therefore, continue to serve and reflect the values of the dominant societies, to protect and reproduce colonial relationships, and continue to

perpetuate social inequity. Macrosocial determinants of health (like culture, governance, or strengths in the context of Indigenous health) should instead be the subject of epidemiologic inquiries and be an integral component in the representation of statistics and numbers. It is therefore our responsibility as social epidemiologists and researchers to be explicit about the values that guide our intellectual enquiry, and our responsibility to refocus on the macro level determinants of health (Marmot, 2012). In the context of Indigenous people, these macro-level factors include recognition of the important impact of colonization and historical events, and in Marmot's own words, must include a focus on action "conducted at the highest intellectual level" (p. vii).

Equally as harmful as ignoring relevant context and community realities, is assuming homogeneity of Indigenous people. This is as much of a concern in calculating rates and numbers as it is for presenting the statistics without information relevant for subgroups of Indigenous people. Stated succinctly, Indigenous community experiences often do not align with official statistics (Smylie, Lofters, Firestone, & Campo, 2012). Taking a "pan-Aboriginal approach" and assuming all Indigenous people have had similar experiences and realities can seriously dilute gaping differences between unique Indigenous groups or silence the voices of smaller groups. It can also cover up subtle variations between unique groups of people, or even groups of communities. While the colonial experience has been a common experience for Indigenous peoples in Canada, New Zealand and Australia, it is important to acknowledge and respect cultural diversity and jurisdictional realities within populations (Smylie & Anderson, 2006). This would require two processes: 1) the disaggregation of data by Indigenous subpopulations because health systems and benefits are different for different groups; and 2) addressing a lack of Indigenous-specific identifiers that are consistent and relevant in major health and social data sources (Smylie & Firestone, 2015), as well as presenting them as independent nation-based data sets with unique histories and with relevant contexts.

1.5 Discussion

Scholars concur that valid concerns over errors in the undercounting of Indigenous people can produce inaccurate denominators and therefore inaccurate population parameters such as mortality or morbidity rates (Freemantle et al., 2015). Any miscounts, omissions, or misclassifications produce inaccurate denominators or numerators and introduce bias that is

impossible to control for in the analysis stage, regardless of what type of quantitative study or statistical technique is used. Inaccuracies in mortality rates as a key indicator of public health policy and programs, for example, further impede the strategic implementation of public health interventions aimed at preventing avoidable mortality in Indigenous communities worldwide (Freemantle et al., 2015). Failing to account for differences between Indigenous groups or Nations such as the Métis, non-status Indian, Status Indian or Inuit in Canada, whose health systems vary quite dramatically and require distinct policy responses, can have serious consequences. Failing to account for differences, by definition, represents *selection or information bias*, and therefore the statistics or studies are not representative of the population to which the results are applied, calling into question the validity of the study/research/data and therefore policy maker's ability to make generalizations and base broad policy decisions on.

A quote by the First Nations Information Governance Centre (2019) is notable and provides a useful summary:

In the 21st Century, data is certainly one of the most sought-after resources. It has the potential to positively or negatively influence decision making, policy, and social change, and ultimately to transform nations. For decades, governments and scholars/ researchers have been collecting, analyzing, and consuming vast amounts of First Nations data under the premise of making informed decisions, being accountable, and developing targeted policies and programs. Although their justifications can often appear sound, strictly Western methods and approaches used have reinforced systemic oppression, barriers, and unequal power relations between Western society and First Nations. This has led to countless laws, policies, and programs, created under the western worldviews/ perspectives that are culturally distorted, discriminatory, oppressive, and harmful to First Nations (p. 59).

Important issues therefore need to be addressed. Health indicators that are inaccurate cannot be relied on to evaluate the impact of health policies, services, and interventions. This raises further questions. How effective have we been at measuring any efforts to close the gap for Indigenous health people in health outcomes? And how might we do better moving forward? What are, and have been, the implications of the decisions that are made based on this inaccurate data? The answer to the second question perhaps lies in the mounting evidence that current gaps between the health of Indigenous people and mainstream populations is widening, and current health policy, programs and services have not made any measurable difference in closing these gaps in the past 15 years, as evidenced by the release of the report on the *Health Status of and*

Access to Healthcare by Registered First Nation Peoples in Manitoba, alternatively known as the First Nations Health Atlas in Manitoba (Katz et al., 2019). The answer to the first questions can, in part, be addressed through dialogue such as this.

One simple solution that has been proposed numerous times and by many advocates is to involve Indigenous people through the entirety of the research project. I have argued that failing to involve Indigenous people in the study or participate in the planning or analysis, interpretation and representation of the data, or to include relevant context in the research violates another premise of valid research by introducing *epistemological* or *context bias*. In working with Indigenous people, failure to include Indigenous voice, perspectives, worldviews or omission of relevant historical, social, and environmental contexts introduces serious biases into the study, by ignoring an Indigenous perspective. The other matter that hasn't been discussed in any detail in this paper, but is equally important, concerns bias that occurs due to inadequate measurement and instruments that are not reflective of the environmental, social and cultural contexts of the population involved. It does drive home the point of how critical it is to involve Indigenous people in the data collection and validating/defining their population as it is to involve them in design, analysis, interpretation and reporting of the study or results.

Walter and Anderson's (2016) comment about statistics being "powerful persuaders" is salient to this discussion because statistics often shape the way a group of people are *perceived* by the public, which is just as harmful as the way in which quantitative data and their analysis can shape health policy. Whether it is within an organization, a community or a nation, policies have significant consequences. Health policy can either make life better, or if not well-informed, can make things significantly worse (Feder & Levitt, 2005). So, it goes without saying, that any errors in the collection of data, using questionable sources of data or errors in the analysis, particularly in the calculation of the denominators, numerators (or both) can introduce significant bias and have serious consequences for the target population. If this population happens to be Indigenous people, the policy outcomes can be disastrous which is evidenced by historical and current-day colonial realities. As researchers, policy makers, students, or responsible members of the public, it is ever more critical today to question who have been the collectors and interpreters of this reality. For the most part, the interpreters of this reality and users of this data have been non-Indigenous people: academics, statisticians, policy makers, consultants, decision makers,

reporters, writers, or any combination of, who are far removed from Indigenous communities (Bishop, 2012); and this perpetuates current-day status quo of unchecked systemic bias.

As tight and as rigorous as the statistical methods employed to analyze data in published studies and reports may purport to be, selection, information and epistemological biases threaten the validity of the data, thus rendering the study or report inaccurate and misleading. This is not a rejection of statistical methods, epidemiology, or quantitative methods – rather it is the revealing of a veil that has been silencing the reality of systemic bias. The importance of high-quality data for an Indigenous community’s development and to support self-determination cannot be underscored enough (Kukutai & Taylor, 2016). High quality data is vitally important to create an accurate baseline, measure improvements or changes in health and social status of a population or create relevant policy and programs. It is also vitally important that we accurately assess the health of Indigenous people and groups within their population groups such as the First Nation, Métis and Inuit in Canada (Smylie et al., 2018). It is therefore important to disaggregate and report on the differences and varying experiences and histories of distinct groups of Indigenous people in the presentation of the results, thus reducing any form of reporting bias.

Social epidemiologists agree with this critique. Marmot (2012) argued that how we present data and indicators, with its origins rooted in epidemiology, the dominant perspective, has been to focus on individual risk factors. Therefore, much of what we know about the health of populations (including Indigenous people) is derived from data that encompasses individual and proximal social risk factors and markers (Dunn, 2012). Without any complementary or contextual information about colonization, historical trauma or experiences such as land expropriation, displacement, oppression, segregation, the Indian Act, and acts of cultural genocide that disrupted pathways of cultural knowledge, language, practices and governance, should we not challenge whether published statistics on Indigenous people can stand alone? Unquestionably, statistics on Indigenous people cannot and should not stand alone. In population health research, training has evolved and is still very much entrenched in western positivism and ontologies that purport that knowledge should be distanced from and even devoid of social context. This is a premise that is based on an assumption that there are “objective” and generalizable truths, the discovery of which will be “biased” if contextual factors contaminate

data collection and analysis (Smylie et al., 2012). While most statistics and traditional epidemiological methods, including variables included in the analysis, are “useful for understanding proximal contributors to health, they cannot possibly reveal the key pathways of macrosocial and economic processes that influence individual well-being” (O’Campo & Dunn, 2012, p. 13).

Involving Indigenous people throughout the entirety of the research as a means of addressing epistemological bias, particularly in regard to omissions of context and Indigenous voice is not a new concept and is becoming more common place, at least it is in Manitoba, as demonstrated by the many partnerships between Indigenous organizations and academic institutions in Manitoba (Katz et al., 2019; Kyoon-Achan et al., 2018; Phillips-Beck et al., 2019). This practice is supported by many scholars, but one lesser practiced and very effective strategy is for Indigenous researchers to “equip ourselves with tools” do research “our own way”, become more “statistically skilled”, and essentially retake some of the research terrain and turn it “into Indigenous space” in what is usually understood – “by whites and Indigenous peoples alike – as white space” (Walter & Andersen, 2016, p. 132). In order for research and statistics to be effective in achieving positive change for Indigenous people and communities directly, we need to confidently use research tools and methods that are both valued and deemed valid within the political and policy spheres where such changes can be made. This is accomplished when Indigenous communities are more literate in the entire statistical cycle (Walter & Andersen, 2016), where Indigenous people’s lives are captured in the interpretation and presentation of the data, or at minimum, population health researchers are aware of the many areas where bias can be introduced and how these biases can be minimized. Learning and planning research to be done my own way is the subject of the next paper.

1.6 Conclusion

In this chapter I have argued that western-designed quantitative research on Indigenous people is inherently biased. Statistical reports, publications and research continue to perpetuate a negative portrait of Indigenous people and may continue to harm them due to deficiencies that threaten the validity of published reports, research and data about Indigenous people. Official data collection and disaggregation of Indigenous groups within Indigenous populations tends to be inadequate and or non-existent. This in turn has had significant consequences on how

problems that Indigenous peoples face are addressed (United Nations, 2020). Despite the deficiencies I have identified as biases in statistical research, good quality Indigenous data is still necessary in measuring health and socioeconomic outcomes for Indigenous people in Canada and worldwide.

Adequate contextual data relating to these issues therefore needs to be incorporated in meaningful ways in order to develop effective initiatives, policy and improve health and social outcomes. This is not possible without disrupting current systems and methods of collecting data on Indigenous people, and without meaningful engagement or inclusion of relevant contextual information on them. Until alternative approaches are taken, statistical reports, publications and research will continue to perpetuate a negative portrait of Indigenous people and continue to bring harm to Indigenous people.

I join Kukutai & Taylor (2016) in reaffirming UNDRIP's position that Indigenous people have a right to self-determination that emanates from their inalienable relationships to lands, waters and the natural world, and this right requires a relocation of authority over relevant information from nation-states back to Indigenous peoples. This includes acceptance and uptake of alternative and culturally informed approaches to doing quantitative and epidemiological research that include Indigenous and decolonizing methodologies.

It cannot be overemphasized that harms to Indigenous people will continue if published statistical data is devoid of any Indigenous context and voice. It will continue to create barriers to developing informed policy and practice decisions or initiatives that can benefit different Indigenous groups within an Indigenous population. In an era of reconciliation which aspires to recognize and address Indigenous social, health and economic inequity, quality data, culturally-informed frameworks and decolonizing approaches are needed (and should be accessible) in ways that would best address the needs of Indigenous people. Recognizing the fundamental human rights of Indigenous people to self-determination as members of sovereign nations carries a responsibility for current researchers to act ethically and respectfully in their roles as well (Moodie, 2010). Consequently, to minimize and reduce bias in the data collection and analysis stage, a great deal of effort and energy should go into the design of a study, who to engage in the planning, and into questioning the sources of the data.

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CHAPTER 2 - Mapping

2.1 Preface

The following paper details how I mapped out the journey for employing a decolonizing framework in population health research. Drawing on Maggie Anderson's Indigenous Framework, the process of preparing and planning addressed some of the key concerns about statistics and quantitative research.

The paper that follows is entitled “*Demystifying an Indigenous and decolonizing approach in epidemiological and quantitative research: two case studies from the field*”. This paper draws on the experiences of working directly with First Nation data in the *Initiatives for Primary Healthcare Innovation and Transformation (iPHIT)* research project, a five-year partnership between the University of Manitoba, the FNHSSM, a community-based Indigenous organization, and eight Manitoba First Nation communities in Manitoba, Canada. During the five-year project, I was the Research Manager, responsible for all matters pertaining to the collection, analysis, and storage of community data and co-author on all publications. I also provided training and support to the First Nation community research assistants. Our research focus was initially on the experiences and innovation in community-based primary health care, but through working with First Nation communities and with First Nations data, our project objectives inevitably intersected with community priorities requiring our team to delve into matters of data governance, relevance, relationality, methods, and methodology. The iPHIT research project, (in which I obtained gainful employment from 2013 to the writing of this dissertation), has been intimately intertwined with my doctoral studies. We worked closely with two project Knowledge Keepers, community leadership, and community advisory committees to ensure that we conducted our research in a respectful manner and with meaningful engagement (Phillips-Beck et. al 2019). The experiences and learnings from this work inevitably influenced the formation of my doctoral research plan and how I could incorporate Indigenous methodologies and a decolonizing framework in a quantitative research project using population-level administrative data.

In the end, it is my story of learning, planning, and carrying out a research project in Manitoba drawing upon and reconciling the strengths of both western and Indigenous methods and methodologies.

2.2 Introduction

Long before I set out on my doctoral research journey, I struggled with how I could accomplish my research in a good way, “*mino-doodaman*”, do only good, as instructed by my Grandmother advisor in the Ojibway language, the language of my ancestors. To do this, I had to reconcile what I had learned in a western-oriented program in population health with what I had come to learn and understand about the current state of Indigenous peoples’ health and wellbeing. I gained this understanding through many years of experience working as a Registered Nurse with an expanded scope of practice in northern and remote communities in Manitoba, and through lived experience as an Anishinaabekwe, and as a mother, auntie, sister, cousin, and student. In the most recent fifteen years, my knowledge base has been advanced through reading extensively, being involved in Indigenous health research, and working within a First Nation organization advocating for the rights of First Nation people in Manitoba. The philosophical divide between western scientific methods and Indigenous or decolonizing methodologies was at the crux of my struggle and was further compounded by a heightened awareness that the underlying causes of disease and inequity are not straightforward and easily explained away by the collection, organization, analysis, interpretation, and presentation of data. I knew that to resolve this struggle, I needed to speak the language of western quantitative researchers, particularly, the language of epidemiology and population health.

In western paradigms, the language I had to learn was the language of statistics. This involved learning about mathematical models, assumptions, techniques, and calculations involving sample populations which, if bias is well controlled, are purportedly representative of larger populations. We are trained to manipulate and interpret the data so that we can make inferences about a particular population from these samples and calculations. There are causal relationships, risks, odds, hazards, associations, interactions, confounders, and almost always, individual-level factors that are very commonplace in epidemiology and population health research. In everything I had read and learned, associations of all sorts were made between lifestyles, behaviors, diseases, geographies, personal attributes, education, income, ethnic origins, identity, and race. However, it has long been recognized that this type of research and the associated inferences have negatively impacted Indigenous people worldwide, and the discourse fueled by such research has been used to justify continued marginalization,

paternalism, and oppression (O’Neil, Reading & Leader, 1998). If quantitative research had contributed to the negative image and portrayal of Indigenous people, I pondered, what would the implications and potential impact of my research be on Indigenous people in Canada?

This paper is therefore an account of how I, an Anishinaabekwe researcher, came to terms with a struggle to balance the western scientific method and a desire to do only good research. Quantitative inquiry, particularly in population health and epidemiology, is an area where I have acquired some level of comfort and experience via my doctoral training and by working both as a research manager and researcher. I share what I have learned from some very wise mentors and by working collaboratively in a research partnership with First Nation people in Manitoba. I then share how these experiences shaped my dissertation. This learning journey for me had to begin with a clear understanding of what I wanted to accomplish in working toward a doctorate in community health sciences and population health. One of my primary goals was to tackle, head-on, the struggle I had alluded to in the opening paragraph: if I wanted to do research in a good way, I had to first learn, to the best of my ability, what it meant to be an Indigenous researcher. Not only did I have to learn the language of statistics and epidemiology, but I also had to circle back and understand what decolonizing research meant to me. In essence, I had to open the space in own my mind for decolonization to occur. The message I share early with you at this point, I borrow from Linda Smith (2012):

Decolonization issuing from many writers in the field is that the process of decolonizing can be extremely ‘messy’, often leading to extreme violence; and that in a political sense it can fail miserably, replacing one corrupt elite with its mimics. The intellectual project of decolonizing has to set out ways to proceed through a colonizing world. It needs a radical compassion that reaches out, that seeks collaboration, and that is open to possibilities that can only be imagined as other things fall into place (p. 23).

I, therefore, seek compassion as I share with you how I begin to understand how to create this decolonizing space and how I navigated the waters in this journey of learning and understanding how to do research in a good way. In the first section, I share my perspectives on decolonizing and Indigenous research, which necessarily is prefaced by a clear understanding of colonization. Based on this understanding, I present my interpretation of what characteristics constitute “decolonizing research” which have been presented as “*decolonizing elements or actions*” within the broader decolonizing agenda. Next, I extract several common threads of

which constitute Indigenous or decolonizing characteristics gleaned from three prominent sources: Berryman, SooHoo, & Nevin (2013), Kovach (2009) and Smith (2012), which are clearly located within the qualitative domain. I labeled these common threads “decolonizing research elements”. Next, I used these elements to critically reflect on two real-world scenarios: a real-world research project (Case Study 1), and my doctoral research (Case Study 2). In the discussion section, I offer my perspective on how these decolonizing research elements intersect with the broader aim of decolonization. Sharing the process by which I came to understand decolonizing research (by unearthing common characteristics found in the literature into concrete tangible elements that perhaps only make sense to me), it is my overall aim to show how a decolonizing and Indigenous framework can be applied in the quantitative domain. To this end, I hope that I am able to contribute to the literature and assist others who may be struggling with the “how-to” when undertaking a decolonizing stance in epidemiological and population health research involving Indigenous people.

2.3 Terminology first: Methodology, Conceptual Frameworks, and Methods

Before proceeding, a brief description of some common terminology is required, particularly, the difference between methodology, conceptual frameworks, and methods. Margaret Kovach (2009) described the difference between conceptual frameworks and methodology in this way: “conceptual frameworks are also known as theoretical frameworks, epistemological frameworks or research frameworks, all of which connote a theoretical knowledge system that governs the research (p. 42)”. Indigenous methodology, in her understanding, incorporates both conceptual framework and methods.

Linda Smith relays Sandra Harding’s (1987) simple distinction: methodology is a theory and an analysis of how research does or should proceed, while research method is about the technique or way of proceeding in gathering the evidence. Smith adds “methodology is important because it frames the questions being asked, determines the set of instruments and methods to be employed, and shapes the analyses” (Smith, 1999, p. 143). Decolonization as it pertains to research, she explains, is a *process*, that engages with imperialism and colonialism at multiple levels. For researchers, “one of those levels is concerned with having a more critical understanding of the underlying assumptions, motivations and values which inform research practices” (Smith, 2012, p. 20). Imperialism is the system of control that secured the markets and

capital investments, and colonialism facilitated this expansion by ensuring that there was European control, by “securing and subjugating” the Indigenous populations. From Smith’s perspective and in the context of research, “decolonization” (or to employ a decolonizing lens or framework) is about *purpose*, as well as an aim to challenge the underlying assumptions, motivations, and values of the academy, including who are valued as the “experts”, who controls the research and what constitutes valid and legitimate research. Simply put, methods are about the technique, and methodology is about the overarching principles behind the process. To situate or embed the research within a decolonizing framework is to be purposeful about an overarching aim for the research, which is to be thread throughout the research. This understanding differs somewhat from Margaret Kovach’s rendering. Kovach (2009) situated a *decolonizing aim* within the domain of ethics, a key step in her Indigenous conceptual framework, which is for her, embedded within Cree epistemology.

2.4 The emergence of decolonizing and Indigenous Methodologies

A movement to change research from a dark, colonial tool used to disempower and control to one that supports Indigenous peoples, their cultures, and communities, and Indigenous-led movements aimed at social change and justice has been underway for decades. As such, the literature on Indigenous methodologies has rapidly emerged (Wingert & White, 2017). There is also a growing body of literature that points to the need for collaborative, culturally respectful, and ethical research involving Indigenous people, which emerged primarily in response to research that has harmed Indigenous people (NSERC, CIHR & SSHRC, 2014). These harmful practices include deceit, exploitation, disrespect for the basic human dignity of participants or their religious, spiritual, or cultural beliefs, commodification and/or appropriation of Indigenous medicines/knowledge, lack of Indigenous involvement, and many other injustices, all under the auspices of “research” (Schnarch & First Nations Centre, 2004).

That is not to imply that effort or progress has not been made in addressing these harms. A brief scan of the literature will confirm that a tremendous amount of time and theorizing has emerged in the past two decades in response to inappropriate research practices involving Indigenous people. Indigenous methodologies and methods have become both systems for generating knowledge and ways of responding to the processes of colonization (Evans, Miller, Hutchinson, & Dingwall, 2014). The development of ethical guidelines has also emerged as a

moral, political, and pragmatic response (Ermine, Sinclair, & Jeffery, 2004; Schnarch & First Nations Centre, 2004). In the Canadian context, these guidelines are concerned with protecting communities and individuals, and encouraging researchers who are conducting research on First Nations, Inuit and Métis Peoples of Canada toward relationships that are more respectful, collaborative, and meaningful. This includes respect for a community's cultural traditions, customs and codes of practice, as found in the joint policy statement issued by Canada's three federal research agencies— the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada (Canadian Institutes of Health Research; Natural Sciences and Engineering Council of Canada; Social Sciences and Humanities Research Council of Canada, 2014). Many communities and regional bodies have also developed their own ethical guidelines. The First Nation Health Information Research Governance Committee in Manitoba (FN-HIRGC) is one example. These bodies and many other Indigenous groups around the globe have established their own principles to guide research in their respective territories (First Nations Information Governance Centre, 2014; McClelland, 2011; The South Australian Health and Medical Research Institute, 2014).

In Canada, the principles of ownership, control, access, and possession (OCAP) are central to many of these ethical guidelines (First Nations Information Governance Centre, 2012). These concepts, originally coined in response to data management, have been applied more broadly to all research involving First Nations as a political and moral expression of self-determination in research, and in response to pervasive colonial research practices within academic institutions (Schnarch & First Nations Centre, 2004). It is no surprise that Indigenous and decolonizing frameworks for research involving Indigenous people, such as Kaupapa Māori research have been gaining traction around the globe.

Indigenous frameworks offer new perspectives, methodologies, conceptual designs, and approaches for healing, restoring culture and strengths of Indigenous people (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Battiste, 2000; Bishop & Ladwig, 2014; Gauld, Smith, & Kendall, 2011; Kovach, 2009; Martin, 2012; Smith, 1999). Reclaiming Indigenous space, voice, and vision through these new frameworks allows for an understanding of how and why colonization has been so pervasive among Indigenous peoples. Reclaiming also allows for an

A Decolonizing Approach in Population Health Research

understanding of what Indigenous people desire and imagine as a better life in a post-colonial context (Battiste, 2007). Battiste wrote, “We could not be the cure if we were the disease” (p. XVIII): a discovery of the “cures” that will heal and restore Indigenous heritage and knowledge begins with engaging in a critique of colonization (p. XVIII). She explains that understanding the relevance of colonization and the efforts to resist oppression in research must first begin with an understanding of what colonization is. To explain why understanding colonization is an important aspect of reclaiming Indigenous space Matsinhe (2007) offers this perspective: “the repressive power of established methodologies in the social sciences and humanities are symptomatic of the problem of modernity in its colonial manifestation. Within the process of modernization, science, methodology and research were the means of colonization” (p. 840).

To begin the process of decolonizing research, as Battiste (2000) urged, we must first begin with a clear understanding of what decolonization is. Prominent Indigenous scholar Michael Hart (2015) offers this insight:

Colonialism involves at least the following elements: (a) the exercise of power and control of one group of people over another group; (b) the reconceptualization of the dominated people in an image imposed by the dominating group; (c) the forced establishment of an alternative social, political, economic and cultural reality for the people facing the colonial oppression; (d) use of racism as a means to entrench and regulate processes and dynamics involved in the oppression; (e) the internalization of the imposed oppressive images and reality both by the member of the dominant society and by the people facing the oppression; (f) the exclusion of the Indigenous peoples perspective and experiences within this colonial reality; and finally, (g) the presence of structural racism and violence that leads to poor health outcomes and death of Indigenous people (p. 149).

In the broadest sense, decolonization can be understood and described in this examination as countering all the elements described above. Reframed in this way, each of the elements of colonization would involve:

- a) empowering the oppressed group of people,
- b) recreating the image of the group,
- c) reestablishing/recognition of the social, political, economic, and cultural reality of the people,
- d) rejecting racism, processes, and dynamics involved in the oppression,
- e) resisting internalization of oppressive images of reality,
- f) inclusion of Indigenous people’s perspectives and experiences within the colonial reality and finally,
- g) reforming the impact of structural racism and violence on health outcomes and death as a result of racism.

These decolonizing elements will be revisited in the discussion. However, just how decolonizing research fits within the larger decolonizing agenda may not be intuitive to the novice researcher seeking to do research in a good way, or it may also be a matter of wide interpretation, causing some confusion. Further complicating matters are questions about decolonizing research and Indigenous frameworks: What are Indigenous frameworks? What makes Indigenous methodologies Indigenous? What exactly is “decolonizing” about decolonizing research? How does this type of research fit into the broader decolonizing agenda? This exercise, and this paper’s review of my past and present work, is my attempt to settle some of these questions. I will revisit them in the discussion.

2.5 What are decolonizing and Indigenous methodologies?

One clearly articulated description of Indigenous and decolonizing methodology comes from Canadian scholar Margaret Kovach. She purports that within the academy, decolonization in research is a “choice on political and on personal levels” (Kovach, 2009) and involves multiple strategies: 1) privileging Indigenous voices that go deeper than the use of Indigenous methodologies; 2) incorporating a relational and holistic foundation; 3) reclaiming as a form of “naming”, a cultural practice upheld in many tribal traditions; 4) fluidity and flexibility in Indigenous research design; and 5) inclusion of the context and place where Indigenous inquiry resides. Decolonizing research, according to Linda Smith (2012), involves *reframing* the context in which research problems are conceptualized and designed, and paying careful attention to the *values and practices* of research; the implications of research on the participants; and the *relationship between research and power*.

From Smith’s perspective, Indigenous methodologies, falling within the domain of decolonizing frameworks, position cultural protocols, values, and behavior as an integral part of the methodology. They are ‘factors’ to be built into the research explicitly, to be thought about reflexively, to be declared openly as part of the research design, discussed as part of the results of a study, and disseminated back to the people in culturally appropriate ways in a language that can be understood. “Coming to know the past” is therefore a critical part of the pedagogy of decolonization, which “requires us to revisit, site by site, our history under western eyes. This in turn requires a theory or approach which helps us to engage with, understand, and then act upon that history. Telling our stories from the past, reclaiming the past, giving testimony to the

injustices of the past are all strategies which are commonly employed by Indigenous peoples struggling for justice” (p. 81). She wrote in 1999:

Why then has revisiting history been a significant part of decolonization? The answer, I suggest, lies in the intersection of indigenous approaches to the past, of the modernist history project itself and of the resistance strategies which have been employed. Our colonial experience traps us in the project of modernity. There can be no 'postmodern' for us until we have settled some business of the modern. This does not mean that we do not understand or employ multiple discourses, or act in incredibly contradictory ways, or exercise power ourselves in multiple ways (Smith, 1999, p. 34).

According to Smith, decolonizing research also involves reframing and taking much greater control over how Indigenous issues and social problems are discussed and handled. One of the reasons why so many of the social problems which beset Indigenous communities are never solved, she argues, is because issues have been framed by outsiders. She wrote “the framing of an issue is about making decisions about its parameters, about what is in the foreground, what is in the background, and what shadings or complexities exist within the frame. The project of reframing is related to defining the problem or issue and determining how best to solve that problem” (Smith, 1999, p. 153). Smith adds that this does not mean a total rejection of Western theory, research or knowledge - but rather it is about centering our concerns and world views and then coming to know and understand theory and research from our own perspectives, acknowledging our past and for our own purposes. One of the challenges to overcome for Maori researchers working in this context has been to retrieve some space.

First, some space to convince Maori people of the value of research for Maori; second, to convince the various, fragmented but powerful research communities of the need for greater Maori involvement in research; and third, to develop approaches and ways of carrying out research which take into account, without being limited by, the legacies of previous research, and the parameters of both previous and current approaches (Smith, 1999, p. 183).

This rings true for First Nation research in Manitoba, as it does for other Indigenous contexts around the globe.

Culturally-responsive methodology has also been proposed as an alternative “anti-oppressive” decolonizing methodology. Culturally responsive methodology challenges all forms of traditional research paradigms that devalue or dehumanize research participants and encourages a research stance where the establishment of respectful relationships with participants is central to both human dignity and the research. This position requires researchers

to develop relationships that will enable them to intimately come to know the ‘other’ whom they seek to study (Berryman et al., 2013). These authors maintain that culturally informed methodology “comes from the same cloth as decolonizing methodologies” (Berryman et al., 2013, p. 19) in that, usurping the basic epistemological assumptions of knowledge production, is essential. Culturally responsive researchers approach their work as “situated practice” by integrating multiple ways of knowing and employing culturally appropriate research protocols. Being culturally responsive requires the researcher to develop contexts where the research community can define their own terms for engaging, relating, and interacting in the co-creation of knowledge.

Making it easy to extract the key characteristics of culturally responsive methodology, Berryman and colleagues are explicit about the main elements. These include: 1) resisting essentialism and generalizations to holistic contextualization; 2) establishing respectful relationships; 3) resisting colonization and promoting the rituals of cultural practice of the participants by challenging power structures; 4) replacing covert agendas with clearly articulated and communicated intentions to ensure transparency; 5) promoting humility, humanity, and empathy; and 4) understanding that validity and reliability or truthfulness and consistency depend on the quality of relationships rather than research tools and procedures. Applying these principles will result in the researcher becoming “culturally responsive” (Berryman et al., 2013).

2.6 Decolonizing and Indigenous Methodology and Quantitative Research

A great deal of what we know and understand about Indigenous methodologies and decolonizing approaches have been derived from qualitative inquiry. Thanks to the scholarly work and strong voices attributed to Indigenous scholars such as Linda Tuhiwai Smith, Michael Hart, Marie Battiste, Margaret Kovach, Leroy Little Bear (and many others) in the past two decades, there is no need to establish that decolonized and transformative approaches in research are necessary. However, decolonizing and Indigenous frameworks in quantitative research have not received the same attention, and there is not a large body of work focused on Indigenous quantitative methodology. As Walter and Andersen explain (2016), mainstream quantitative research and its associated statistics are quite problematic in the context of Indigenous people and the statistics employed in their methods are far from neutral. These authors explain that the statistical methods, including the variables that are selected and how the data is presented, are all

still very much shaped by the nation state's changing social, cultural, and economic priorities and norms. In fact, population statistics have an evidentiary base that reflects and constructs particular visions considered important to the nation-state and “for” Indigenous people, especially in first world countries where population statistics influence the provision and funding of social services. The numbers and statistics become a foundational lens through which Indigenous people are perceived in their respective nation-states and how we, as Indigenous people, engage in many of our relationships with government actors (Walter & Anderson, 2013).

Adding to, and compounding this partiality, are researchers' preoccupation with measuring differences and deficits, and the disconnect between current systems of population health data collection, management, and analysis from the communities they describe (Smylie et al., 2012). For data to become a tool for social empowerment and social change, these authors argue, the social structuring of data governance and management, and population-based data systems must be transformed from systems that reinforce social exclusion to social resources that actively contribute to social, economic and political solutions that are better able to reduce health inequities in Indigenous populations. This disconnection and social exclusion are due to design and methodologies that fail to match the needs, customs, and standards of Indigenous communities (Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011). There is also a need to focus on the social determinants of health and wellbeing, as outcomes for Indigenous people have not improved substantially in the past twenty years (Daniel et al., 2009).

Recognizing the deficiencies of quantitative research as it relates to Indigenous people is one matter. How we apply a decolonizing and/or an Indigenous framework and reorient quantitative methods, including population-based research, and data systems into social resources in quantitative research is another. As stated previously, examples of these instances are very scarce in the literature.

How then might a researcher incorporate an Indigenous (and therefore a decolonizing) stance in an epidemiological study, one that can stand up to the apparent rigors of scientific inquiry, meet the expectations of Indigenous scholarship and at the same time contribute to social, economic and political solutions? What is the relevance of all those concepts such as “strength-based”, “culturally-responsive”, “Indigenous methodologies” and “decolonizing approaches” for quantitative researchers? All this terminology and associated discourse about

decolonizing research can be very confusing, at least it was for me as a novice independent researcher. I had lived, breathed, and worked in Indigenous health for nearly three decades. If it was confusing for me, how confusing must it be for those who want to do research in a good way who have not acquired the years of experience or who are not Indigenous? Decolonizing research, whether it aligns with Indigenous methodologies, culturally responsive research, or falls within the domains of other approaches have their underlying concepts or theories, and each has their respective authorities. I am not, by any stretch of the imagination any one of these, but from what I have been able to ascertain in my years of learning is that there are some commonalities in these approaches. These commonalities can be applied to quantitative methods.

As demonstrated thus far, all these concepts (decolonizing/Indigenous/conceptual frameworks/methodologies) have been explained or are perceived differently in the literature, depending on the context, culture, or continent for that matter. Therefore, after synthesizing and discerning various viewpoints, the critical examination that follows offers my interpretation of what constitutes decolonizing and Indigenous elements in research - and then applies these elements to reflect on my past and present work from the perspective of my own cultural lens.

2.7 The way I learned (aka Methods)

The context for this critical reflection stems from the two case studies: 1) the Initiatives in Primary Health Innovation and Transformation (iPHIT) program of research in partnership with First Nations in Manitoba; and 2) a dissertation in population health research, conceptualizing and initiating my research. I began my research journey by first reviewing the literature to understand what is meant by decolonizing research methodologies, most of which have been explained previously. I then used this understanding to review these two research studies. As the volume of literature on Indigenous methodologies and decolonizing approaches is varied and primarily narrative, I chose three of what I perceived were the most comprehensive publications describing the key elements of Indigenous and decolonizing methodology in detail. These three references included Linda Smith's (1999) and (2012) edition of *Decolonizing Indigenous Methodologies*, Margaret Kovach's (2009) *Indigenous Methodologies: Characteristics, Conversations, and Contexts* and Berryman, Soohoo and Navin's (2013), *Culturally Responsive Methodologies*. Unfortunately, the literature on strength-based approaches is very sparse and not enough to draw any conclusions about common characterizations, so a

A Decolonizing Approach in Population Health Research

strength-based approach had to be excluded. All the while I acknowledge its relevance and the challenge it presents to population health researchers and deficit-focused research.

From these three references, in Table 1, I extracted what was described as the “key characteristics” of the decolonizing strategy in the respective methodologies, described previously. The second task was to map the common characteristics from all three sources into groups or themes of similar characteristics. At the risk of summarizing some deeply philosophical concepts, I created a new column (Column 4 of Table 1). I labeled “Common decolonizing elements”.

Table 1 - Synthesizing the common decolonizing elements of 3 prominent sources

	Smith	Kovach	Berryman et. al	Common decolonizing elements – 9 points
Decolonizing Characteristics	Resisting/challenging power/authority in the academy	Reclaiming Indigenous space	Challenging and equalizing power and structures	1. Shifting power & reclaiming governance over research
	Inclusion of Indigenous people			2. Meaningful engagement & involvement of Indigenous people
	Relationality to individuals, space, land, water, nature	Incorporating a relational and holistic foundation	Establishing respectful relationships	3. Relationship building relationality
	Situating self and reflexivity	Self-location	Authenticity, humility, and reflectivity	4. Reflexivity/critical reflection and positioning
	Coming to know the past & contextualization of Indigenous people	Inclusion of the context and place where Indigenous inquiry resides	Resisting essentialism and generalizations to holistic contextualization	5. Contextualization (acknowledgement of the historical, social, political and cultural reality of the people)
	Respect/inclusion of Indigenous people epistemology, voice and worldview	Privileging Indigenous voice & epistemologies that goes deeper than use of Indigenous methodologies	Resisting colonization by promoting the rituals of cultural practice of the participants	6. Privileging Indigenous knowledge, voice epistemology worldview and holistic frameworks
	Inclusion of cultural protocols, and values	Fluidity and flexibility in Indigenous research design		7. Respect/inclusion acknowledgement of Indigenous culture & protocols
	Reframing of Indigenous people			8. Reconceptualization, including knowledge translation/sharing
	Attention to the implications of the research on Indigenous people			9. Purpose and implications of research oriented toward the benefit for Indigenous people

A Decolonizing Approach in Population Health Research

The next task was to comment on how the two case studies (iPHIT and my doctoral research) aligned with or planned to meet the challenges within each element. Last, but not least, I then mapped each decolonizing element with how I perceived they aligned with a “Decolonizing action”, in advancing the broader decolonizing agenda, “actions” I modeled from Michael Hart’s (2015) elements of colonization (Table 2). In the discussion, I elaborate further on how each case study worked toward the broader aim of decolonization with respect to each decolonizing element. Some may disagree with my analysis and interpretation, and that is perfectly acceptable. However, for my purpose, the aim was to gauge whether the two case studies in research (iPHIT and planning my dissertation work) aligned with, or achieved some measure of success in, meeting what I perceived to be decolonizing benchmarks in research.

Table 2 - Mapping decolonizing research elements to Hart's Decolonization Actions

Common decolonizing elements	Decolonizing Actions, adapted from Hart (2015)
1. Shifting power & reclaiming governance over research	Empowering the oppressed group of people, recreating the image of the group
2. Meaningful engagement and involvement of Indigenous people	Empowering the oppressed group of people, recreating the image of the group
3. Relationship building, relationality	Reestablishing/recognition of the social, political, economic and cultural reality of the people, but acknowledging the social, political, economic and cultural strengths
4. Reflexivity/critical reflection and positioning	Empowering the oppressed group of people
5. Contextualization (acknowledgment of the historical, social, political and cultural reality of the people)	Reestablishing/recognition of the social, political, economic, and cultural reality of the people
6. Privileging Indigenous knowledge, voices, epistemologies, worldviews, and holistic frameworks	Recreating the image of the group
7. Respect, inclusion, and acknowledgment of Indigenous culture and protocols	Inclusion of Indigenous people perspectives and experiences within the colonial reality
8. Reconceptualization, including knowledge translation and sharing	Reforming the impact of racism on health outcomes and deaths because of racism
9. Purpose and implications of research oriented toward the benefit for Indigenous people	Reestablishing/Recognition of the social, political, economic and cultural reality of the people, but acknowledging the social, political, economic and cultural strengths

As previously noted, what exactly decolonizing research “is” has been interpreted somewhat differently by different scholars and identified within different methodologies. It has also been my observation that the discourse surrounding decolonizing methodologies has been

highly theoretical and primarily focused on qualitative inquiry. However, through this exercise of attempting to decipher and synthesize the core characteristics of decolonizing research, I have learned that this approach can be taken in any research, whether it be qualitative or quantitative. The following discussion demonstrates how these decolonizing elements can be applied pragmatically toward a decolonizing aim in research. I acknowledge that this synthesis may risk being an oversimplification or misinterpretation of some deeply philosophical concepts on my part, but for me, this exercise served to unpack and untangle how these highly conceptual constructs can be interpreted and applied to either assess a present course of action or map out a future quantitative research journey.

2.8 Learnings (Findings)

2.8.1 Case 1 – Initiatives in Primary Health Innovation and Transformation (iPHIT) program of research.

The iPHIT program of research was a five-year research collaboration between researchers from the University of Manitoba, eight Manitoba First Nation communities, and FNHSSM, also recognized by the traditional name “*Nanaadawewigamig*” which means “A Healing Place” in the Anishinaabe language. FNHSSM was established in 2013 by the Assembly of Manitoba Chiefs (AMC) Chiefs in Assembly, the political organization representing sixty-three First Nations in Manitoba. Academic and First Nation partners agreed-upon four goals for the overall iPHIT research project: 1) describe community-based primary health care (CBPHC) service provision in First Nation communities by focusing on the strengths, key factors, and innovations in health care provision that have helped to maintain individual, family and community wellness; 2) explore perspectives of First Nation people living on-reserve on CBPHC and why mainstream approaches may be failing; 3) compare the models of governance, community engagement, strengths and CBPHC service delivery across communities, and provide opportunities for communities to learn from each other; and 4) build collaborative relationships with communities and decision-makers to support the implementation of CBPHC innovation to improve health and wellbeing in First Nation people in Canada (Phillips-Beck, Kyoon-Achan, Lavoie, Krueger, Kinew, Sinclair & Katz, 2019).

The following describes how the iPHIT program of research aligned with the common decolonizing element or characteristic found in column 4, Table 1.³

2.8.1.1 Shifting power and reclaiming governance over research/ meaningful engagement and involvement of Indigenous people.

In this section, shifting power and participation/engagement will be discussed together, as they are related to some degree. This is not to say that participation and engagement of Indigenous people are equivalent to overcoming power imbalances or are similar constructs as they are quite different conversations to be had. However, in a pragmatic sense, governance, engagement, and participation are closely intertwined. In the iPHIT project, contesting power in the research relationship came in the form of leveling power differential between the academy and community, represented by (FHNSSM) in a shared governance model (Phillips-Beck et al., 2019). The project management for the iPHIT research was transferred entirely to the FHNSSM and with the Research Manager to oversee the training, data collection, transcription, analysis, knowledge translation, and publication process including joint decision-making with and including the community research teams. This research arrangement allowed for a level of community participation and engagement not previously tested at the University of Manitoba and to circumvent institutional policies requiring the project to hire degree-prepared research assistants. As such, non-degree prepared local research assistants were hired locally (later termed LRAs) in the eight participating research communities to collect data and assist in the data analysis. These actions clearly required a level of trust and negotiation within the academy on the part of the university-based researchers and were effective in eliminating “needless hierarchies” and restoring power imbalances (Kyoon-Achan et al., 2018; Phillips-Beck et al., 2019). These actions were also critical for creating opportunities for an unprecedented level of participation involving Research Coordinators, Health Directors, Elders, Knowledge Keepers, and LRAs in the research. Health Directors and LRAs were regarded by the academic researchers as critical members of the research team. They participated in collecting and viewing the data, interpreting their meanings, and providing relevant context in all matters of data presentation, including the

³ In these descriptions that follow, the discussion some categories will be collapsed for brevity sake, such as shifting power and reclaiming governance over research and meaningful engagement and involvement of Indigenous people

quantitative and population-level data (Kyoon-Achan et al., 2018). This level of engagement is only possible through a shared governance model and by transferring resources to an organization such as FNHSSM to coordinate the research function as a bridge between the academy and communities. In such a model, accountability is achievable in all directions from researcher and communities, between university and FNHSSM, and between FNHSSM and communities, and the reverse. Paramount to this accountability is trust and transparency; and this level of trust is not possible except through ongoing and multiple forms of engagement allowing for regular communication and sharing of knowledge (Phillips-Beck et al., 2019).

At the start of the iPHIT research project, one of the primary goals was to do respectful research by following sound ethical principles. From a decolonizing standpoint, the power imbalance shifted to First Nations and their representative First Nation organization and allowing for meaningful engagement to occur. This is congruent with decolonizing methodologies, including that which is considered Indigenous or culturally responsive research. Berryman et al., (2013) contend that in seeking a culturally responsive and decolonizing stance, we draw on critical theory that “asks us to address the power differentials within the research context and unlearn our hegemonized notions of conducting research on people rather than with people. Unlearning involves visualizing the derailing or peeling back the tracks of oppressor/colonizer, and erasing the vestiges of uninvited strangers, in order to reclaim space and resources, and re-territorializing the intellectual and/or physical landscapes that were taken or oppressed” (p. 14). This is consistent with Smith (2012) and Kovach (2009) who agree that one cannot engage in a discussion of decolonization without first addressing the complex problem of power relationships.

2.8.1.2. Relationship building, relationality.

Prior to the proposal submission for the iPHIT research, the FNHSSM invited eight First Nation communities, representing different models of care, geographical locations, and four of the five spoken Indigenous languages in Manitoba to participate in the research project. All eight communities invited the FNHSSM research team to make presentations to community leaders before a decision could be made to participate. Through the course of the first year of the research, the Research Manager continued to make several visits to the communities, make presentations, and meet with leaders in the communities. Once funding was released, the visits

consisted of assisting the Health Directors to hire research assistants locally. Maintaining and nurturing this research relationship was an ongoing endeavor through the course of the five years and critical to the success of the collaboration. The FNHSSM Research Manager held community bi-yearly workshops to keep the communities informed about the research, or to share community-specific findings thereafter. The knowledge-to-action strategy also included yearly workshops that highlighted community innovation and strengths and were critically important for maintaining trust, sharing of wise practices, and acknowledging the intercommunity relationships between communities (Phillips-Beck et al., 2019).

Establishing respectful relationships and respecting the relationality of Indigenous people to their lands, space, territory and each other are hallmarks of Indigenous frameworks (Kovach, 2009). This is consistent as well with Smith (2012) who wrote, “in Indigenous research frameworks, relationships matter. Respectful, reciprocal, genuine relationships lie at the heart of community life and community development” (p. 125).

2.8.1.3. Reflexivity/critical reflection and positioning.

The iPHIT project team acknowledged that there were clear differences in values between community partners and researchers. Academic researchers were very cognizant that they brought their own values to the research process and that community partners came from very different life experiences (Kyoon-Achan et al., 2018). This awareness called for a very different approach to knowledge sharing and in meetings with First Nation research partners. Academic researchers often took the back seat in the room, transforming themselves as listeners, silencing their own opinions, or at times acknowledging their positions as outsiders. Elders, Knowledge Keepers, and community members were encouraged to speak freely and without interruption. The researchers positioned themselves as co-learners and voiced that they learned so much more from the communities than they had envisioned at the start of the project. These discussions were pivotal in informing the research or determining priorities. This could not be accomplished without a continuous process of reflection on the direction of the research.

Berryman et al. (2013) argued that in seeking a culturally responsive and decolonizing stance, we must “unlearn” western practices that involve a huge measure of humility, humanity, and empathy - which recognize how researchers’ presumptions of superiority dominate their

participation as researchers. In other words, to be humble requires one to be reflective and to reposition themselves not as a colonizer but, as they did in the iPHIT project, as a co-learner.

2.8.1.4 Context (acknowledgment of the historical, social, political and cultural reality of the people).

In the iPHIT project, not only did the team work together over the course of a year to develop the study proposal, but they also focused on building relationships, and on understanding the cultural contexts and perspectives of First Nations (Kyoon-Achan et al., 2018). Understanding this historical context, particularly the colonial relationship between First Nations people and the Canadian government, and the impact this relationship had on the development and delivery of First Nation health care, were important elements that were considered and incorporated in the design of the iPHIT project. This relevant context in both the iPHIT and in my dissertation research must begin with an understanding that the current state of health and ongoing socioeconomic conditions have been directly the result of colonization (Waldram, 2013). This includes an understanding that the First Nation health system is fragmented, piecemeal, and disjointed; designed without input from First Nation communities and based on a funding model that contradicts current evidence of effective primary health care. Nor has this health system been responsive to their needs (Lavoie, Forget, O’Neil, 2007). The iPHIT project was very clear in that it focused on the current state of the “health system” and community strengths, rather than on the deficits of the community.

2.8.1.5 Privileging Indigenous knowledge, voice, epistemology worldview and holistic frameworks.

One of the first activities of the iPHIT project was to understand the meaning of primary health care from a First Nations perspective. This information was captured qualitatively and by hearing from both Knowledge Keepers and members of the community. From these stories, a First Nation Wellness Framework was developed and validated by the First Nation communities and leaders. This framework situated mental wellbeing as a critical component of the primary health care system that is missing or neglected in current models (Kyoon-Achan et al., 2018). The knowledge gleaned from this upfront qualitative work, then was used to inform the quantitative work that followed, particularly with the inclusion of mental health conditions

among the group of conditions that were “sensitive” to the provision of ambulatory primary healthcare.

Another example of respect and inclusion of Indigenous voice can be found in one of the quantitative studies. This study examined administrative data to determine hospitalization trends for Ambulatory Care Sensitive Conditions (ACSC) in First Nations in Manitoba. Indigenous scholars and FNHSSM staff with expertise in Indigenous health participated in all decisions for data extraction and interpretation. FNHSSM also ensured that community voices and perspectives were heard, represented, and reported. Health Directors and communities were invited to participate in the analysis and interpretation at community and regional workshops. General statistical methods and data were explained to First Nations in plain language and in a format that was understood by them (Kyoon-Achan et al., 2018).

These two examples of incorporating Indigenous voice (community, Knowledge Keepers and Indigenous scholars’ perspectives) is consistent with Smith’s (2012) position that “decolonization, does not mean a total rejection of all western theory, research or knowledge. Rather, it is about centering our concerns and world views and then coming to know and understand theory and research from our own perspectives and for our own purposes” (Smith, 2012, p. 89). Integrating multiple ways of knowing within research protocols aligns with both Indigenous and culturally responsive frameworks (Berryman et al., 2013; Kovach, 2009). Being culturally responsive requires the researcher to develop environments where the community can define, in their own ways, the terms for engaging, relating, and interacting in the co-creation of knowledge (Berryman et al., 2013). Datta (2018) also argued that Elders and Knowledge-holders should be respected as the “knowers” and researchers should not take credit for discovering Indigenous or community knowledge.

2.8.1.6 Respect/inclusion/acknowledgment of Indigenous culture & protocols.

As part of the overall iPHIT program of research, Knowledge Keepers were invited to participate in the initial planning and introductory meetings in each First Nation community. They were also integral to the advisory circles formed in each participating First Nation and in the yearly research team meetings. Local protocols were followed in each of these meetings. This often meant passing a gift of tobacco or sacred medicine to the Elders or Knowledge Keepers. Two Knowledge Keepers were invited to join the regional research team. They shared teachings

and began meetings with prayer and smudging. They often grounded the meetings with teachings filled with naturalistic metaphors and gentle reminders as to why we had all come together - this was to benefit and make life better for “our” people. “In practice, compliance (to ethics and protocols) involved clarifying specific requirements to all partners and encouraging adherence to stated and evolving community-based research protocols whether spoken or unspoken” (Kyoon-Achan et al., 2018, p. 8). Besides, Indigenous scholars, with previously established networks and relationships with First Nations in Manitoba were part of the conceptualization of the research project and ensured that these cultural protocols were followed. Elder involvement and respect for their cultural protocols within the folds of the research are consistent with Indigenous research paradigms which acknowledge and respect the contribution of Knowledge Keepers as a critical component of the research (Datta, 2018; Pidgeon, 2019).

2.8.1.7 Reconceptualization, including knowledge translation/sharing.

The analysis of health administrative data in the iPHIT project focused on the performance of varying models of primary health care in First Nation and rural/remote communities which included feedback and insights from participating communities at community and regional workshops. These perspectives were included in all presentations and knowledge translation activities and clearly focused on health systems. According to Smith (2012), there are diverse ways of disseminating knowledge and of ensuring that research reaches the people who have helped make it. Two important ways not always addressed by scientific research are reporting back to the communities and sharing knowledge with the people who can benefit from the research.

Just as important as context, the reconceptualization of Indigenous people is characteristic of decolonizing methodology. According to Smith (2012), both ‘friends of the natives’ and those hostile to Indigenous peoples conceptualized the issues of colonization and European encroachment on Indigenous territories in terms of a problem of the natives. The “natives” were, according to this view, to blame for not accepting the terms of their colonization (p. 166). From this perspective, reconceptualization, therefore, involves reframing the problem so that the gaze is clearly off the Indigenous people. For the iPHIT project, the quantitative research involved seeking information from research participants about their experiences with the “health care system” and on the performance of the primary health care system. All

publications following these discussions included relevant social, historical, and cultural contexts. Although chronic illnesses were captured in the survey data, disease patterns and multi-morbidity were linked back to dimensions of primary health care, rather than on behaviors or personal attributes.

It was common practice as well to co-present or make space for the Indigenous representatives to present at conferences and forums. “Collective presentation” is an important aspect of centering Indigenous voices in culturally informed frameworks as well (Datta, 2018). The iPHIT project demonstrated that this power can be shared in a mutually respectful way.

2.8.1.8 Purpose and implications of research oriented toward benefit for Indigenous people.

University and Indigenous community represented by FNHSSM worked collaboratively for over a year to develop the research plan, and clarify objectives for the study (Kyoon-Achan et al., 2018). University-based researchers in collaboration with community-based partners kept the team focused on the study goals, ensuring that the objectives aligned with the funding requirements, and kept the team engaged in understanding and addressing community priorities. A great deal of time and effort went into supporting community priorities that had been validated by the data. For instance, one community identified that they needed to focus on working more collaboratively. As such, a junior researcher was assigned to continue working with the community and work with them on this goal. The researcher visited the community several times over the course of two years to help them work on their collaborative integrated model. This is consistent with Linda Smith’s perspective: “positivist epistemological and methodological concerns may well be set aside so that researcher can focus instead on addressing the concerns and issues of the participants in ways that can be understood and controlled by the participants. Within this stance, the same concerns and issues also become those of the researchers, and the participants become part of the common purpose and group that drives the research. In this way, both the researcher and the participants can experience beneficial outcomes from the research process” (Smith, 2012, p. 12).

In summary, the preceding section described how the iPHIT program of research aligned with the nine decolonizing elements found in Table 1, Column 4. These points included: 1) Shifting power and reclaiming governance over research; 2) Meaningful engagement and involvement of

Indigenous people; 3) Relationship building, relationality; 4) Reflexivity/critical reflection and positioning; 5) Contextualization (acknowledgment of the historical, social, political and cultural reality of the people); 6) Privileging Indigenous knowledge, voice epistemology worldview, and holistic frameworks; 7) Respect/inclusion/acknowledgment of Indigenous culture and protocols; 8) Reconceptualization, including knowledge translation/sharing and lastly, 9) Purpose and implications of research-oriented toward the benefit for Indigenous people. The section that follows critically reviews the plan for my dissertation, Case Study 2, mapped onto each of the 9 points.

2.8.2 Case 2 - My doctoral research: A path forward

A mandatory component of my doctoral program is to demonstrate proficiency in research and create new knowledge. My research project examined a cohort of mothers and babies to assess the impact of the federal policy of evacuating women residing in rural and isolated First Nation communities in Manitoba out to urban locations to deliver their babies. The overall objective was to generate evidence in response to the Truth and Reconciliation Commission of Canada (TRCC) Call to Action #19, calling upon all levels of government to close the gap in measurable maternal and child outcomes. Currently, women are required to leave home at 36-38 weeks gestation, regardless, if they are low or high-risk. Hence, there was a dual purpose for this study. The first is to understand quantitatively the impact of the federal evacuation/OFC policy on maternal, infant, and child health outcomes. The second aim was to position traditional knowledge and science at the forefront to inform the entire research process and present-day childbearing policy and practices. The following discussion demonstrates how the research process I adopted for my doctoral research maps against the nine decolonization elements outlined in Table 2.

2.8.2.1. Shifting power & reclaiming governance over research & meaningful engagement & involvement of Indigenous people.

As my doctoral dissertation was primarily a sole undertaking, contesting power structures manifested in two ways. First is in the form of a critique of a colonial health policy that has taken control over women's bodies. The evacuation policy, also known as the OFC policy, remained the focus of the analysis and critique, rather than on the characteristics of the women or families that continue to endure the hardship of separation from place, territory, and family during

childbirth. Contesting power also took the form of shifting away from mainstream and western approaches to doing population health research. In western paradigms, population health research is bound by rigid protocols, procedures, and analysis which are perceived by western-trained researchers to be decontextualized. Not so, according to Walter & Andersen (2016) as statistics and its associated analysis “do not describe reality - they create it. In doing so, they not only influence how the phenomena they describe are understood, they also shape their expected explanations” (p. 9).

This project is a deliberate deviation from expected western protocols by demonstrating that actively involving Knowledge Keepers, incorporating Indigenous knowledge, critiquing colonialism, contextualizing and reconceptualizing Indigenous people, positioning or repositioning oneself, and building in a measure of reflexivity in the discussion does not take away from the validity of the research findings. In other words, using a decolonizing methodology to define, conceptualize, and operationalize Indigenous quantitative methodologies in ways that stimulate the imagining of quantitative research and operate within, and reflects Indigenous historical, cultural, and racial methodological values, priorities, and frameworks as described by Walter & Andersen (2016), only makes the research stronger.

In carrying out my research I had a responsibility to conduct my research following solid and robust statistical practices and techniques. However, to be true to my theoretical underpinning and align my work with Indigenous methodology, I set out on my dissertation pathway by grounding my research in ceremony, by incorporating a Grandmother advisor on the academic committee, and by seeking direction from a Circle of Knowledge Keepers to guide the research in a good way. This was my decolonizing stance, and how I exercised self-determination through my research. I began by mapping out a quantitative research journey that rejected western notions of who are the experts and acknowledged the essential role of communities and Knowledge Keepers to inform the research. I, therefore, included traditional teachings, voices and the perspectives of Knowledge Keepers and Grandmothers in the analysis and in the discussion of the results.

2.8.2.2 Relationship building, relationality.

In an epidemiological or population health-based study, relationship-based research can be perceived as challenging or some may find it is difficult to identify what relationships need to

be established. However, in my doctoral research, the primary relationship to be established was clear. It involved me personally building a relationship with my own history. I had to reconnect and relearning the teachings of my ancestors. One of the first teachings I received from my Grandmother advisor, Sherry Copenace, was to learn the importance and purpose of the water songs, and the role the water songs and associated teachings had in keeping women and babies healthy for countless generations before. With this insight, the relationship between my history, my culture, my teachers, and my research had to first be established. I had read and learned from Margaret Kovach's Indigenous Framework and taking her advice I began a two-year-long period of preparation. I listened to woman's teachings at the *Return of Our Families to Mide-Aki (Kind Hearted Mother Earth) – A Gathering at the Sacred Site of Manito-Api* in 2016, on the Anishinaabe sacred space now called Bannock Point in the Whiteshell provincial park in Manitoba. I took every opportunity to listen to Grandmother's teachings in ceremony or at several other gatherings organized by FNHSSM and other projects working toward reclaiming birth and space for Indigenous women to care for pregnant woman. In the summer of 2017, I invited Sherry Copenace to officially launch my doctoral research journey. I held this ceremony on my very own piece of prairie land in Treaty 1 Territory, the traditional land of the Anishinaabe, Cree, and the homeland of the Métis Nation. From this point on, Sherry remained a critical member of my academic team and continued to provide guidance, teachings, or relevant cultural knowledge when needed.

The relationship to my history, culture, and heritage had to be made in the form of reaching out to a Circle of Knowledge Keepers as well, based on the advice of Dr. Kathi Avery Kinew. She advised me one day when discussing my research idea that I had important lessons to be learned from both grandmothers as well as grandfathers. I, therefore presented my thesis topic and possible questions to explore at a Knowledge Keepers gathering organized by FNHSSM in 2017. At this gathering, I gained valuable insights into the role of men and families in caring for pregnant women. I learned how racism and racist policies are still very current and continue to harm families. I learned about changes that are required on multiple levels, not just at the health system level, but the level of the family and community in relearning important teachings and practices. I learned that relationships were required on multiple levels in my

research: personally, with teachers, Knowledge Keepers, communities, policymakers as well as at the level of the health system.

2.8.2.3. Reflexivity/critical reflection and positioning.

As this is a doctoral program in a mainstream western-oriented program in population health, I positioned myself as an Anishinaabekwe, a learner and emerging scholar with the intent on taking a decolonizing approach that challenges western approaches to doing population health research. This stance had been largely supported by my academic advisors but began very much as a mystery to them at the onset. My proposal and proposal defense began with positioning myself as Anishinaabekwe and with an acknowledgement of the traditional land and territory upon where we stood. I also acknowledged I was still very much on a journey of discovery. This discovery entailed learning what traditional teachings and knowledge were important and relevant for my research, and an awareness of how and what I learn is influenced by my western training.

I also acknowledged that, although I am Anishinaabe working within or alongside the territory of my ancestors, I am still very much an outsider/insider due to my western training. This reflexivity is threaded throughout the dissertation. This is consistent with Linda Smith's (2012) message: "insider research has to be as ethical and respectful, as reflexive and critical, as outsider research. It also needs to be humble. It needs to be humble because the researcher belongs to the community as a member with a different set of roles and relationships, status and position" (p. 233). Her position about research needing to be humble is consistent with Berryman and colleagues (2013), who emphasized that humility is one of the hallmarks of culturally responsive research. These authors maintain that culturally responsive researchers must resist superiority and self-interest and serve the social good of the research. With this in mind, I remained cognizant of my privilege as an outsider/insider trained in a mainstream and western institution and made every effort to set aside a self-centered agenda and to seek answers in a humble way that served the greater good of the community.

2.8.2.4. Contextualization (acknowledgment of the historical, social, political and cultural reality of the people).

My dissertation work clearly focused on the "system" and the colonial policy of forcibly removing women from their communities to give birth. In the population-based study, all

outcomes were positioned as an outcome of this policy. Women living in remote and isolated communities in Canada are expected to seek care from health care providers, who for the most part, are trained in western biomedical systems. Despite this expectation, the women (who are for the most part First Nation) face differential access to primary health care services due to geographical isolation, population size, funding shortfalls, the health care funding model of the community, or from complexities arising from dually operating federal-provincial-regional health systems with ambiguous or poorly defined responsibilities (Lavoie, Boulton, & Dwyer, 2010).

Factors included in the research were system-level factors such as access to primary health care, place of delivery, receipt of provincial benefits, rather than individual level risk factors. The dissertation work deliberately took the focus away from the women which was consistent with Walter & Andersen's (2016) position to reverse “the gaze” of research from ourselves and onto the colonizer settler population. Context, in this dissertation, includes the insights of Knowledge Keepers, particularly around teachings about birth, birthplace, and the connection to land and territory (Katherine Whitecloud, personal communication, Knowledge Keeper’s Gathering, 2018). This context is important to include in my dissertation work as well as factors that have impacted the present-day reality of Indigenous communities. In doing so, it attempts to achieve the goal of “reconceptualizing” the problem as one originating in colonization.

2.8.2.5 Privileging Indigenous knowledge, voice, epistemology, worldview, and holistic frameworks.

The advice, stories, teaching, and cultural knowledge obtained from the Knowledge Keepers and Grandmother advisor informed the entire research and were integrated into the findings, particularly the cultural teachings and stories about the responsibilities of life-giving. These insights were integral to framing the findings and the knowledge translation strategies. The teachings, stories, and songs passed down from generation to generation kept women healthy and brought healthy babies into this world. Unfortunately, I also learned these songs and teachings “have been lost or forgotten by our women and we must relearn them. They bring with them the responsibility to care for the life and the waters that surround our babies” (Sherry Copenace, personal communication, 2017). The discussion for the scientific paper has

incorporated the history of this oppressive policy and the insights and perspectives of my Grandmother Advisor and Knowledge Keepers.

2.8.2.6. Respect/inclusion acknowledgment of Indigenous culture & protocols.

Following Margaret Kovach's (2009) advice to prepare oneself (the researcher) to undertake research, as I have indicated previously, a well-respected Anishinaabe Grandmother Advisor, known for her cultural and women's wisdom, was invited to join the doctoral or dissertation supervisory team as a cultural teacher. Along with the launch ceremony in the summer 2017, learning the teachings of the "water song" and responsibilities of life-giving from an Anishinaabe perspective, she also advised me to host a feast to honor the water song and all women past and present. This feast was held in 2018 as per Anishinaabe protocols prior to writing the research proposal. In the Knowledge Keepers' workshop in February 2018, where I sought the advice of a Circle of Knowledge Keepers, cultural protocols were followed in the form of small gifts or tobacco. Grounding the research in ceremony, hosting a feast in honour of the water songs, past and present, are consistent with Indigenous methodology, and a decolonizing aim in Kovach's decolonizing framework.

2.8.2.7 Reconceptualization, including knowledge translation/sharing.

Like the iPHIT project, regardless of the outcomes that were chosen in the analysis, the main independent variable for my doctoral study is the presence or absence of the OFC policy as a government-enforced colonial practice. The analysis focused on community or system-level factors, rather than on individual characteristics or deficits. The evacuation policy impacts families in approximately a third of rural and remote First Nation communities in Manitoba. Therefore, communities were divided into two groups, those that enforce the OFC policy (evacuating women two to four weeks before their due date), and those communities that allowed women to remain at home with their families until childbirth is imminent. Some descriptive statistics were shown, but with relevant contextual information and factors. The information and knowledge co-created with the Knowledge Keepers/Grandmother Advisor will be shared first with First Nation communities in Manitoba through a First Nation Health Technicians network, a network of community Health Directors. This information will be presented in a format that is written in plain language and includes relevant contextual and historical information such as the history of the evacuation policy. This approach is consistent

with the advice given by (Berryman et al., 2013; Kovach, 2009; Smith, 2012; Walter & Andersen, 2016) by framing the research to avoid problematizing Indigenous people.

This approach serves to “reconceptualize” the issue as well, as its focus is on policy change and advocates to transform childbirth experiences and practices, instead of on individual behavior such as exercise, diet, smoking, alcohol use in pregnancy, etc. As reported in other studies, there is a desperate need to decolonize childbirth practices, which involves repatriating childbirth, and “de-medicalizing” the birth experience as well as reclaiming teachings long-forgotten (Phillips-Beck, 2010).

2.8.2.8. Purpose and implications of research oriented-toward benefit for Indigenous people.

The doctoral research plan began with the end and purpose in mind. At the forefront, key questions posed by Knowledge Keepers had to be answered: Whose purpose will this research serve? Who will benefit from the findings? Whose knowledge will be privileged and what will happen if the results do not show what we thought they might? As such, the purpose of the dissertation was dual and clear: 1) generate evidence concerning childbirth practices and outcomes, and 2) elevating First Nation voices and creating space for traditional knowledge to inform the research process as well as current child health practices, policy, and possible solutions. Informed by the Grandmother Advisor and Knowledge Keepers, the following objectives were included in the proposal:

1. Investigate differences in maternal and infant *outcomes* between women who travel for birth prior to their due dates to those who are not required to leave home.
2. Position traditional teachers, Knowledge Keepers and Grandmothers’ voices as “knowers”/ context experts and prioritize traditional wisdom in all knowledge aspects of the research project.
3. Inform present day childbirth policy, improve childbirth care pathways and culturally grounded care for all First Nation women and families in Manitoba.

Through the process of thoughtful planning to undertake the research in a good way, and to employ a decolonizing stance, a third purpose arose in the dissertation work. This purpose was to demonstrate that decolonizing and Indigenous approaches are possible in western quantitative research, particularly in epidemiological and population-based studies using health administrative data. This additional purpose benefited Indigenous people in building awareness about how quantitative research can be done in a good way while using western methods and

solid statistical analysis. The dissertation also provides important information about what cautions need to be considered when research is done of this nature. The focus, therefore, remained on the policies, inequities, and on the consequences of colonization and the systems of oppression that manifest in rules and research practices that continue to oppress Indigenous scholars as well as the impact that oppressive policies have on women, families, communities, and societies.

2.9 Mapping decolonizing research elements to Decolonization Action (Discussion)

The preceding review of the case studies (iPHIT program of research and the doctoral dissertation) have demonstrated that research done ethically and responsibly can be decolonizing, whether it is intentionally planned as such, or done collaboratively with meaningful Indigenous people's involvement from the start. Both studies have elements (or characteristics) that are consistent with Indigenous methodologies or culturally responsive research as described by scholars (Berryman et al., 2013; Kovach, 2009; Smith, 2012). The exercise of breaking down the common elements of decolonization was a reflective process and heightened my awareness about where and how my western training and systemic biases can potentially harm Indigenous people, thus building my knowledge base about decolonizing research. This process of untangling, consolidating and reflection is consistent with Datta (2018) who observed that decolonization is an ongoing process of becoming, unlearning, and relearning who we are as researchers and educators, taking responsibilities for participants (p.2), and I add, responsibility for ourselves as Indigenous researchers.

Yet, two questions remain: How do the decolonizing research elements intersect with the broader decolonizing agenda? and, why is understanding this relationship an important part of Indigenous Scholarship? In answering the latter question, I bring you back to the position shared by several authors (Battiste, 2000; Kovach, 2009; Smith, 2012), that understanding and critiquing colonization is a necessary aspect of decolonizing and Indigenous research methodologies. However, comprehending and having an awareness of Indigenous people's experiences of colonization is not sufficient if aiming to employ a decolonizing framework. Having an awareness about Indigenous people's experiences of colonization is like smokers having an awareness that smoking is bad for their health. Claiming to have this knowledge does not necessarily translate into practice. As Battiste (2000) argues, Indigenous scholarship must

move from the passive to the active. It must move from an understanding of colonization to action, in the form of resistance and transformation. This transformation must counteract the effects that colonization has had on Indigenous people. According to Battiste, “mapping colonization” is just the start of the journey, the opening door from her Indigenous medicine wheel perspective. “Diagnosing colonization” is the next step. This step is a process of exploring the unquestioned and conflicting assumptions that underpin oppressive relationships of colonization. Battiste (2000) argues these steps are necessary in research before it can be a place of healing Indigenous peoples.⁴ This healing is the transformation that research and Indigenous scholarship should strive to achieve.

In the context of research, I began the process of mapping colonization by cross-referencing the common decolonizing elements I synthesized from the three sources (Kovach, Smith and Berryman, and colleagues) with the decolonizing actions, based on Hart’s summary of colonization (see Table 2 column 2). In practice and within the context of research, decolonizing action number 1) involves *the inclusion of Indigenous people’s perspectives and experiences within the colonial reality* and should underpin all dimensions of decolonizing and Indigenous methodology. As Leroy Little Bear (2000) wrote in *Reclaiming Indigenous Voice and Vision*, “one of problems with colonialism is that it tries to maintain a singular social order by means of force and law, suppressing the diversity of human worldviews” (p.78). The inclusion of Knowledge Keepers and cultural protocols to inform and ground the research and its findings are the means by which Indigenous worldviews and insights can be revealed. Equally important, is positioning Indigenous people as the “knowers” in the research relationship. We are reminded of Datta's advice (2018) that academic researchers should be considered learners instead of discoverers.

Decolonizing action number 2) to *recreate the image of the group* is also central in the broader decolonizing agenda. Privileging Indigenous voices, perspectives, and worldviews in all knowledge-related aspects of the research process, regardless if you are looking at numbers or stories, is a deliberate act of resistance to western approaches that are typically led by non-

⁴ Battiste described the process of decolonization of education metaphorically in the form of the Medicine Wheel concept consisting of four doors or directions that illustrate the interconnectedness and process of decolonization. The Western door, mapping the contours of colonization; the North diagnosing colonization; the Eastern door “healing ourselves” and culminating in the south, a place of reclamation and growth of our knowledge systems.

Indigenous experts or knowers who tend to problematize Indigenous people (Walter & Andersen, 2016). These perspectives can provide “radically different insights into the statistical Indigene” (p.82), which is critical for recreating and reconceptualizing the image of the oppressed in the broader decolonizing agenda.

The third decolonizing action, *of reestablishing/recognition of the social, political, economic, and cultural reality of the people* can appear to be less visible in research. However, according to Margaret Kovach (2009), “decolonization” in research involves moving beyond a critique of colonization, to a critique of “the colonial relationships that persist inside academic institutions” (p. 84). This occurs by creating space in the academy, in research, and society for an Indigenous perspective so that it is no longer neglected, set aside, mocked, or dismissed. She argues that part of reestablishing or recognizing the social, political, economic, and cultural reality of the people, all of which are deeply intertwined and rooted in colonization, involves critically examining the colonial relationship that manifests itself in western-based policies and practices that govern research. It is not just about identifying and commenting on Indigenous oppression, but it is about transforming and “taking action” within the academy. This action involves maintaining our cultural epistemological positioning, shifting power away from researchers in controlling the research process and outcome, and weaving a decolonizing analysis throughout the research.

The iPHIT project began this action by reestablishing and acknowledging the role of First Nation leaders, Knowledge Keepers, and community members and by respecting them as active members of the research team (Phillips-Beck et al., 2019). This is consistent with Indigenous scholars’ perspectives on decolonizing research (Kovach, 2009; Smith, 2012). Datta (2018) argued that Knowledge-holders need to be considered as equal partners in the research because of the traditional knowledge that they impart. He wrote, Knowledge holders “carry the traditional teachings, the ceremonies, and the stories of all our relations” (p.18). However, until Indigenous organizations are considered legitimate research entities and have equal access to research funding, there is still yet more work to be done in achieving a post-colonial reality for Indigenous research. What the iPHIT research team was successful in doing was to acknowledge the political, social, and cultural reality of the First Nation communities in all presentations and publications of their findings by including the insights and relevant context provided by the

Knowledge Keepers. Indigenous scholars on the team, informed by these insights, were either sole presenters or partnered with their university counterparts at major conferences throughout North America, Europe, and New Zealand. Similarly, in planning the way forward, my doctoral dissertation clearly focused on the social and political realities that are faced by First Nation and Indigenous women in all presentations and future publication of the results, by keeping the focus on health policy and system change. Doing so is to acknowledge the current realities that negatively impact the lives of women, babies, and families residing in rural and remote communities in Manitoba.

The decolonizing characteristic described as *relationality or relationship building* fits also within decolonizing action 3) through the *recognition of the social, political, economic, and cultural reality of the people* in the larger decolonizing agenda. Relationality in a decolonizing framework has been described in many ways and is quite complex. It can refer to relationships to the participants, to other researchers, or described as connections to the land, water, territory, history, culture, treaties, and other peoples. Indigenous inquiry, Kovach (2009) argued, is relationship-based and relationships take a central position within an Indigenous framework. From an ethical standpoint, building relationships between researcher and the people (community) involves respectful, reciprocal, genuine relationships which lie at the heart of community life and community development (Smith, 2012). How building relationships and acknowledging the relationality of Indigenous people to their respective territories, water, land, or treaties intersects with the larger agenda of decolonization can be a matter of many interpretations but within this context, it involves acknowledging the social, political, economic and cultural strengths (including knowledge) of the people and taking the necessary time to build those relationships.

Decolonizing action 4), *empowering the oppressed group of people* is perhaps easier to recognize. In this interpretation, to be reflexive and aware of one's position of power, or repositioning yourself as a co-learner, taking a humble, humanitarian or empathetic stance or grounding yourself as an Indigenous learner, serves to level out the traditional western research hierarchy. Doing so empowers the research participant's community and Knowledge Keepers to become the "knowers" in the co-creation of knowledge. With knowing, comes power, as Berryman and colleagues (2013) state "the connection between power and knowledge is clear"

(p.3). When posing and addressing the question “who or what controls knowledge?” the researcher looks at the politics of access. Not only is epistemology important in understanding how others view the world, but it is also essential that researchers be clear about their own epistemology and ability to see beyond their limited understanding of knowledge production. In the iPHIT project, with such actions as the transfer of resources and shared governance with an Indigenous community-based organization, the inclusion of Knowledge Keepers as advisors, and hiring local research assistants, we were able to transform, to some extent, the historical power imbalance inherent in research and research funding requirements.

In planning the way forward in my doctoral dissertation, actions such as positioning Knowledge Keepers as ‘knowers’ and the inclusion of a Grandmother Advisor as an active member of the thesis committee served to recognize their traditional role of authority in the realm of knowledge. The inclusion of Knowledge Keepers as advisors was also transformative, as it is not commonly practiced or taught in population health research training in the University of Manitoba’s department of community health sciences, although I do acknowledge its wider practice by Indigenous researchers and within Indigenous research departments across Canada and other colonized countries around the world. The same goes for reflexivity. Being aware and cognizant of your positioning, or even repositioning oneself as a learner, by reflecting on power structures and leveling current power differentials are all actions working toward empowering Indigenous people and fall well within the larger frame of decolonization. This goes in tandem with what should be one of the benefits of research - providing communities with knowledge and the ammunition or supports to combat oppressive policies and structures (Thompson, Molina, Viswanath, Warnecke, & Prelip, 2016).

The decolonizing elements I grouped under *reconceptualization* (including knowledge translation and sharing) intersects with the broader decolonizing aim to *reform the impact of racism on health outcomes and deaths due to racism*. Reconceptualizing the problem and redirecting the gaze away from individuals is a decolonizing research strategy (Walter & Anderson, 2013) and dovetails directly into the larger context of decolonization. This is also consistent with Linda Smith’s (1999) decolonizing agenda, a strategy she called *intervening*: “the various departments and agencies involved in such a project are also expected to be willing to change themselves in some way – to redirect policy, design new programs or train staff

differently. Intervening is thus directed at changing institutions that deal with Indigenous peoples, and not at changing Indigenous peoples to fit the structures” (p.147).

The decolonizing characterizes grouped together in the decolonizing elements labeled *contesting institutional power structures* include Indigenous governance, accountability to Indigenous people, and transparency. *Meaningful engagement*, on the other hand, includes the concepts of participation and inclusion. Both of these decolonizing elements intersect with two decolonizing actions: a) empowering the oppressed group of people, b) recreating the image of the group although it can be argued that contesting current power structures and working toward Indigenous sovereignty (in this context research sovereignty) is *the* basic premise that underpins all decolonization actions, as stipulated in Articles 3 & 4 of the United Nations Declaration of the Rights of Indigenous People Article 3 and 4 (UN General Assembly, 2007). Entrusting grandmothers, Elders and Knowledge Keepers to frame the research questions or tell the story in their “own way” fits within the broader context of decolonization through the process of positioning them as “knowers” (as in other decolonizing actions), and not as participants in the study and allowing their voice to be heard. Governance and ownership of data (and research in general) is also a process directly related to empowering and working toward self-determination in research (First Nations Information Governance Centre, 2019).

The forced evacuation of women from rural and remote communities which occurs primarily in First Nation communities in Manitoba and throughout Canada is essentially an exercise of power. On an individual level, evacuated women are confronted by a lack of choice, not only in the decision to leave the community but during labour and birth. Evacuation impedes a woman’s ability to make decisions along with her family and community near the end of her pregnancy, and during her labour and birth; it also impacts the way in which a First Nation woman expressed herself through community celebration and ceremonies (Lawford & Giles, 2012). My dissertation, therefore, fits into the broader context of decolonizing aim by advocating to return the power of childbirth back to women and communities, a decolonizing action beginning at the earliest stages of life.

Last, but not least, the most significant decolonizing element is to *reorient the purpose and implications of research-oriented toward the benefit for Indigenous people*. These elements intersect with broader decolonizing action to recognize the social, political, economic

and cultural reality of the people. This was the least difficult to map. Both programs specifically began with this aim in mind as stated in the research objectives of both case studies.

2.10 Final thoughts (Conclusion)

In summary, in answering the question, *what exactly does decolonizing mean in the context of quantitative research*, I have extracted and described some common threads of what elements can be described and ascribed to as “decolonizing” in research. These characteristics were drawn primarily from the qualitative domain and from of three prominent scholars or sources. I then used these common threads or elements, which I have termed “decolonizing elements” to critique two case studies. I then mapped these elements onto the broader decolonizing action, based on Harts’ description of colonization to show how they are, in essence, aligned with the broader decolonizing agenda.

My claim that Indigenous and culturally informed methodologies all fall under the umbrella of “decolonizing” research may not be entirely correct, but it is my account. Common to all three methodologies is a desire to restore the balance of power in the research relationship, actively involve Indigenous people in the research, are relational-based and are respectful of Indigenous epistemologies, culture, and world views. This also includes working toward overt Indigenous agendas and self-determination in research. Reliance on strength-based indicators is an approach that can be built directly into the design of the project at the onset but if the type of data limit this approach, such as it often is in using secondary and administrative data sources, elements of decolonizing methodology can be built into a quantitative program of research as demonstrated by the two case studies.

In this paper, a decolonizing approach has been elevated to an overarching framework under which both Indigenous and culturally informed methodologies are embedded. Both case studies have incorporated elements of decolonizing methodology in different ways but both projects involved paying close attention to the “process” of working with Indigenous people. The way this occurs can be planned just as carefully as you would in choosing statistical methods. For the iPHIT project, having an Indigenous organization with Indigenous scholar representation on the team from the start was purposeful to ensure that the research followed sound ethical guidelines, including the principles of OCAP – ownership, control, access, and possession over the research process (Phillips-Beck et al., 2019). Careful consideration of each decolonizing

element or characteristic can be planned at the forefront of each research project. The first case study (iPHIT) moved beyond merely meeting these ethical guidelines into a shared decolonizing space, as the research relationship matured. This space is the place where research relationships and arrangements are negotiated in partnership with Indigenous people and can incorporate the strengths of both western and Indigenous ways of doing research. In some sense, this has been referred to as a two-eyed seeing approach (Martin, 2012). In the case of the iPHIT project, as it often is in research partnerships with Indigenous people, this relationship moved beyond “two-eyed seeing”, to two-worlds “walking” together in a shared research space and in a shared governance model. This shared journey is action-based and process-oriented, and the space where decolonization occurs.

In planning and staying the course in my doctoral journey, by dissecting what I perceived to be decolonizing elements of decolonizing and Indigenous research methodologies, I have been able to demonstrate how a decolonized stance is possible in an epidemiological study using population health data. Use of a decolonizing methodology in quantitative research does not at all preclude the use of complex statistical methods to make one’s point, but rather gives added meaning, strength, and purpose for the Indigenous people involved. In other words, it is the path that is shared and whose purposes are served that “decolonizes” quantitative research.

Through this exercise, I have been able to illustrate common elements from several decolonizing strategies that can be incorporated into a quantitative program of research. They can be applied or adapted and are useful as practical benchmarks to plan or assess future quantitative research. A research journey can be planned and well thought out using a matrix such as the one used in this critique. For us to achieve these ends, Indigenous scholars and non-Indigenous allies must work collectively to ensure that Indigenous peoples’ voices are heard and valued (Battiste, 2000). However, until such time Indigenous organizations such as FNHSSM are recognized by research funding bodies as legitimate research entities, and decolonized approaches in quantitative inquiry are not on the fringes of the academy, we must work together toward this end. A decolonizing framework in my research was to first begin by careful reflection and an examination of my own biases and assumptions that have been learned in western institutions and training, and by paying careful attention to avoid perpetuating the power differential that is pervasive in western institutions. Unequivocally, there is no other pathway

that I would rather follow in undertaking my doctoral journey. After much learning and reflecting, there was no other option for me to use anything other than a decolonizing approach embedded within an Indigenous framework to guide my overall dissertation study. I end with these words of wisdom regarding Indigenous research methodology:

Such inquiry should meet multiple criteria. It must be ethical, performative, healing, transformative, decolonizing, and participatory. It must be committed to dialogue, community, self-determination, and cultural autonomy. It must meet people's perceived needs. It must resist efforts to confine inquiry to a single paradigm or interpretive strategy. It must be unruly, disruptive, critical, and dedicated to the goals of justice and equity.

(Denzin, Lincoln, & Smith, 2008, p. 2).

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A Decolonizing Approach in Population Health Research

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CHAPTER 3 Doing research in a good way: “Mino-doodaman” (The Study)

3.1 Preface

In the proceeding paper, I shared my story of learning, planning, and carrying out a research project in Manitoba, and charting the course for my dissertation research, drawing upon and reconciling the strengths of both western and Indigenous methods and methodologies. The third paper of this dissertation reports on a cohort study utilizing administrative data from the Population Research Data Repository at the University of Manitoba’s Manitoba Centre for Health Policy. This paper that follows is entitled “A retrospective cohort study utilizing an Indigenous framework and linked administrative data to compare differences in maternal and child outcomes by the presence or absence of the federal ‘out for confinement’ (OFC) policy in Manitoba First Nation Communities, 2005-2015.”

This study focused on the impact of the OFC policy, a colonial health policy that has forced Indigenous women living in rural and remote communities in Canada to leave home and family to give birth to their babies. The paper intentionally targets a scientific and health policy audience and presents the results and analysis of this retrospective study. In keeping with a decolonizing approach, this study focused on the health system and on the policy that impacts women and families rather than on the women themselves. I incorporate teachings obtained in the preparatory phase of the research and the wisdom of an advisory circle of Grandmothers/Knowledge Keepers to interpret and report on the data.

3.2 Introduction

This retrospective cohort study examined the impact of the federal policy of evacuating women residing in rural and isolated First Nation communities in Manitoba at 36-38 weeks gestation to urban locations to deliver their babies. The overall objective was to generate a baseline of key markers that may be sensitive to this policy in response to the TRCC Call to Action #19, which calls upon all levels of government to close the gap in measurable maternal and child outcomes between Aboriginal and non-Aboriginal communities (Truth and Reconciliation Commission of Canada, 2015). These measurable outcomes include infant mortality, maternal physical and mental health, birth rates, and infant/child health - indices where Indigenous people rank the highest or fare the poorest. This study is the first of its kind to incorporate both an Indigenous framework, decolonizing elements, and western methods to link

whole-population level administrative data to determine whether there is an association between being evacuated for birth and maternal, infant and child health outcomes. In this paper, I use the term “Indigenous” when referring to the broader original peoples native to the lands of Canada, New Zealand or Australia. I use the accepted term “First Nation” to refer to one of the three recognized Indigenous Peoples in Canada (First Nations, Métis, and Inuit), who have registered Indian status recognized by the federal government in Canada. However, where citations or references use other nomenclature such as “Aboriginal”, the original text has been retained.

The release of the TRCC report highlighted that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies and called directly upon the federal, provincial, territorial, and Aboriginal governments to recognize and implement the health-care rights of Aboriginal people (Truth and Reconciliation Commission of Canada, 2015). While the TRCC focused primarily on the devastating impact of residential schools and child welfare policies, there remains a present-day policy that continues to impact First Nation women and families in a profoundly negative way (Kornelsen, Kotaska, Waterfall, Willie, & Wilson, 2010; Lawford & Giles, 2012; Olson & Couchie, 2013, Phillips-Beck, 2010). This policy is known as the federal government’s OFC policy, sometimes referred to as the maternal “evacuation policy” (Lawford & Giles, 2012). This policy demands and enforces the systematic removal of women from their communities at 36-38 weeks gestation to urban centres, often hundreds of kilometers away, to deliver their babies (Phillips-Beck, 2010). In Canada’s large urban centres, the women await the delivery of their babies and recover during the immediate postpartum period, typically in isolation from their families and communities (Lawford & Giles, 2012). This policy has been referred to as an ‘invisible’ federal policy, since the details of this policy remain largely undocumented, but its practices can be located in the Health Canada Clinical Practice Guidelines for federal northern nursing stations. It has also been viewed as an ongoing system of oppression (Cidro, Bach, & Frohlick, 2020).

Removing women to deliver their babies has been widely implemented since the 1970s (and in some communities since the 1950s), has impacted women living in remote First Nation communities, regardless of whether they are First Nation, Métis, or non-Indigenous. However, for First Nation women and for First Nation people living on reserve, the provision of care and transportation costs fall under the jurisdiction of the federal government, and up until 2017,

transportation costs for maternal evacuation were only granted for the expectant mother, and only allowed for the provision of an escort if the mother was under the age of 16 or had some type of disability. This meant that the majority of women traveled to the city to give birth alone, without any social support (Olson & Couchie, 2013). Fortunately, under immense pressure from Indigenous scholars and women's advocacy groups, this medical escort policy changed in 2017 and the federal government began to allow pregnant First Nations women to leave home with a travel companion to accompany them while they were out for confinement.

Not all women and families living in First Nation communities are subject to this policy. Geographically isolated communities often do not have the population, resources, or capacity to support infrastructure or staffing for the full spectrum of maternity care. Women residing in communities that are not isolated or are within a reasonable driving distance from a delivery centre can remain at home until delivery is imminent. The result is a collection of maternal/child health services with disparate administrative, governance, and implementation systems (Smith, Edwards, Varcoe, Martens, & Davies, 2006). In Manitoba, this roughly translates as a little more than half the First Nation communities being within 2 hours driving distance of a delivery centre, and 26 of the 63 First Nation communities routinely evacuating women to deliver their babies. In Manitoba, the OFC policy generally operates in the 26 communities with a nursing station model of care. The nursing stations are nurse-managed primary care units, staffed by nurses who function with an expanded scope of practice (Katz et al., 2019; Lavoie, Phillips-Beck, Kinew, & Katz, 2020). This expanded scope of practice includes the provision of routine primary care (Tarlier, Johnson, Browne, & Sheps, 2013). According to the Strengthening Families, Maternal Child Health Program Advisor, three of the most populated First Nation communities in Manitoba with the largest birth rates - greater than 100 births a year - are among those 26 communities that evacuate their women to give birth (Campbell, 2019).

The OFC policy, and the removal of birth from communities, have been the subject of much criticism. It has been described as a "colonial policy whose practices reveal the extent of the colonial and patriarchal manner in which Canada, in cooperation with the medical establishment, developed policies that had a directly negative impact on First Nations women, their families and communities. The implementation of this policy has been reported to have made little difference in maternal and infant health outcomes" (Lawford & Giles, 2012, p.334).

A volume of qualitative work has shed light on the OFC policy, particularly in the past 10 years, regarding the damage it has inflicted on Indigenous women and families. These harms include family and individually perceived stress, family discord, family breakups, separation/isolation, anxiety, fear, depression, loneliness, and interference in the bonding experience (Phillips-Beck, 2010; Olson, 2013). Phillips-Beck (2010) argued the practice of removing and isolating women from their communities and families continues to advance the agenda of colonization, accomplished through the disruption of celebration and cultural practices (such as traditional rituals to name and welcome the child) and traditional knowledge pathways. The loss of cultural knowledge in caring for pregnant women and babies has had dire consequences on individuals, communities, identities and on health outcomes as noted by the Royal Commission on Aboriginal Peoples (RCAP) and others (Kornelsen et al., 2010; Lawford & Giles, 2012; Olson & Couchie, 2013; Royal Commission on Aboriginal Peoples, 1996). This is in stark contrast to how it was in the past. Aboriginal women gave birth in their communities where traditional cultural practices and celebration were important for establishing strong community roots for the mother, her infant, and the family. Children born in their own communities developed a clear sense of their individual and community identities that helped them to become resilient and responsible members of that community (Society for Obstetrics & Gynecology Canada, 2010).

It is no wonder that returning birth to remote and Indigenous communities is at the forefront of much discussion for Indigenous women, communities, and scholars. However, addressing the harms of the OFC policy is not the “cure all”, nor a simple task. It involves untangling the longstanding jurisdictional impasse between federal and provincial governments, acknowledging inequity in how health care is delivered in these settings, and understanding how the policy directly impacts the ability to provide maternity and midwifery care in these settings.

Implementation of maternity and midwifery care in Indigenous communities, whether it is western or traditional midwifery care, has become very much dependent on the relationship between the federal and provincial governments in multiple provinces in Canada, and mitigating possible tensions in that interaction, rather than focusing on the immediate health needs of Indigenous peoples in their communities. Solutions (and reconciliation) to address the harm that the OFC policy has caused must occur on multiple levels: in communities, in the policy arena, between Indigenous organizations and governments, and between and within governments. This

includes acknowledging that all levels of government (local/provincial/federal), including Indigenous governments, are intimately intertwined in this conversation (Olson & Couchie, 2013). There is no better way to begin this conversation with all levels of governments and decision makers than to speak in the language of numbers and statistics, and to begin this conversation from the perspective of an Indigenous woman, mother and researcher. Although the impact of this policy has been long known and written about in multiple mediums, this is the first study of its kind to explore the impact this policy has on a population level.

However, population health and research methods have been critiqued for their portrayal or lack of engagement of Indigenous people (Marmot, 2012; Smylie et al., 2012; Walter & Andersen, 2016). As Dunn (2012) argued, epidemiology “dominated by the trappings of positivism, it is a field in need of further development of epistemological frameworks that can adequately incorporate richer explanations of the phenomena we study” (p. 24). Unfortunately, there are limited data and published studies on the development and inclusion of Indigenous frameworks in epidemiology and population health to model after. This study is one component of a larger dissertation exploring the use of Indigenous frameworks and voice in population health research.

3.3 Methods

3.3.1 Indigenous Framework

A decolonizing approach, embedded within an Indigenous framework adapted from Margaret Kovach (2009) guided this research project. As such, this project, in partial fulfillment of the doctoral program in the department of community health sciences at the University of Manitoba, began with a year of preparation. Prior to the writing of the proposal, I sought advice from a Grandmother Knowledge Keeper whose area of expertise was in women’s teachings. She advised me to begin by learning about the traditional role of caring for pregnant women and in childbirth. From this point onward, she agreed to join the academic committee and attended all scheduled team meetings and made herself available to advise on all matters of protocol and provide insights on traditional/cultural knowledge related to the research topic. She was regarded as the Grandmother and cultural advisor on the academic team from this point, and she officially launched the research journey with a traditional ceremony in the summer of 2017. Additionally, upon her advice, guidance was sought from the FNHSSM Knowledge Keepers Council in 2018

regarding my research question and outcome variables. They provided insights on the traditional role of family, traditional practises of the past and the impact of removing women from their communities. This information was valuable in finalizing the research questions and choice of variables. At a subsequent workshop, the Knowledge Keepers Council gave their blessing on the final research question and outcome variables after some discussion on the limitations of the administrative data. In February 2020, the guidance of the Knowledge Keepers Council was sought in viewing the preliminary results. This approach and methodology are the topic of a concurrent manuscript. While being aware of the space that is needed to capture Indigenous voice and vision, western concepts are used to explain the study design and methods in a manner that will be understood by western trained researchers.

The study was approved by the Health Research Ethics Board (HREB) at the University of Manitoba and the provincial Health Information Privacy Committee (HIPC). As the study population is primarily First Nation women living on reserve, further permission was obtained from the First Nations Health Information Research Governance Committee (FNHIRGC) of FNHSSM.

3.3.2 Study Design

A retrospective cohort design was selected, utilizing administrative data held in the Manitoba Population Research Data Repository (Repository) housed at the Manitoba Centre for Health Policy (MCHP). MCHP is a research unit that carries out population-based research on health services, population and public health, and the social determinants of health within the Department of Community Health Sciences, in the Max Rady College of Medicine, Rady Faculty of Health Sciences at the University of Manitoba. The Repository is a comprehensive collection of administrative, registry, survey, and other data about residents of Manitoba that are procured from a variety of government department administrative datasets, such as healthcare visits to hospitals, physicians, emergency departments and specialists, homecare, and personal care homes; pharmaceutical prescriptions; education; social/family services; income assistance and social housing; justice; and various registries such as the Manitoba Health Insurance Registry and Vital Statistics Mortality Registry.

The data are de-identified so that individual interactions with services can be linked but cannot identify the people seeking them. De-identified means that personal identifiers, such as

names and addresses, are removed before the data are transferred to the Repository to protect privacy. Each record comes with a scrambled identifier which allows for data linkage between each record in each various health and social dataset.⁵ For this study, data were obtained from:

- *Manitoba Hospital Abstracts file* including data related to childbirth such as, region/location of birth, facility type, delivery of an infant, sex, birth weight, gestational age at delivery, multiplicity, and breastfeeding initiation. Maternal factors were included such as diagnoses of maternal distress/depression, pre-existing or chronic illness in pregnancy, procedures such as C-section deliveries, and information on all hospitalizations for birth.
- *Medical Claims/Medical Services file* to determine services provided, ambulatory care visits, confirmed chronic diseases in pregnancy and other comorbidities including information on physician claims visits. Information was obtained from the Manitoba Prenatal Care (PNC) record to determine the date of initiation of PNC and the number of prenatal visits to calculate PNC utilization.
- *Drug Program Information Network file* including drug dispensations for Manitoba residents (including Registered First Nations) regardless of insurance coverage or final payer. Information on all prescription medications dispensed related to psychological disorders or chronic illness.
- *Manitoba Health Insurance Registry* including information on all women eligible for health care in the province including demographic information such as age, age at first birth, marital status, number of children born to women, and residential postal codes.
- *Healthy Child Manitoba* file to determine receipt of the Government of Manitoba prenatal benefit for pregnant women.
- *Manitoba Child and Family Services information* including applications and intake information to determine whether children were taken into care.

⁵ see more about MCHP at http://umanitoba.ca/faculties/health_sciences/medicine/units/chs/departamental_units/mchp/about.html

Figure 1: Manitoba Population Research Data Repository



3.3.3 Cohort development and exclusions

Data were extracted for all women residing in First Nation communities who gave birth in Manitoba between the fiscal years 1995 to 2018 (23-year time frame) using the most recent years of data, 2005-2015, to determine the final cohort. This included both First Nation and non-First Nation women as they are all subject to the same policy, although most women would be First Nation. This timeframe allows for the exclusion of a prior diagnosis of pre-existing chronic illness 10 years prior to delivery and to capture the diagnosis of maternal psychological distress eight months following the birth. Likewise, this timeframe allowed identification of children going into care one year following the birth of the focus child. Due to the likelihood that mothers would have had more than one child during the study period, one random child was selected per mother and included in the analysis. This was done to remove the effect of multiple deliveries and biases due to lack of independence between all observations. Maternity records that could not be linked to the notification of birth record lacked a recorded gestational age, did not have

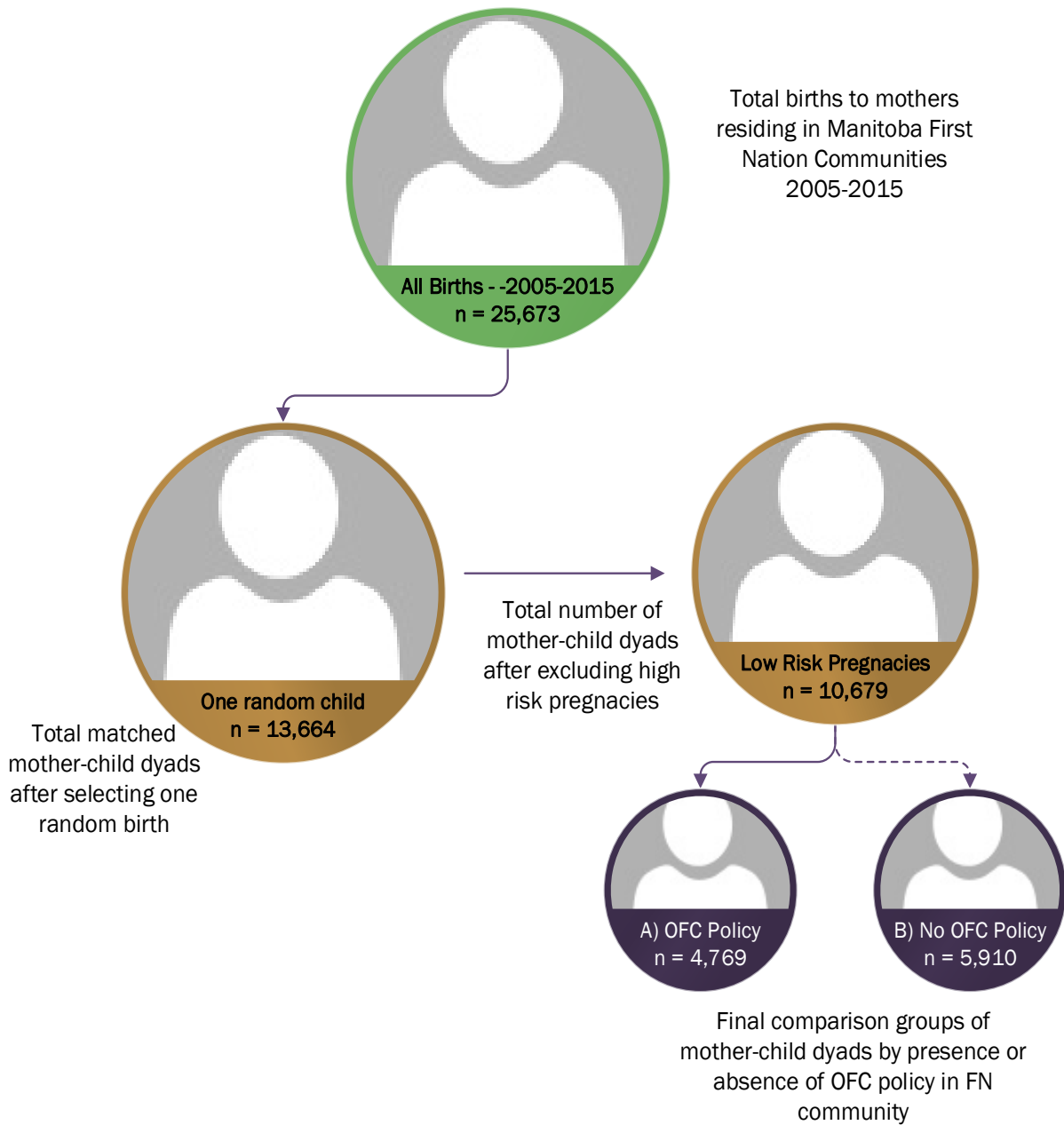
information on the PNC record or did not have a personal identification number (not covered by Manitoba Health) were excluded.

To create two comparable groups with equal likelihood of receiving similar levels of PNC, and to decrease bias resulting from more frequent health care visits and hospital care associated with high-risk pregnancies, only low risk deliveries were chosen for each cohort. Low risk pregnancies were defined as mothers who gave birth between the ages of 16-35 to singleton babies and did not have gestational diabetes or preexisting medical conditions such as diabetes, renal disease, and hypertensive disorders and maternal psychological distress. Conversely, high-risk pregnancies were defined as those where either the mother, the baby, or both had a higher-than-average chance of developing complications due to a health problem that the mother had before she become pregnant, or could have developed during pregnancy or delivery (CIHI, 2004).

Previous studies in a similar Manitoba population showed that medical conditions such as multiple births, hypertensive disorders, diabetes, maternal psychological distress and other chronic illnesses are associated with lower odds of inadequate PNC. Additionally, pregnant women with medical risks may seek out more PNC, or may have more PNC due to increased follow-up and/or referrals to specialists, compared to those without the conditions (Heaman et al., 2018). Multiple births are also considered to be high-risk given their increased risk for miscarriage, preterm birth, gestational diabetes, pre-eclampsia, and other health issues requiring more frequent monitoring and potentially more specialized birthing skills, placing higher demands on health care providers. Like multiple births, births by women over 35 are often considered high-risk because of their increased risk for birth defects and other pregnancy complications (CIHI, 2004). More recent evidence in Canada suggests that women over 35 are not at increased risk, depending on age at first birth (Schummers et al., 2018), however, based on the information at the time of this dissertation work, and current practices in First Nation communities, exclusions included: mothers considered high risk due to presence of pre-existing chronic illnesses, multiple births such as twins or triplets, or age less than 16 and greater than 35 years. Rather than exclude mothers with a history of previously diagnosed maternal psychological distress, this was included in all 8 models to determine if there was an association with the selected outcomes.

Mothers were divided into two groups: A) those from communities that enforced the OFC policy (generally, those communities that have a nursing station model of care and are either isolated or semi-isolated and enforce the OFC policy), and B) those from communities with no OFC policy.

Figure 2: Cohort Tree



3.3.4 Outcome variables and covariates

With these previous studies in mind, and after discussions with the Knowledge Keepers Circle and a review of the literature, the following outcome variables were selected: 1) Inadequate PNC, 2) Breastfeeding initiation, 3) Child taken into care in the 1st year of life, 4) maternal psychological distress (prenatal & post-natal), 5) Large for Gestational Age (LGA), 6) Small for Gestational Age (SGA), 7) Preterm Birth and 8) Infant death in the 1st year of life. These variables are defined below, and data sets are identified (see Table 3).

Table 3 - Variable descriptions and definitions

Variable	Definitions and data sources
1. Inadequate PNC Utilization:	<p>Adequacy of PNC utilization was obtained through the Manitoba prenatal record, physician claims and hospital separation abstracts and calculated using the Revised Graduated PNC Utilization Index (Alexander & Kotelchuck, 1996; M. I. Heaman, Green, Newburn-Cook, Elliott, & Helewa, 2007).</p> <p>The R-GINDEX is useful in studying the relationship with pregnancy outcomes because it assigns a lower percentage of women to intensive care than other indices of PNC and is less likely to demonstrate effect modification by gestational age when studying the association of inadequate PNC with low birth weight or being small for gestational age (Heaman et al., 2019).</p> <p>With this index, PNC is normally divided into three categories: 1) Inadequate/no PNC, 2) Intermediate adequate or 3) Intensive/adequate. However, as all high-risk women were excluded in this study, and assuming lower risk women would have similarly accessed standard number of PNC visits as recommended by their health care provider in Manitoba, adequacy of PNC was modeled as a dichotomous variable and defined as 1=Inadequate PNC (receiving no care/inadequate care) and combining all other categories as 0=Adequate PNC as per (Brownell, Chartier, Au, & Schultz, 2010).</p> <p>In this regrouping, Inadequate PNC was defined as mothers with a low score on the Revised-Graduated PNC Utilization Index (R-GINDEX), generally mothers commencing care after the first trimester >13 weeks of pregnancy, and received less than the recommended number of PNC visits and/or no PNC was accessed.</p> <p>Adequate PNC was defined as those mothers who received a higher score on the R-GINDEX (generally as having received the recommended number of visits to a primary care provider, or more) and having commenced care in the first trimester.</p>
Size for Gestational Age was obtained from hospital separation abstracts and includes:	
2. SGA birth:	A birth was considered to be SGA if the birth weight was at less than the 10th percentile for gestational age and sex using a Canadian standard as defined in (Heaman et al., 2012).
3. LGA birth:	A birth was considered to be LGA if the birth weight was above the standard 90th percentile for gestational age and sex using a Canadian standard as defined in (Heaman et al., 2012).
4. Preterm birth	Data were obtained from hospital separation abstracts. Preterm birth was defined where the gestational age of the infant is less than 37 weeks as defined in (Heaman et al., 2012).
5. Breastfeeding initiation	Breastfeeding data were obtained from the hospital separation abstracts. Breastfeeding initiation is identified as any live born newborn hospitalization (defined with ICD-9-CM codes V30 to V39 or ICD-10-CM) where partial or exclusive breastfeeding was instituted while in hospital (Heaman et al., 2012).

Variable	Definitions and data sources
6. Maternal psychological distress	Maternal psychological distress was defined as the presence of any hospital abstracts or physician billing claims coding depression or anxiety between 8 months before the birth and 12 months after birth as defined by (Heaman et al., 2007; Heaman et al., 2012). As per Heaman and colleagues (2012), the Perinatal Services and Outcomes in Manitoba report a woman is considered to have prenatal psychological distress if in the eight months prior to giving birth (or hospital discharge in case of a stillbirth) she had: one or more hospitalizations with a diagnosis for depressive disorder, affective psychoses, neurotic depression, or adjustment reaction OR one or more physician visits with a diagnosis for depressive disorder, affective psychoses, or adjustment reaction OR one or more hospitalizations with a diagnosis for anxiety disorders OR one or more prescriptions for an antidepressant or mood stabilizer OR one or more physician visits with a diagnosis for anxiety disorders AND one or more prescriptions for an antidepressant or mood stabilizer OR one or more hospitalizations with a diagnosis for anxiety states, phobic disorders, or obsessive– compulsive disorders OR two or more physician visits with a diagnosis for anxiety disorders.
7. Child/children in Care	Data were obtained from the Child and Family Services Information System (CFSIS) and Child and Family Services Application Data. Children in care was defined as children removed from the care of their original families for more than a day because of a situation where authorities have deemed their family unable or unfit to look after them properly. In some cases, children are voluntarily placed into care by their parents or guardians (Brownell et al., 2010).
8. Infant Death	Data on infant death was obtained from Vital Statistics data and is defined as a death of a liveborn infant in the first year of life.

3.3.5. Main exposure predictor variable

The main exposure variable was the presence of the OFC in the community, as ascertained by determining which type of community the women resided in (those that sent women out prior to their delivery with an OFC policy compared with those communities that did not have an OFC policy). The determination and presence of the OFC policy in the First Nation community was made based on a recently published report, *The Health Status of and Access to Healthcare by Registered First Nation Peoples in Manitoba* (Katz et al., 2019), and verified by the primary author’s 25 plus years’ experience working in the First Nation health sector.

3.3.6 Covariates

A similar process (as was taken in the selection of outcome variables) was undertaken in the selection of covariates and included those variables reported in the literature. Included in the analysis of covariates were a) receipt of Healthy Baby Benefit (HBB), b) maternal age, c) maternal age at first birth, d) marital status, e) location of birth, Manitoba’s Regional Health Authorities (see below), f) birth order, and g) previous diagnosis of maternal psychological distress. The HBB introduced in 2001 in Manitoba by the Healthy Child Manitoba Office is a targeted income supplement for low-income women (Brownell et al., 2016).

Location of birth variables were created from Manitoba's five regional health authorities (RHA). Each RHA has a Board of Directors which is appointed by the Minister of Health, Seniors and Active Living in accordance with the provisions of The Regional Health Authorities Act. Health authority boards are accountable to the Minister of Health, Seniors and Active Living for the mandate, resources, and performance of the health authority. They are geographically organized as such, with the Winnipeg RHA representing the largest urban centre in Manitoba. The five RHA's in Manitoba are abbreviated as following in the analysis:

- Winnipeg (WP)
- Interlake - Eastern (IE)
- Southern - Santé Sud (SO)
- Prairie Mountain (PM)
- Northern (NO)

3.3.7 Analysis

With one random child chosen per mother, summary statistics were produced for each outcome variable and cross tables produced by whether the community had an OFC policy or not (OFC policy being the primary predictor variable). Quantitative data and differences between two groups were analyzed using Student t-test for maternal age and maternal age at first birth. Significance was set as $p < 0.05$. Equality for variance was tested utilizing the Folded F-test. As such, finding equal variances for maternal age at birth of first child, the Pooled t-test statistic was used to compare differences and finding no equal variances with maternal age at first birth, the Satterthwaite method was used to derive the t-value. Squared ranks test (non-parametric Wilcoxon t-test) was used to derive the z-scores for the number of PNC visits and the Kruskal-Wallis test was performed to test for equality of variance for both. Secondly, each of the eight outcome variables were then treated as dichotomous variables and eight regression models were run independently using SAS V9 to calculate odds ratios and confidence intervals to determine association between each outcome variable and the OFC status of the community.

All models were run testing for an interaction between maternal age and age at 1st birth. Finding no significant interaction, maternal age and age at 1st birth were included in each model as independent variables. All models initially were run with time as a confounder, divided in increments of 5 years. However, finding no statistically significant effects, time was removed

from each model. Goodness of fit for each model was measured using Pearson's Chi-square statistic.

Table 4 - Regression models and covariates included in model

Regression Models/Outcome variable	Covariates
1. Inadequate PNC	a) receipt of HBB, b) maternal age, c) maternal age at first birth, d) marital status, e) location of birth (RHA), f) birth order g) previous diagnosis of maternal psychological distress *
2. Breastfeeding initiation	a-g and h) location of birth
3. Child in care 1 st year of life	a-g and h) location of birth
4. Diagnosis of maternal psychological distress post-term	a-g and h) location of birth
5. Large for Gestational Age (LGA)	a-g and h) location of birth
6. Small for Gestational Age (SGA)	a-g and h) location of birth
7. Preterm birth	a-g and h) location of birth
8. Infant died in 1 st year of life	a-g and h) location of birth

*The RHA/location where the birth occurred was not included in Model 1 (PNC) due to illogical sequence of events, given the hospital of birth could not possibly predict the adequacy of PNC.

3.4 Results

The number of babies delivered to women residing in a First Nation community between 2005-2015 was n=25,861. After selecting one random child per mother, and after excluding all high-risk women, the final cohort numbered n=10,679.

Table 5 - Characteristics and differences between mothers (both First Nation/non-First Nation) who had a live birth and residing in First Nation Communities in Manitoba 2005-2015

n= 10,679										
	Community has an Out for Confinement Policy								Test statistic	p
	No				Yes					
	Mean	Std Dev	Min	Max	Mean	Std Dev	Min	Max		
	n=5,910				n=4,769					
Maternal age at birth	24.4	5.0	15.0	35.0	23.7	5.0	15.0	35.0	t=7.78	<.0001
Mother's age at first birth	20.9	4.0	13.4	34.9	19.8	3.0	13.3	34.8	t=16.36	<.0001
# of children at child's birth	2.2	1.4	1.0	11.0	2.4	1.7	1.0	12.0	z=4.33	<.0001
# of PNC visits	9.3	3.9	0.0	35.0	8.1	4.2	0.0	36.0	z=19.18	<.0001

The mothers’ mean age in the OFC group was slightly lower than in the communities with no OFC policy (0.7 years less), as was the age at which they had their first baby (19.8 compared to 20.9), which were both statistically different ($t=7.78$ $p<.0001$ and $t=16.36$ $p<.0010$, respectively). The parity of women at the time of selection of the one random child was statistically different. The average number of PNC visits was statistically different with 1.2 visits less for women in the communities with an OFC policy ($z=19.18$ $p<.0001$), without accounting for the trimester in which PNC was initiated and the gestational age of the child as used as the final calculation of inadequate PNC using the R-GINDEX method.

Table 6 - Odds Ratios of each outcome variable by presence of OFC Policy in First Nation Community 2005-2015

Model/outcome variable	OFC Policy				Adjusted OR (95% CI)
	No n=5,910		Yes n=4,769		
		%		%	
1. Inadequate PNC	1539	26.0	1874	39.3	1.64 (1.51, 1.79)
2. Breastfeeding initiation	4017	68.0	2522	52.9	0.55 (0.50, 0.61)
3. Child in care 1 st year of life	298	5.0	213	4.5	0.98 (0.79, 1.21)
4. Diagnosis of maternal psychological distress	817	13.8	253	5.3	0.43 (0.36, 0.51)
5. LGA	1033	17.5	839	17.6	1.04 (0.92, 1.18)
6. SGA	350	5.9	301	6.3	1.25 (1.03, 1.52)
7. Preterm birth	336	5.7	290	6.1	0.91 (0.76, 1.10)
8. Infant died in 1 st year	43	0.7	36	0.8	0.96 (0.58, 1.60)

Location of birth was not included in Model 1 (PNC) due to illogical sequence of events, the hospital of birth could not possibly predict the adequacy of PNC. **BOLD** – Statistically significant

Table 6 shows the numbers, frequencies and results from the logistic regression for each of the eight outcomes examined. These findings indicate that the OFC policy was significantly associated with inadequate PNC (OR 1.64 CI 1.50, 1.78), SGA (OR 1.25 CI 1.03, 1.52) and inversely associated with breastfeeding initiation (OR 0.55 CI 0.50, 0.61) and being diagnosed with maternal psychological distress (OR 0.43 CI 0.36, 0.51) after adjusting for various factors outlined in the methods. No association was found between residing in a community with an OFC policy and LGA, preterm birth, or whether the infant was taken into the care or died in the first year of life. Each outcome variable showing significant results will be discussed further.

Table 7 - a) Model 1: Odds of Inadequate PNC and covariates

Odds Ratio Estimates – Inadequate PNC		
	Point OR estimate	95% Wald Confidence Limits
Mother resides in a community with OFC Policy Yes vs No	1.64	(1.51, 1.79)
Receipt of HBB Yes vs No	0.85	(0.78, 0.93)
Maternal age	0.94	(0.92, 0.95)
Age at 1st Birth	0.97	(0.97, 1.01)
Married/Common law Yes vs No	0.49	(0.41, 0.58)
Birth order 2 nd or 3 rd vs 1 st born	1.84	(1.63, 2.07)
Birth order 4+ vs 1 st born	3.76	(3.06, 4.62)
Previous diagnosis of maternal psychological distress Yes vs No	0.79	(0.69, 0.91)

Overall, the proportion of women who delivered a baby between 2005-2015 who resided in a First Nation community in Manitoba and had inadequate PNC was 32% (3413/10,629). The proportion of women residing in community with an OFC policy with inadequate PNC was much higher at 39.3% (1874/4769), compared to the proportion of women in a community where no such policy existed at 26% (1539/5910). The odds of having inadequate PNC for women living in a community that has an OFC policy was 1.64 times higher compared with women residing in communities that do not. This main effect was modified (increased) by birth order (OR 1.84 if born 2nd or 3rd and OR 3.76 if born 4th or later) and decreased by ~50% if they were married. The odds of having Inadequate PNC decreased slightly if they had received the HBB (OR 0.85), or they had a previous diagnosis of maternal psychological distress (OR 0.79).

Table 8 - b) Model 2: Odds of Breastfeeding Initiation and for covariates

Odds Ratio Estimates - Breastfeeding		
	Effect Point Estimate	95% Wald Confidence Limits
OFC Policy in First Nation Yes vs No	0.55	(0.50, 0.60)
Receipt of HBB Yes vs No	0.90	(0.83, 0.98)
Maternal age	1.03	(1.01, 1.05)
Age at 1st Birth	1.05	(1.05, 1.07)
Married/Common law Yes vs No	2.13	(1.81, 2.51)
Hospital RHA NO vs IE	1.10	(0.80, 1.49)
Hospital RHA SO vs IE	1.14	(0.83, 1.57)
Hospital RHA PM vs IE	0.83	(0.60, 1.13)
Hospital WP vs IE	0.99	(0.73, 1.35)
Birth order 2 nd or 3 rd vs 1 st born	0.63	(0.56, 0.71)
Birth order 4+ vs 1 st born	0.41	(0.33, 0.50)
Previous diagnosis of maternal psychological distress Yes vs No	1.05	(0.93, 1.19)

The overall proportion of women in the study population that initiated breastfeeding was 61%, while the proportion of women residing in a community with no OFC policy was much higher at 68% (4017/5910) compared to the proportion of women who resided in community with an OFC policy at 53% (2522/4769). This is also far below the breastfeeding initiation rates for women across Manitoba at 83% (Martens et al., 2016). The odds of initiating breastfeeding for women living in a community that has an OFC policy were 45% lower compared to women residing in communities without OFC policy. The odds of the mothers initiating breastfeeding increased if they were married (OR 2.1 CI 1.81, 2.51). In the first run, the location of birth was significant, but when stratified by RHA, the differences were non-significant compared to the reference category, the Interlake Eastern RHA. The odds of initiating breastfeeding is modified (decreased) if they were other than the first born (OR 0.63 CI 0.56, 0.71), if born 2nd or 3rd and (OR 0.41 CI 0.33, 0.50) born 4th or later, and decreased very slightly if they received the HBB. Having a previous diagnosis of maternal psychological distress was not statistically significantly associated with whether mothers initiated breastfeeding.

Table 9 - c) Model 4: Odds of maternal psychological distress and for covariates

Odds Ratio Estimates		
	Effect Point Estimate	95% Wald Confidence Limits
OFC Yes vs No	0.43	(0.36, 0.51)
Receipt of HBB Yes vs No	1.19	(1.04, 1.38)
Maternal age	1.01	(0.98, 1.04)
Age at 1st Birth	0.99	(0.96, 1.02)
Married/Common law Yes vs No	0.65	(0.50, 0.85)
RHA NO vs IE	0.64	(0.42, 0.98)
Hospital RHA SO vs IE	0.54	(0.35, 0.84)
Hospital RHA PM vs IE	0.99	(0.66, 1.51)
Hospital RHA WP vs IE	0.69	(0.46, 1.04)
Birth order 2 nd or 3 rd vs 1 st born	1.27	(1.04, 1.55)
Birth order 4+ vs 1st born	1.51	(1.09, 2.08)
Previous diagnosis of maternal psychological distress Yes vs No	7.66	(6.62, 8.86)

The overall proportion of women who developed maternal psychological distress during pregnancy and the first two years after delivering a baby was 10% (1070/10679). The proportion of women who developed maternal psychological distress residing in community with no OFC policy was higher (13.8%) compared to 5.3% for the women that resided in a community with an OFC policy. Residing in a community with an OFC policy was inversely associated with the development of maternal psychological distress (OR 0.43 CI 0.36, 0.51). Factors associated with reduced odds of developing maternal psychological distress in pregnancy and the 2-year interval following the birth were whether the women were married (OR 0.65 CI 0.50, 0.85), and delivered their babies in the Northern RHA (OR 0.64 CI 0.42, 0.98), Southern/Sud RHA (OR 0.54 CI 0.35, 0.84) as compared to the Interlake Eastern RHA (ref category). Factors associated with slight increased odds were whether the mother received the HBB (OR 1.19 CI 1.04, 1.38) or if child was 4th born or higher (OR 1.51 CI 0.4, 0.84). Having a previous diagnosis of maternal psychological distress was strongly associated with the development of maternal psychological distress (OR 7.67 CI 6.62, 8.86).

Table 10 - d) Model 6: Odds for Small Gestational Age and covariates

Odds Ratio Estimates		
	Effect Point Estimates	95% Wald Confidence Limits
OFC Yes vs No	1.25	(1.03, 1.53)
Receipt of HBB Yes vs No	1.15	(0.97, 1.35)
Maternal age	1.05	(1.01, 1.08)
Age at 1st Birth	1.00	(0.96, 1.04)
Married/Common law Yes vs No	0.81	(0.60, 1.08)
RHA NO vs IE	0.63	(0.36, 1.10)
Hospital RHA SO vs IE	0.98	(0.56, 1.74)
Hospital RHA PM vs IE	0.66	(0.37, 1.19)
Hospital RHA WP vs IE	0.76	(0.44, 1.31)
Birth order 2 nd or 3 rd vs 1 st born	0.59	(0.46, 0.75)
Birth order 4+ vs 1st born	0.62	(0.41, 0.93)
Diagnosis of maternal psychological distress Yes vs No	1.20	(0.95, 1.52)

The proportion of women who had an SGA baby for all women in the study cohort was 6.1% (651/10679), however it was higher in the OFC group at 6.3% compared to 5.92% in the no OFC group. The odds of having an SGA baby is 1.25 times higher for women in the communities with OFC policy (CI 1.03, 1.53). Factors that mitigated the likelihood of having an SGA baby was being born 2nd or 3rd (OR 0.59 CI 0.46, 0.75), or 4th or later (OR 0.62 CI 0.41, 0.93), or being born in a RHA outside of the Interlake Eastern RHA with the exception of the Southern/Sud RHA.

3.5 Discussion

Women residing in communities that have an OFC policy and send women out of the community for a period of time prior to their deliveries have increased odds of having inadequate PNC and with having an SGA baby. Having an OFC policy in place was also associated with decreased odds of initiating breastfeeding and being diagnosed with maternal psychological distress after adjusting for a) receipt of HBB, b) maternal age, c) maternal age at first birth, d) marital status, e) location of birth (Manitoba’s RHA), f) birth order, and g) previous diagnosis of maternal psychological distress. There were no relationships found between the OFC policy and the other outcomes, LGA, Infant Mortality, Children going into care or preterm birth. Only those outcomes with a significant relationship will be discussed.

Higher odds of inadequate PNC for women residing in a community that sends women out to have a baby was somewhat surprising, considering that women generally have access to community health nurses (and visiting physicians) who are able to provide routine PNC within their community (Glover et al., 2013; Tarlier et al., 2013). However, this finding validates feedback obtained from the Knowledge Keepers that women may seek care later in pregnancy or not at all if they fear having to leave the community. The Circle of Knowledge Keepers provided this insight even prior to seeing the results and verified after seeing the results that this fear is real, as women often have other young children (or infants) at home that need to be cared for, or they fear being in unfamiliar environments alone during a very sacred life event. They also pointed out the PNC as an indicator is only defined in western terms and the care from grandmothers, mothers and traditional healers is not acknowledged. Sending women away from their communities to deliver their babies furthers the modern-day colonizing agenda of assimilation by disrupting traditional practices of supporting childbearing women and the transmission of important cultural knowledge. Elder Katherine Whitecloud (2019) provided this perspective, for which she surmised that the “practice of sending women away to have their babies severs the child’s connection to their lands, to their families and to important cultural traditions, particularly the very important first rite of passage - which is passing from the spirit realm to the physical through birth and welcoming the child into the world.” The birth cohorts included in the analysis had their babies prior to 2017 when the federal escort policy changed. Since 2017, the federal government now allows the partner or significant other to accompany the women. At least now, Elder Whitecloud voiced, the partner or significant person in the women’s life can be there to welcome the children and celebrate the birth. This welcoming may include traditional welcome songs sung in the language of their ancestors if they so wish. It would be interesting to see if this policy change has any significant impact on maternal and child outcomes in the future.

Other mitigating factors of PNC adequacy included a receipt of the HBB (which was available to all low-income pregnant women regardless if they were living on or off reserve), and being married were consistent with other studies in Manitoba (Brownell et al., 2010; Brownell, Chartier, Nickel, & Chateau, 2016). A small financial supplement (approximately \$81 per

month) and community support would seem rather insignificant but can go a long way in providing the necessary incentive or means for low-income women to seek out PNC.

Having a previous diagnosis of maternal psychological distress as a modifying factor for inadequate PNC is perplexing. A possible explanation is the presence of a nursing station within the community. Women residing in communities with a nursing station, (thus subject to the OFC policy) may be more likely to be connected to a primary care provider by nature of seeking care for their mental health and would have been more likely to obtain PNC through this pathway. However, it is more likely that this inverse association between maternal psychological distress and inadequate PNC is a limitation of the data collected and housed in the repository, as prescription medications and physician claims are not always captured in federal nursing stations.

An important point made by the Knowledge Keepers Circle is worth mentioning. At a workshop looking at the preliminary findings, the Knowledge Keepers discussed at length how inadequate the PNC indicator is. They voiced that it does not capture the care and teaching provided by grandmothers/aunts and other family. Men, too, had a role. They indicated that the way PNC is measured in western systems is not consistent with their worldview. In fact, it is quite problematic (a composite of the number, frequency and gestational age PNC was initiated) and as such, it does not provide any indication about the level and type of care the women receive from friends, family and other community supports that may have influenced the mother's ability to access mainstream PNC through the primary healthcare system. This shortcoming speaks to how the health system (and data captured by administrative systems) privileges certain health practices and is silent on others. While it makes sense that population health researchers use these databases, there is inherent bias, and systemic racism at play in our inability to ask questions about a population of people who employ other health practices. It is important to acknowledge the limitations of the measurements and indicators raised by the Knowledge Keepers in studies such as this, as often these findings inform policy, practice or guidelines that impact women and families. Furthermore, the fact that Inadequate PNC is mitigated by being married or in a common law relationship as a proxy measure for support (OR 0.49 CI 0.41 0.58) speaks to the importance of this support beyond western mainstream health

systems. The indicator for measuring adequacy of PNC for Indigenous women lacks specific community and cultural context and must be re-evaluated.

In terms of breastfeeding initiation, having an OFC policy in the community was associated with lower odds. Interestingly, the HBB was associated with a slight reduction of the odds of breastfeeding, while being married improved odds significantly. The negative association with breastfeeding initiation and the HBB is not consistent with a previous study (Brownell et al., 2016) and a future study could potentially investigate further. On the other hand, a receipt of the HBB benefit may in fact represent a proxy for income, as the benefit is only available for low-income women⁶. Overall, these findings seemed intuitive to the study Knowledge Keepers and consistent with their observations. Women who must leave home for birth may anticipate a long or arduous journey home and choose not to initiate breastfeeding. Or, they may have previous negative experiences with breastfeeding challenges and lacked the necessary post-partum supports such as midwives, lactation consultants or culturally matched doulas in the critical days following the birth. The OFC policy which requires women to first leave home to give birth, *also requires them to return home after birth as soon as possible*, and by the most cost effective means possible. For some women, this means that they must travel in a bus for 10-12 hours, or travel by plane with inconsistent scheduling due to weather and other staffing challenges. According to the Knowledge Keepers, it is not uncommon for a mother to wait for 5-6 hours at an often-crowded airport with her 1-2-day old infant only to have their flight delayed for hours then cancelled. Compounding these challenges is a general lack of coordination and communication between the federal and provincial health systems. This unnecessary jurisdictional disconnect does not allow for women to connect to the provincial public health support system while they are away from home following the birth of their babies. Cooperation between provincial and federal health systems to provide a clear communication structure and support system for mothers travelling for birth could potentially identify and address any early breastfeeding challenges the mothers may encounter. It is highly likely that previous experiences and an inability to access public health support may have influenced the decision to breastfeed their babies in their second or subsequent deliveries.

⁶ The HBB is available to lower income families and the is based on income. It ranges from \$10.00 to \$81.41 a month.

At first glance, having decreased odds of experiencing maternal psychological distress for women residing in a community with an OFC policy was also perplexing. However, from the perspective of the study Knowledge Keepers, this phenomenon is very telling about an access to primary health care issue. As one grandmother shared her thoughts, “this makes perfect sense when you really look at it.” The women in our communities that send their women away to deliver their babies also have access to primary health care services and perhaps, are getting the support they need after having their babies. It does not mean that sending women away is good for their mental health, it just means something else. Women living in our communities may be extremely stressed due to poverty or living in unhealthy relationships no matter if they leave home for birth or not. During pregnancy, emotional stress is not good, especially after delivering a baby alone. This is not a good situation for our women and babies. In our traditional knowledge and ways, we knew this through years of observation. We did not talk about what chemicals in the body were being released, as western scientists speak about, but we knew that stress was not good, and so we took care of our women. “We had our ceremonies, our celebrations to help, but today we rely mostly on western medicine” (Sherry Copenace, 2020). As an inadequate PNC, this also could be a limitation of the data that may not capture diagnoses of maternal psychological distress in communities that have a nursing station model of care (Lavoie et al., 2020). Having a previous diagnosis of maternal psychological distress being strongly associated with the development of maternal psychological distress (OR 7.66 CI 6.62, 8.86) is a strong argument for increased support and services for women in their pre-reproductive and reproductive years before, during and following their pregnancies.

Access to western medicine and primary health care support (as is available generally in communities with an OFC policy), or perhaps more specifically having access to a somewhat coordinated system of support, albeit one needing much improvement, would therefore appear to reduce the odds of developing maternal psychological distress. This finding is consistent with another Manitoba study which found that the presence of a nursing station model of care (primary health care in the community) was associated with reduced admission rates for Ambulatory Care Sensitive Conditions (ACSC), and particularly those for mental health conditions (Lavoie et al., 2020; Lavoie et al., 2010). In this sense, having access to primary health care, and some measure of coordinated care may perhaps be somewhat protective. Even

though the 2020 study led by Lavoie and colleagues demonstrated that communities with PHC services had reduced admission rates, when all First Nation communities were combined, a considerable gap in well-being between First Nation and non-First Nation communities remained, and much work has yet to be done to close this gap (Lavoie et al., 2020).

Proportionately, the rates of SGA babies in the overall cohort at 6.1 is consistent and lower than the Manitoba rate which ranged from 6.7% (2003/04) to 7.6% (2006/07) as found in the Perinatal Services and Outcomes in Manitoba Report (Heaman et al., 2012), nor is it surprising. First Nation women, or women residing in First Nation districts (Martens et al., 2010; Luo, 2010) have been found to have the highest rates of LGA babies in other studies, as compared to the general Manitoba rates, which presents whole other challenges in childbirth. Likewise, the 651 SGA age babies born to low-risk mothers in 2005-2015 could potentially have an impact on their health and the health care system. Understanding the events and factors that contribute to their occurrence is of utmost importance. From the perspective of the Knowledge Keepers Circle, this finding goes hand in hand with the level of stress that First Nation women or women residing in First Nation communities are undergoing; addressing this stress as a consequence of colonization is critical.

3.5.1 Study Limitations

This study has several limitations. As with all observational designs, causal relationships cannot be inferred. As well, data extracted from the MCHP Repository are generally collected for administrative purposes, other than research, although the use of a comprehensive collection of administrative, registry, survey, and other data for research purposes has been validated (Jutte, Roos and Brownell, 2011). This does not preclude the possibility that data may have been incomplete or miscoded. As well, some physician claims, and pharmaceutical data may not be captured by health systems in First Nation communities and therefore may undercount the actual number of diagnoses or events. As pointed out by the Knowledge Keepers Circle, mainstream PNC indices do not capture appropriate contextual information or quality of the care received that may be relevant and influence healthcare seeking behavior for women living in First Nation communities. The author is also very mindful that this study was focused squarely on health systems and government policy. Although some descriptors were necessary, this study therefore purposely lacked individual level characteristics such as First Nation status, education status,

smoking, alcohol and substance use or any other individual factors that would allow for another level of analysis that take the focus away from health systems and policy discussion. The exclusion criteria may have missed pregnancies that are in fact high risk, which could have potentially biased the data toward the null as well.

One strength, and what is different about this study is what I described in an earlier section by the “inclusion of a decolonizing lens” to “understand” and go beyond identifying the colonial impact and seek meaningful change. This will be the focus of another publication. The main decolonizing strategy in short was to situate Indigenous people as “knowers”, and to create two unique vantage points for Indigenous people who know things about our Indigeneity that sits outside of the likelihood of western disciplines to discover or analyze. Secondly, as Walter and Andersen (2016) pointed out, Indigenous people are uniquely positioned to critique interactions between colonizer majorities and colonized Indigenous people on their own terms. The Knowledge Keepers Circle, in this respect, was integral to the interpretation and perspectives included in the findings.

3.6 Conclusion

The policy and practice of removing women from their communities indicated by the presence of the OFC policy has several measurable associations, such as increased odds of inadequate PNC, decreased rates of initiating breastfeeding and increased odds of having a small for gestational age baby. While an inverse relationship was found with the diagnosis of maternal psychological distress, this finding is likely more telling about a data collection or an access to primary health care issue and increased opportunities to tap into additional support in communities that have primary care providers, rather than being a protective factor, as pointed out by the Knowledge Keepers. In their words, this policy continues to oppress Indigenous women in Canada by taking away their choice on where and how to give birth to their children, and severs the connection of their children to their birthplace and land (Whitecloud, personal communication, Knowledge Keeper Gathering, 2018).

This population-level study, and other like studies can assist in answering the TRCC Call to Action #19 to establish measurable goals “to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends” to close the gap. Government at all levels must work with Indigenous

A Decolonizing Approach in Population Health Research

people, communities and organizations to address this harmful policy and establish a long-term vision to move birthing services close to home for the thousands of women considered low-risk, and babies who lose their connection to their families, ceremonies and the land due to the forced evacuation that only continues to serve the colonial agenda.

This study is also significant for demonstrating that an Indigenous and decolonizing approach can be utilized when undertaking a quantitative study. This is done by careful reflection on the purpose of the research, grounding the research in ceremony, meaningful engagement with Indigenous people and inclusion of their voices through the continuum of a research project. It is here that we enter the spaces of struggle and solidarity in the deepest sense possible, generating historically new counts and practices that can respond locally to colonialism, and we are able to generate spaces of recovery and healing that become the fertile soil for seeds of inquiry and research that are inherently political, ethical, and *accountable to the communities*. This is how Indigenous people can begin to reclaim our research; by first decolonizing the spaces that make research possible, and in the end, identities are also transformed (Zavala, 2013).

Reconciliation also requires that a new vision, based on a commitment to mutual respect, be developed and understand that the most harmful impacts of residential schools have been the loss of pride and self-respect of Aboriginal people (Truth and Reconciliation Commission, 2015). The OFC policy, along with past colonial policies such as residential schools have done considerable damage to Aboriginal families and the path to rebuilding Aboriginal nations is in rebuilding Aboriginal families (Royal Commission on Aboriginal People Canada, 2006). To begin the process of rebuilding our nation, and restoring our sense of nationhood, self-determination must begin in the womb (Simpson, 2006).

It is therefore critical that Indigenous people are at the centre of this inquiry and are able to utilize their own methodologies that are equally valid, and that we are central in the creation of our own identities by reclaiming our rights and cultural practices around birth. There is no better way to do this but to speak the language of the colonizer, and to tell our stories with our own voices, informed by generations of wisdom and observation. This is the space where Indigenous and western science meet.

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CHAPTER 4 – Reflecting on:

“Bi-zin-doi-zhen” listening intently and “Weweni Anokiin” doing the work in a good way

4.1 Preface

This last paper reflects on my research journey and describes the methodology that I used and perceived to be personally decolonizing. I present a unique Anishinaabe process for doing quantitative research and an adaptation and application of Kovach's (2009) Indigenous framework to the quantitative domain. Her Indigenous research cycle became a guiding framework and launching point for four years of preparation and exploration. I document a process that may be adapted to other Indigenous research contexts and communities. Overall, this dissertation represents a journey for me as an Indigenous woman in a mainstream doctoral program in population health, learning to employ both western methods and a decolonizing framework to critique a colonial and still very contemporary health policy. This last paper is therefore appropriately subtitled: “Bi-zin-doi-zhen” listen intently and “Weweni Anokiin” doing the work in a good way and represents an Anishinaabe perspective on how western quantitative research and Indigenous methodology intersect.

4.2 Introduction

I begin this chapter by acknowledging once again the many teachers in this journey, my academic advisors, my circle of Knowledge Keepers, and most importantly, my Grandmother Advisor. If not for every one of you and your gifts and contributions, my journey would have been more difficult than it was (if not terminated) at many points in the past five years. Although this is the last paper in my story of meandering the crossroads between Indigenous and western approaches to research, this conclusion is not the finale. My journey of discovery that had a definite beginning in 2016 will continue well beyond the publication of this dissertation. God willing. I can only relay to you my final thoughts now and share with you how I navigated and understood these two divergent roads. Linda Smith (2012) referred to this crossroad as the “intersection of two powerful worlds, the world of Indigenous peoples and the world of research” (p.19). In one sense, this journey has been one of exploration, and on the other hand, it has been one of reconciliation. This paper will therefore serve two purposes. First and foremost, I will share insights in navigating the path between the two worlds. These insights are centred around two powerful lessons I learned in my research journey: “Bi-zin-doi-zhen” listen intently

and “Weweni Anokiin” do the work in a good way. The second aim will be to propose a simple framework for population health research that is centred around these two concepts.

The methodology that I employed in my research is both theoretical and applied. In one respect, it aligned with social epidemiology and sought to incorporate the lived reality and conditions that led to (and are responsible) for the health of the population I worked with. As such, I included context and alternative explanations for health inequity (Marmot, 2012). In another sense, the methodology was concerned with ensuring that my work was culturally safe and culturally grounded. Although I modeled my approach after Kovach’s (2009) Indigenous framework, it involved several actions that were not always fluid, nor did they move in a circular motion. It involved taking that initial step forward, pausing, listening, then taking a few more steps forward, then a few steps sideways, glaring down the pathway, recalibrating, listening again, reflecting, and then repeating all over again. The journey did begin as Kovach advised, with preparing myself as a researcher by listening to a Grandmother Advisor and Knowledge Keepers, and by being open and receptive to learning from my teachers. Then began the careful process of planning. Planning involved mapping out the two pathways in the journey; one involving the science, the other involving the people. As I embarked on this pathway, there was the occasional pause to listen, to reflect, let life unfold, evaluate, and occasionally change course. It is the way that I have learned to research that is both scientifically sound and true to my spirit as an Anishinaabekwe.

My dissertation is organized in this fashion. The first chapter of my dissertation examined why a decolonizing framework for doing quantitative research was needed. The second paper is an accounting of the preparation involved, about learning from my teachers, mentors, and from real world experiences, then mapping my way forward. The third paper details putting all that I learned to the test and applying an Indigenous and decolonizing framework to carry out a population-based study, in a good way. This final paper is a braiding of all the pieces together: sharing the path I have travelled, the lessons learned and reflecting on how this journey may assist others in doing research in a good way.

From my perspective, there is no other way to reconcile western quantitative inquiry and Indigenous methodologies but to weave in Indigenous context, history, voices, and perspectives into the quantitative design. It must begin at the time of the formation of the research question/s

and continue throughout the entire research cycle and well into the sharing of the research findings. It is not a mixed-methods approach, but a merger of Indigenous and quantitative methodology. It involves a good measure of listening and learning, then conducting yourself and carrying out your work in a good way, the product in the end, incorporates the lived reality of Indigenous people's lives. I must acknowledge that this methodology is not novel, or original, as it is one that the Manitoba Centre for Health Policy strives for in its research involving First Nation, Inuit, and Métis people (and perhaps used by many others), but whose approach may have been buried within the publications and reports or overshadowed by its findings.

4.3 Why is a decolonizing approach needed in quantitative research?

At the beginning of my doctoral journey, I sought an answer to this question. I revisit the question here again. For many years research has not benefited Indigenous people, has been unethical or inflicted further harm on Indigenous people (First Nations Information Governance Centre, 2019; Schnarch & First Nations Centre, 2004). Indigenous scholars argued that there was a grave need to decolonize research and foster institutional environments that make space for Indigenous methodologies (Battiste, 2000; Kovach, 2009). This is also true for quantitative research (Smylie & Firestone, 2015; Walter & Andersen, 2016). Unfortunately, models of decolonizing approaches in the quantitative realm remain scarce which may in part be due to the scarcity of Indigenous people trained in statistics and quantitative methods.

Decolonizing research has been described as research that centres Indigenous voice, vision, perspectives, worldviews, and epistemologies. It also involves engaging in a critique of colonization and critically examining the underlying assumptions and values that shape the research (Battiste, 2000; Kovach, 2009; Smith, 1999). Based on these premises, paper 2 of my dissertation represented my effort to understand the meaning of colonization and the main characteristics of decolonizing and Indigenous methodologies. I therefore extracted, and admittedly, offered my interpretation of the key elements that characterize decolonizing research based on the scholarly insights of Battiste, Kovach, Smith, and Berryman and colleagues. These nine key elements are in summary:

1. Shifting (balancing) power and reclaiming governance over research
2. Meaningful engagement and involvement of Indigenous people
3. Relationship building, relationality

4. Reflexivity/critical reflection and positioning
5. Contextualization by acknowledgment of the historical, social, political, and cultural reality of the people
6. Privileging Indigenous knowledge, voice, epistemology, worldview, and holistic frameworks
7. Respect/inclusion and acknowledgment of Indigenous culture & protocols
8. Reconceptualization of Indigenous people in knowledge translation/sharing; and
9. Purpose and implications of research-oriented toward the benefit for Indigenous people

Underpinning all these elements is a critique of colonization. This critique includes challenging the widely accepted notion that western methods and ways of knowing are the only objective and true science (Data, 2018; Walter & Andersen, 2016). This attitude of superiority only serves to marginalize Indigenous methods and ways of knowing by denigrating them as folklore or myth (Datta, 2018). However, this resistance to the attitude of superiority does not require that researchers reject all western methods and theories (Smith, 2012). If the research or researcher is to engage in a critique of colonization, it must begin with a broad understanding of what colonization is (Battiste, 2000).

In Paper 2 of my dissertation, I therefore argued that decolonizing research intersects with the broader aim of decolonization in that they represent an anti-oppressive approach that seeks to restore the balance of power in research and work toward Indigenous people's self-determination (Battiste, 2000; First Nations Information Governance Centre, 2014; Kovach, 2009; Schnarch & First Nations Centre, 2004; Smith, 1999). It was not my intention to argue why decolonizing research is important for Indigenous people, its importance underpins all aspects in this dissertation work. However, if it has not been clear enough to this point, Russell Bishop (2013), founding professor for Māori Education in the Faculty of Education at the University of Waikato, New Zealand, makes this point about educational disparities between Indigenous and mainstream youth:

What precludes significant advancement being made in addressing the issue of disparity is that the discursive framework of those proposing the solutions remains one of neocolonialism that continues to serve the interests of the dominant elite. These frames most often ignore more persistent and ongoing racism within societies and take little account of Indigenous peoples' aspirations for self-determination through analyses and understandings of their preferred Indigenous epistemologies (p.184).

It is with this understanding, and teachings I received along the way, that I began to operationalize how quantitative research can be decolonized and aligned with Indigenous methodology. I propose only two underlying principles, based on the Anishinaabe concepts to *Bi-zin-doi-zhen*, listen intently, and *Weweni Anokiin*, to move forward and work in a good way. These are (very purposely) not abstract concepts, but action-oriented tenets for quantitative oriented minds who may not have the disposition, inclination, time or opportunity to embark on a yearlong journey of preparation and learning due to pressures to publish or make tenure, but still desire some direction on how to do research in a good way with Indigenous people. From the two tenets, I suggest several processes or approaches of doing research in a good way, based on my interpretation of the nine common elements of decolonizing research. The processes (or strategies) are not all that different from those that appear in the qualitative domain, and are very much aligned with Margaret Kovach's (2009) preparatory phases in her Indigenous framework. I provide examples of how I applied these strategies into my dissertation study.

The two underlying tenets are flagged by action pillars for decolonizing quantitative research in the graphical representation in what I have termed the Two Principles (TP) Anishinaabe research cycle. The framework begins with *Bi-zin-doi-zhen* “listen” to the people, moving on toward *Weweni Anokiin* to “do the work in a good way” and circles back again with *Bi-zin-doi-zhen*, “listen within”. I share how I applied a decolonizing framework by coming to understand and incorporate decolonizing elements throughout the entire research process in my research journey. The points are not ordered in the sequence I have suggested above, nor can they be neatly ordered. Decolonizing elements are often embedded within Indigenous frameworks and frameworks should be respected as such, to provide some structure and a point of reference.

4.4 Lessons learned

4.4.1 Tenet 1 (Listen) Bi-zin-doi-zhen

If the research is to truly acknowledge and privilege Indigenous knowledge, voice, epistemology, and worldview, the start of the research cycle must begin with listening and learning. One of the first tasks I embarked on was to *further my understanding of colonization*. If I were to engage in a critique on colonization, I had to clearly understand what role colonization had played in creating the issue (western dominance over research and the

devaluation of Indigenous methods). Even as I was Anishinaabe and had grown up in Anishinaabe territory and had worked in Indigenous health for my entire career, I needed to have a clearer sense of what exactly is meant by the term “colonization” as advised by Marie Battiste (2000). The first question I, therefore, faced in starting this research journey was “how can I begin to engage in a critique of colonization if I do not fully understand what colonization is?” My entire life, my humble beginnings, my family, my career have been immersed in First Nations’ context, but I had to pause because I had never really thought about the meaning of colonization or traced back what role colonization played in creating the issue that I was so passionate about and about to explore? To do this, I sought out relevant literature and spoke to many colleagues and mentors. One critical suggestion came from a mentor I admired deeply, Dr. Kathy Avery Kinew. She suggested I read a book entitled the *Social Determinants of Health in Manitoba*. In there I found a useful chapter and summary of the elements of colonization (Hart, 2015).

The second task in the listening process was to understand what was meant by decolonizing research. Although the volume of literature is expansive I looked to four prominent scholarly sources on the topic, (Battiste, 2000; Berryman et al., 2013; Kovach, 2009; Smith, 2012). With insights from these sources, I landed on several key elements/characteristics of decolonizing and Indigenous methodologies. On these elements, I overlaid the nine key decolonizing actions, derived from Hart’s rendition of colonization (in bold italics below). With this exercise, I began to gain a better understanding of how decolonizing research intersects with the broader decolonizing agenda.

To gain a better understanding of the issue from Indigenous peoples’ perspective, I had first ***to seek out and build a relationship with teachers, mentors, and Knowledge Keepers (and in some cases, organizations) familiar with the issue or topic***. I fully acknowledged that my training was in a western institution and that my time as a student has been primarily spent on learning western concepts and methods. I had to take the necessary time to learn from those that had far more knowledge about Indigenous ways and methods. I sought advice from Dr. Kinew, a long-time colleague who worked within the First Nations Health and Social Secretariat of Manitoba and fought tirelessly for Indigenous research sovereignty. She had many established relationships with the two major universities in Winnipeg. She advised me who would be

appropriate to talk to. She also pointed out to me, as an employee of the same organization, I too had long-standing relationships with many First Nation communities and worked with Elders and Knowledge Keepers in various capacities in my work. I need not start from scratch. I also had many opportunities to attend traditional ceremonies and gatherings organized by Indigenous organizations within Manitoba. I was also fortunate enough to listen to a Grandmother's teachings on the topic of women's rights and responsibilities as caregivers one summer before I began my doctoral journey. I learned and came to know what cultural protocols were appropriate. My primary teacher was my Grandmother Advisor, Sherry Copenace who joined my thesis committee and advised me in all things protocol and process. Based on her advice I began a year-long period of listening and learning about past and present practices around childbirth. This was an education not based on western processes and methods but steeped in traditional stories and ceremony.

To ***ground the research in ceremony and include local cultural protocols (if this is what is advised)***, may not be an easy task for non-Indigenous or novice researchers employing an Indigenous framework. Some prior research experience is necessary. Even as I had established relationships, I still had to ***inquire about and follow local protocol and customs regarding all aspects of ceremony. including the opening meetings and workshops with Indigenous people.*** With my dissertation work, my Grandmother Advisor suggested that I organize a ceremony and feast to begin my research journey in a good way. I did so as I was instructed in the summer of 2017. Should a launch ceremony be suggested in any research, as it was in mine, seek the guidance of Knowledge Keepers or partner Indigenous organizations as to what protocol is required. It meant asking them who would be the most appropriate individual to lead or attend the ceremony. In my research, it involved a passing of a gift of tobacco and providing an honorarium to cover expenses for the Knowledge Keepers who attended. It was also necessary to have my launch ceremony out on the land, held on my property out in the country. Grounding the research in custom or ceremony meant to me having each meeting begin with a prayer, or by inviting a Knowledge Keeper to start by sharing their opening thoughts, do smudge ceremony or ceremony according to local custom. The important element to consider, should one desire to do good research, is to invite the Knowledge Keepers to all meetings and include Indigenous people

in all discussions of the research. Plan in your budgets these offerings of small gifts or honorariums to all Knowledge Keepers and Elders at all meetings and gatherings.

For those that do not have established connections with Indigenous communities or organizations, one of your first tasks is to ask. Find a researcher who may have worked previously with an Indigenous community or organization and seek out their advice. Approach the organization/scholar and inquire who would be the most appropriate individual to talk to. If there is an existing resource, like a women's council, Elders council, gatherings, or Knowledge Keepers group, ask how you may be invited to speak to them. These groups (if they exist) may be more than willing to share their insights on your topic or remain involved in your project. Take the time to inquire about what protocol should be followed, whether it be a gift of tobacco or another appropriate gift. The researcher should be cognizant that the knowledge and insights Knowledge Keepers and Elders may share are their intellectual property, and follow all ethical guidelines of the respective Nations, organizations, communities, or institutions.

Once a teacher, Knowledge Keeper, group, or organization has been found, a decolonizing approach requires researchers to *listen intently, and seek to understand how Indigenous people perceive and have been impacted by the issue*. Once I was able to secure the Grandmother Advisor to join the thesis committee, the next order of business was to converse with the Knowledge Keepers and learn more about my proposed topic from their perspective. I requested permission from the organizers to have a meeting with Knowledge Keepers on the topic of racism in the health care system (which was very appropriate to my research interest). The research topic I was concerned about was the issue of removing women (primarily First Nation and Métis) from their communities to give birth. I was given one hour on the agenda. At this pivotal meeting, I introduced myself, and firmly located myself as a learner. I introduced my research issue, which did not require much explanation as two of the Grandmothers were very knowledgeable and passionate about the issue and had spoken about the issue for many years. From my brief five-minute introduction, I listened not for one hour, but two. This is to be expected. The workshop organizers respected the Knowledge Keeper's direction and control over the agenda and did not interrupt the free flow of dialogue. From this conversation, I learned that I had a tremendous amount *yet* to learn about the issue. I heard from the Knowledge Keepers' wholistic perspective how this policy harmed women, children, and families not only

physically, but emotionally, spiritually, and mentally as well. They also spoke about the impact it had on entire communities and on traditional midwifery practices and how it disrupted critical cultural and knowledge pathways. They spoke about the important connection between place of birth/territory and the development of a clear sense of identity and belonging. They spoke about how the OFC policy further compounds the stress of childbearing women who are already under a great deal of stress due to poverty and life circumstances. The Knowledge Keepers were very clear in that that they had known for many generations how stress negatively impacts the growing baby. “The science of epigenetics is only now just beginning to catch on”, they joked. From these important discussions, I was able to gain considerable insight into some of the possible outcomes and variables that could be included in my research. I also learned that the issue of caring for pregnant women is multidimensional, and inadequately measured using western constructs and methods. This context became so important in framing the issue and went far beyond any western conceptualization of PNC which was important to note in any future scientific publication.

In keeping with the decolonizing aim, a great deal of care had to be taken to *contextualize and reframe the issue from the perspective of Indigenous people*. As just mentioned, Knowledge Keepers, Elders, and individuals familiar with the research topic can be very valuable in this respect and can have an entirely different viewpoint on the issue or can have different perspectives on the variables or outcomes that are included in the research. For instance, as I spoke about one of the outcomes I was proposing to include in the research (adequacy of PNC), I was challenged to think about the measurement I was employing. The Knowledge Keepers took issue with the fact that the adequacy of PNC indicator is often used to place judgement on women and places the blame entirely on her if the benchmarks are not achieved. PNC is often measured in the number and frequency of visits to a health care provider and when the mother first initiated care, I explained. They gently explained that PNC utilization measurements did not consider the role of grandmothers, family, or community programs in supporting healthy pregnancies. It also did not consider multiple challenges that women face from the unavailability of primary care providers within the community, lack of childcare, poverty, lack of transportation, or lack of information about the importance of PNC. This contextual information is critical to include when presenting the findings on the research,

whether it occurs in scientific conferences, presentation, or publication format, regardless, if the research design is entirely quantitative, data-driven and highly numerical. Even as my positioning was as an Anishinaabekwe, I had lived many years in an urban environment and was still required to learn ***Indigenous peoples' understanding, context, and perspective on the issue.*** If I was to contextualize and ground the issue in Indigenous perspectives as advocated by Indigenous scholars, I had to take the time to learn about the historical, social, political, and cultural reality of Indigenous peoples lives and how they understand they have been and continue to be impacted by the issue you plan to study. If there is one nugget of advice in this endeavor, be ***respectful in the way the contextual information is included in the presentation/publication and acknowledge the insights and contribution of Knowledge Keepers/teachers/organizations in the work.***

Fortunately, the Knowledge Keepers circle agreed to remain involved and function as my advisory circle as I embarked further on the dissertation research. Their final piece of advice from that initial conversation included acknowledging that I, as one trained in western research methods, had the necessary knowledge and skills to plan the research from there on and they entrusted me to come back with the research plan. Six months later I was able to present them with my research plan and some discussion took place at this follow-up meeting about what was possible to explore, based on the limitations of the data that was available to me with the population health research design that was developed. I explained what data was available to me, and how this data could be used to explore maternal and child health outcomes quantitatively. They provided their blessing and advised me to return when I had some information to share. Following this, I presented and defended my research proposal to my thesis committee in the fall of 2018.

4.4.2 Tenet 2 Weweni anokiin: move forward, working together with good intent

As with the listening and learning period, ***meaningful engagement and involvement of Indigenous people are required throughout the entire research project.*** This often involves a period ***of forming and building the relationship*** with the study population/communities/organizations. This also involves ***developing a plan for multiple points and different levels of engagement throughout the entire research.*** This ideally should begin at the earliest stage of research by talking to key knowledgeable people about the research interest

or funding opportunity. Engagement with Indigenous people should be planned for at every stage of the research project from the conception of the research idea, to planning for the research including selecting the outcomes and variables to include in the analysis, to the proposal writing, and carrying out the research - including interpretation and presentation of the findings. This is not a novel idea, and many ethical guidelines have included such approaches. In my dissertation work, I was able to invite and include the Grandmother Advisor teacher in my thesis committee. This also can be done in any research environment. In the process of exploring who would be the best mentors or Knowledge Keepers to help you learn about the issue from their perspective, consider inviting the Knowledge Keeper to be part of your core research team and or forming an advisory circle of Knowledge Keepers. Do this with good intent, and not just to satisfy partnership criteria on your funding application. Have a conversation with, and respect how much, the Knowledge Keepers can or are willing to be involved. In my dissertation work, I had tapped into a Knowledge Keepers circle to advise me on the selection of outcome variables that were relevant to them. It meant listening carefully to the stories of how they or their families are impacted. In these stories, I located the elements which could be captured in the data.

4.4.3 Share the research space and resources

What does this mean? A key decolonizing element in research involves transforming power differential in the research relationship. For Indigenous scholars, it often involves contesting power structures within the academy or doing research that is true to your spirit or philosophy (Kovach, 2009; Smith, 2012). For Indigenous people or organizations, it may mean reclaiming or sharing governance over research. In university-led research, it may involve creating research partnerships or collaborating with Indigenous organizations. In my dissertation work, the choice I made was to include a Grandmother Advisor and work with a Knowledge Keepers circle to guide the work. In any quantitative research project, a similar structure can be created. The ideal that many Indigenous scholars and organizations are striving for is to have Indigenous governance and ownership of the research. However, in most cases, a shared governance model is possible (Phillips-Beck et al., 2019).

Sharing the research space also involves *sharing the funding resources and doing the research together or having an Indigenous organization coordinate the research entirely*. Regardless of the study design, plan for the *transfer of resources to an Indigenous organization*

to recruit, hire and house research so that they can meaningfully participate in the data collection/analysis and data management. Although my dissertation was a sole undertaking, I shared lessons from the field in Part 2 of my dissertation. There are always opportunities to partner with Indigenous organizations to build up their research teams, inventory of skills to manage the data, and carry out the research. Investments in Indigenous organizations and people can have many other unintended outcomes and benefits, such as tapping into existing Indigenous networks and facilitating relationship building with Indigenous communities. I am a good example of these unintended consequences. My work within a First Nation organization began in policy and programs and transitioned naturally in the direction of research. I began working as a research collaborator in my policy field. Then an opportunity came along to work as a Research Manager in a large research collaboration. The transition to graduate school to pursue a doctoral degree seemed very natural and was supported by the organization where I work. I was able to secure study time during the academic year. Although I have been named principal investigator on two funded research projects, and co-investigator on many other projects, this dissertation solidifies my pathway as an independent researcher.

Multiple forms of engagement, and involving Knowledge Keepers, facilitates the process of reconceptualizing how Indigenous people are represented in the research. Relevant context and framing the issue from the standpoint of Indigenous people should be built into all knowledge translation products and sharing results more widely. A good example of this is found in the recently released report entitled “*The Health Status of and Access to Healthcare by Registered First Nation Peoples in Manitoba*” (Katz et al., 2019). This research was done in a partnership model between the University of Manitoba and the First Nations Health and Social Secretariat of Manitoba. The knowledge translation products were purposely designed with simple but powerful images reminding the public about the underlying causes of illness and disability, depicted as roots of a tree symbolizing colonization in the graphic design. These graphic design images are powerful in relaying vital contextual information that the high burden of illness and disability are phenomena rooted in colonization and historical trauma. Sharing knowledge in a good way is one outstanding piece of my dissertation work at this point but is planned for. The important point to take home is that engaging and learning from Knowledge Keepers provides an opportunity to reframe how Indigenous people are presented in research and

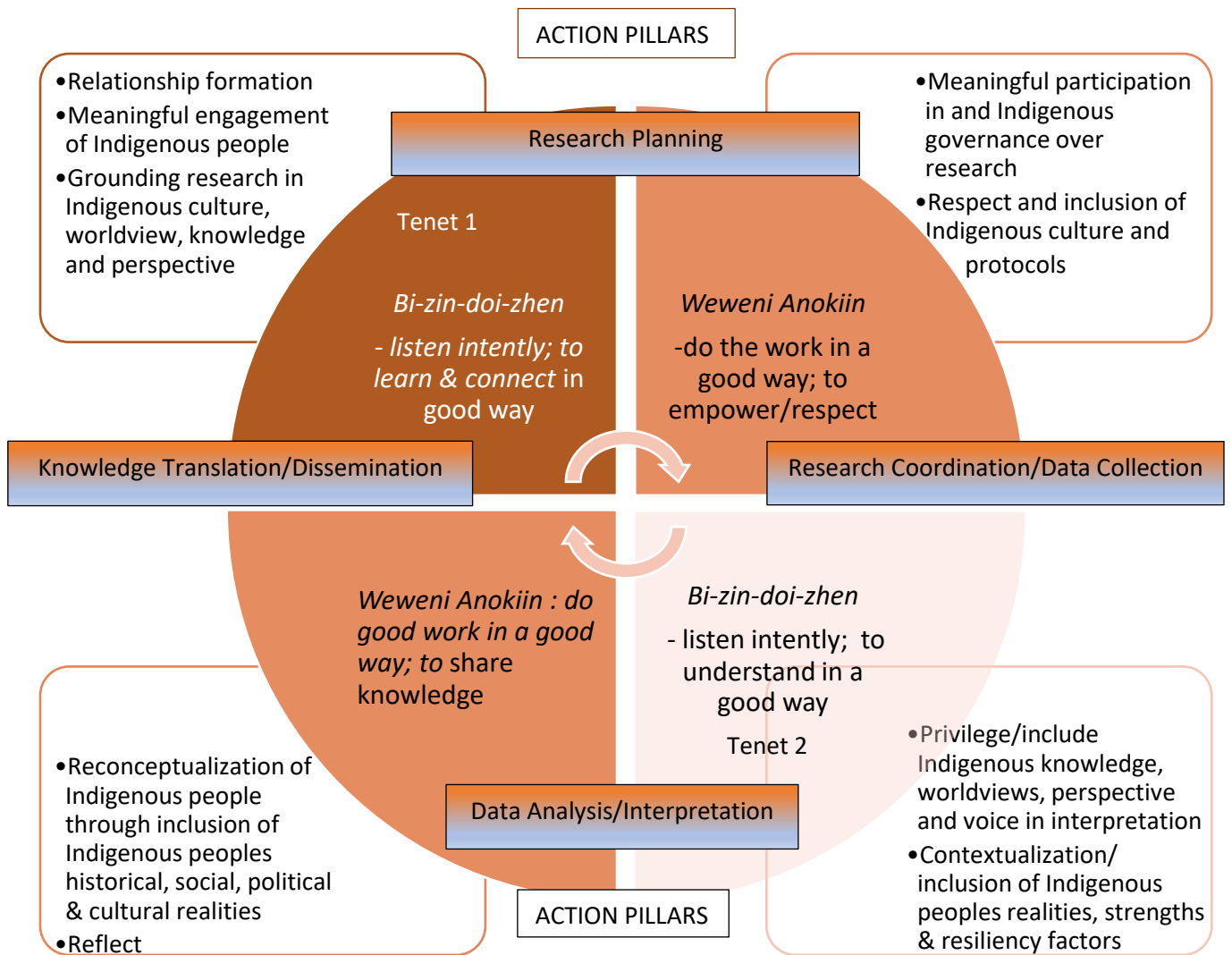
more importantly to the public. Networking and partnerships with Indigenous communities make these opportunities easier.

4.4.4 Tenet 1 revisited - *Bi-zin-doi-zhen* (Listen inward)

The last and final step involves *Bi-zin-doi-zhen*. Listen intently once again. In my dissertation work, I had the luxury of being able to pause, reflect, evaluate, and occasionally redirect the work when necessary. Early into my studies, I had experienced a significant loss in my family and had to step away from the studies to heal. It gave me some much-needed time to reflect on my research journey and redirect my energies elsewhere for a short time. It also gave me additional time to learn. In the end, I reflected on whose purpose I was working toward and found greater resolve to continue the research pathway. Indigenous Scholars labeled this as reflexivity, flexibility, and fluidity (Battiste, 2000; Kovach, 2009; Smith, 2012). I call this listening to the heart and following the direction of the spirit, important teachings I received from my Grandmother Advisor. Researchers, regardless of funding and institutional constraints should remain open to taking the occasional pause, reflect and evaluate the present course of action and be prepared to find alternative pathways in achieving the research goals.

So how do you apply all the above in a quantitative study? A population health study? The following framework shows the relationship of the two primary tenants of the Two Principle Anishinaabe Framework and associated action steps or strategies that I have explained narratively in the preceding section. I overlaid examples of decolonizing actions that align with each tenant and with each stage of research in the widely accepted western notion of the scientific research process. The western model is typically a linear process, but to show this relationship to the Two Principle Anishinaabe Framework it is graphed in a circular model. It begins with 1) research planning: identifying problem, formulating research questions and theory/hypothesis development 2) data collection/coordination, 3) data analysis, and circles back to 4) knowledge translation. I end with a useful table and summary of how decolonizing elements are aligned and respond to each stage of the western research process.

Figure 3: The intersection of decolonizing research and western research process



A Decolonizing Approach in Population Health Research

Table 11 - Decolonizing Strategies for Quantitative Research Design

Western Paradigm	Decolonizing approach	Action & Strategies
Research Planning: Identifying problem, formulating research questions, theory, hypothesis & design	Relationship formation, meaningful engagement of Indigenous people, grounding research in Indigenous culture, worldview, knowledge and perspective, meaningful participation in and Indigenous governance over research, respect and inclusion of Indigenous culture and protocols	<ul style="list-style-type: none"> • Broaden understanding of colonization & Indigenous peoples, including Indigenous ethical principles/OCAP • Seek out possible teachers/knowledge keepers/organizations familiar with research topic • Find forums/meetings to present research idea & learn about issue from Indigenous people's perspective • Listen for ideas for research, design possible indicators/variables based on discussions with Indigenous people/knowledge keepers • Listen for and include community strengths, strength-based or resiliency factors as variables in the analysis, if possible • Form advisory circle and/or find knowledge keeper advisor • Seek out Indigenous people/communities or scholars as researchers • Develop options for research design - survey/administrative data/clinical data etc. for consideration • Develop and draft list of outcomes/variables/instruments based on discussions with Indigenous peoples • Present research design including outcomes/variables to knowledge keeper advisor/advisory circle • Begin drafting proposal that includes relevant context/Indigenous perspectives in collaboration with Indigenous team members/advisors • Build into budget resources that allow for transfer of resources to Indigenous organization for coordination/data collection
Data Coordination/Collection	Meaningful participation in and governance over research, respect and inclusion of Indigenous culture and protocols	<ul style="list-style-type: none"> • Partner with Indigenous organization or community & transfer resources to coordinate research • Hire local research assistants/Indigenous students to carry out research if possible • Seek advice from knowledge keepers about launching the research in a good way & building in local ceremony, or customs throughout research project
Data Analysis/Interpretation	Privilege/include Indigenous knowledge, worldviews, perspectives and voice in the interpretation; Contextualization of Indigenous people through inclusion of Indigenous peoples historical, social,	<ul style="list-style-type: none"> • Focus & frame the analysis on policy or institutional processes – and relationship to colonization • Provide relevant context/Indigenous voices & perspectives in presentation & publication of findings • Include relevant historical factors, policy & social context/role of colonization & voices of

Western Paradigm	Decolonizing approach	Action & Strategies
	political & cultural realities, strengths and resiliency factors	Indigenous peoples in the discussions/discourse in publications <ul style="list-style-type: none"> • Organize meetings with knowledge keepers/Indigenous community to present preliminary findings & listen to feedback & perspective
Knowledge Translation	Reconceptualization of Indigenous people through inclusion of Indigenous peoples historical, social, political, and cultural reality/reflection	<ul style="list-style-type: none"> • Present findings in summary/plain language format back to advisory circle/advisors for feedback & perspectives • Include Indigenous peoples as co-authors/presenters at every forum/conference • Sharing your reflections & experiences on the research process & include in all presentations and publications • Consider a methods paper to increase awareness of and scholarly writing on doing research in a good way

4.5 Final thoughts

In this final paper, I have very briefly shared insights into my journey of finding a path between the two divergent roads, one in the direction of quantitative research and the other road where Indigenous people are located. These insights are centred around two powerful teachings received throughout my research journey: “*Bi-zin-doi-zhen*” to listen intently and “*Weweni Anokiin*” carry out the work in a good way. This dissertation proposed a simple framework for population health research that is centred around these two concepts. My research journey has been one of exploration and learning. It was in seeking to understand from Indigenous scholars before me how a decolonizing stance can be taken and applied in a pragmatic way to quantitative methods that lead me to the place where these two roads came together. It is there that my struggle to reconcile both worlds began to subside. As my Grandmother advisor instructed, “When we let the spirit guide, you will do your research with good intent, and with a good heart.” As I meandered down these pathways, I found myself in the space where the two roads diverged, and I also found the places and spaces where western science and Indigenous methodology intersect. In this space, in this intersection, we listen, we learn, and let the spirit guide us.

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Appendix A –Letter of Permission from HIRGC



FIRST NATIONS HEALTH AND SOCIAL SECRETARIAT OF MANITOBA

January 31, 2019

Wanda Phillips-Beck
[REDACTED]

Re: Moving toward family-centred and culturally informed care: maternal, birth and infant outcomes for a cohort of First Nation women who travelled for birth in Manitoba, 2005-2015

Thank you for application to the Health Information Research Governance Committee dated January 18, 2019.

The Health Information Research Governance Committee (HIRGC) has been mandated by the Assembly of Manitoba Chiefs-in-Assembly to provide ethical review and guidance of research that includes First Nations to ensure First Nations benefit from research undertaken within Manitoba. The governing principles HIRGC abides by are: Free, prior informed consent on a collective and individual basis; (ii) First Nations OCAP principles, that First Nations have Ownership, Control, Access and Possession of their own data; (iii) First Nations ethical standards, and, (iv) Benefits to First Nations (governance, employment, etc.).

The HIRGC reviewed your application and were excited to hear about your research proposed, and just had one note regarding the statement "As no individual community is identified, all data will be in aggregate or table form and will not be shared without the consent of the FN-HIRGC"; please note, HIRGC does not need to be accessed each time you are sharing the data with your communities.

HIRGC wishes you success and look forward to hearing the results.

In the Spirit of Truth and Reconciliation,

FIRST NATIONS HEALTH AND SOCIAL SECRETARIAT OF MANITOBA
[REDACTED]

Leanne Gillis
HIRGC Administration

Appendix B - Approvals from University of Manitoba, REB



HEALTH RESEARCH ETHICS BOARD (HREB) CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES Full Board Review

PRINCIPAL INVESTIGATOR: Wanda Phillips-Beck	INSTITUTION/DEPARTMENT: U of M and MCHP/Community Health Sciences	ETHICS #: HS22528 (H2019:052)
HREB MEETING DATE: January 28, 2019	APPROVAL DATE: March 5, 2019	EXPIRY DATE: January 28, 2020
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable): Dr. Josée Lavoie		
PROTOCOL NUMBER: NA	PROJECT OR PROTOCOL TITLE: Moving toward family-centred and culturally informed care: maternal, birth and infant outcomes for a cohort of First Nation women who travelled for birth in Manitoba, 2005-2015	
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: NA		
Submission Date(s) of Investigator Documents: January 7 and February 20, 2019 (Received)		REB Receipt Date(s) of Documents: January 7 and January 20, 2019

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
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Protocol:

Proposal (undated) including Clarifications as per Letter received February 20, 2019 and Revised REB Submission Form and Retrospective Chart or Record Review Form submitted February 20, 2019

Draft 2	submitted
	January 7, 2019

Consent and Assent Form(s):

Other:

CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this *Certificate of Final Approval* at the *full board meeting* date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

Appendix C Approval Letter from HIPC



June 06, 2019

Wanda Phillips-Beck
First Nation health and Social Secretariat of Manitoba
Department of Community Health Sciences
University of Manitoba
Wphillips-beck@fhssm.com

HIPC No. 2018/2019 – 63
File number to be quoted on correspondence

Re: Moving toward family-centred and culturally informed care: maternal, birth and infant outcomes for a cohort of First Nation women who travelled for birth in Manitoba, 2005-2015

Dear Ms. Phillips-Beck,

The Health Information Privacy Committee has considered and *approved* your request for access to data for the purposes of the above named project.

Any significant changes to the proposed study design should be reported to the Chair/HIPC for consideration in advance of their implementation. Also, please be reminded that any manuscripts and presentation materials resulting from this study must be submitted to Manitoba Health, Seniors and Active Living for review. Specifically, manuscripts must be submitted *at least 30 calendar days* prior to the intended publication and presentation materials must be submitted *at least 10 calendar days* prior to the presentation.

Researcher Agreement will need to be completed before work on this project can commence. This will be initiated by MCHP. If you have any questions or concerns, please do not hesitate to contact Saila Parveen, Committee Coordinator at (204)786-7204.

Yours truly,



Teresa Cavett, B.Sc., M.D., C.C.F.P., F.C.F.P., M.Ed.
Chair, Health Information Privacy Committee

c.c. D. Malazdrewicz

Manitoba
spirited energy

Appendix D – Infographic on Decolonizing Strategies

<p>1. Western Paradigm Research Planning: Identifying problem, formulating research questions, theory, hypothesis & design</p>	<p>Decolonizing Approach: Relationship formation, meaningful engagement of Indigenous people, grounding research in Indigenous culture, worldview, knowledge and perspective, meaningful participation in and Indigenous governance over research, respect and inclusion of Indigenous culture and protocols</p>
<p>Action & Strategies</p> <ul style="list-style-type: none"> • Broaden understanding of colonization & Indigenous peoples, including Indigenous ethical principles/OCAP • Seek out possible teachers/knowledge keepers/organizations familiar with research topic • Find forums/meetings to present research idea & learn about issue from Indigenous people's perspective • Listen for ideas for research, design possible indicators/variables based on discussions with Indigenous people/knowledge keepers • Listen for an include community strengths, strength-based or resiliency factors as variables in the analysis • Form advisory circle and/or find knowledge keeper advisor • Seek out Indigenous people/communities or scholars as researchers • Develop options for research design - survey/administrative data/clinical data etc. for consideration • Develop and draft list of outcomes/variables/instruments based on discussions with Indigenous peoples • Present research design including outcomes/variables to knowledge keeper advisor/advisory circle • Begin drafting proposal that includes relevant context/Indigenous perspectives in collaboration with Indigenous team member/advisors • Build into budget resources that allow for transfer of resources to Indigenous organization for coordination/data collection 	
<p>2. Western Paradigm Data Coordination/Collection</p>	<p>Decolonizing Approach: Meaningful participation in and governance over research, respect and inclusion of Indigenous culture and protocols</p>
<p>Action & Strategies</p> <ul style="list-style-type: none"> • Partner with Indigenous organization or community & transfer resources to coordinate research • Hire local research assistants/Indigenous students to carry out research if possible • Seek advice from knowledge keepers about launching the research in a good way & building in local ceremony, or customs throughout research project 	
<p>3. Western Paradigm Data Analysis/Interpretation</p>	<p>Decolonizing Approach: Privilege/include Indigenous knowledge, worldviews, perspectives and voice in the interpretation; Contextualization of Indigenous people through inclusion of Indigenous peoples historical, social, political & cultural realities, strengths and resiliency factors</p>
<p>Action & Strategies</p> <ul style="list-style-type: none"> • Focus & frame the analysis on policy or institutional processes - and relationship to colonization • Provide relevant context/Indigenous voices & perspectives in presentation & publication of findings • Include relevant historical factors, policy & social context/role of colonization & voices of Indigenous peoples in the discussions/discourse in publications • Organize meetings with knowledge keepers/Indigenous community to present preliminary findings & listen to feedback & perspective 	
<p>4. Western Paradigm Knowledge Translation</p>	